Newmarket

IgniteData

# The future of healthcare and life sciences research

## The importance of improving the UK's data infrastructure

**EVENT WRITE-UP**

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# Introduction

The UK is uniquely positioned to lead in the use of health data for research, innovation, and improved patient care. With a single national health service and rich longitudinal data covering the population from birth to death, the potential for meaningful insight is immense. Yet for more than a decade, barriers to interoperability have undermined efforts to realise this potential. Despite the availability of technical solutions, the fragmented nature of NHS systems and a cautious data culture have made progress uneven.

The Sudlow Review, commissioned in 2023, renewed attention to these issues. Its findings emphasised that the barriers to effective data use are not just technical, but legal, organisational and cultural. The review called for urgent action to streamline data access, build trust through transparency, and create mechanisms that make high-quality health data reliably available for research. Its publication marked a turning point in the national conversation, highlighting that the UK's data assets are too important to remain underused.

Recent developments have begun to shift the policy landscape. The Data Use and Access Bill, introduced in 2025, provides a legal framework for improving data sharing across sectors. It includes new powers for the Secretary of State to mandate interoperability standards among IT suppliers–ensuring that NHS systems are better connected and that data can flow more freely for public benefit. This legislation, alongside initiatives like the forthcoming Health Data Research Service (HDRS), signals a more coherent approach to enabling safe, responsible access to health data for research and innovation.

The Future of Life Sciences brought together leaders from across the NHS, government, academia and industry to explore how the UK can move from aspiration to implementation. Through focused discussions and international insights, the event examined how we can finally overcome long-standing barriers and build a system where data is not just collected–but used meaningfully to improve health outcomes, accelerate research, and support a thriving life sciences sector.

# Event Summary

# Fireside Chat: Reflections on the UK Health Data Landscape

The opening fireside chat between Lord O'Shaughnessy and Professor Cathie Sudlow, author of Independent Reviewer of UK Health Data, explored the personal, structural and political dimensions of the health data ecosystem in the UK.

**From Clinic to Data Leadership**

Cathie Sudlow began by describing her transition from clinical work to health data as a gradual process, shaped by key mentors and a longstanding interest in public health. Early involvement with UK Biobank proved pivotal, deepening her understanding of data's role in advancing population health. Frustration with systemic inefficiencies, she noted, became productive through the encouragement of allies: "If you can convert frustration into something constructive, that's a privilege."

**The Sudlow Review: Process and Purpose**

Commissioned in May 2023, the Sudlow Review sought to improve how health data is used in the UK. Sudlow emphasised the importance of sustained dialogue across sectors, calling the review "a process, not an event." Of its five recommendations, she highlighted the need to streamline data processes–stressing that the obstacles are as much legal, cultural and attitudinal as they are technical. NHS leaders, she argued, are often paralysed by perceived risk: "Patients expect better from us." She called the system overly protectionist and criticised the failure to leverage the UK's rich data resources for public benefit. Comprehensive stakeholder engagement was central to the review's findings.

**Tackling Fragmentation**

On the causes of fragmentation, Sudlow cited historical legacy and structural competition within the NHS. While the open market fosters innovation, it also breeds incoherence. She proposed a more "controlled market" and incentive frameworks at all levels to reward effective, secure data use. Legal reforms could help unlock technical benefits, and internationally, the UK remains well placed to lead in health data research.

She described the NHS as operating like a group of independent entities with siloed systems, and praised the pandemic-era collaboration that temporarily broke down these barriers. The challenge now is to embed that spirit systemically.

# Fireside Chat: Reflections on the UK Health Data Landscape

**Responsibility, Design and Public Benefit**

Discussion turned to the proposed £6 million data service hosted by the Wellcome Trust. While its design remains undecided, Sudlow suggested it could hold ultimate responsibility for system-wide data coordination. She questioned the boundary between primary and secondary care data, arguing that "data should drive change, not be boxed by legacy silos."

On the balance between mandating access and using incentives, Sudlow reflected on the success of COVID-era emergency powers in enabling data use. Trust and belief in public benefit, she said, are key to maintaining momentum–and to generating economic value.

Referencing the phrase "critical national infrastructure" in the report, she agreed this description was appropriate in retrospect.

**Clinical Practice and Cultural Change**

Sudlow called on clinicians to help lead change by embedding automation tools, standardising data capture and fostering interoperability: "We need systems that speak to each other."

When asked about barriers to change, she pointed to risk aversion within the system and the need to distribute accountability more fairly. Cultural fear, she argued, must be addressed if innovation is to flourish.

Responding to a challenge on the gap between strategy and delivery, she acknowledged the continued struggle to rebuild clinical trials post-pandemic.

Quality research, she stressed, depends on quality data. She also identified inefficiencies in current recruitment models and called for governance frameworks to unify disparate efforts into a coherent research ecosystem.

In conclusion, Sudlow advocated for both personalised medicine and large cohort trials: "It's not either/or. The UK is uniquely placed to do both–and we should."

# Fireside Chat Speakers

**Lord James O'Shaughnessy, Senior Partner, Newmarket Strategy**

James has operated at the highest levels of government, including as a Minister at the Department for Health & Social Care, as Director of the No.10 Policy Unit, and as an advisor to DHSC Ministers during the COVID-19 crisis. As Minister his responsibilities included implementing the Life Science Industrial Strategy, delivering a new pricing scheme with the pharmaceutical industry, chairing the National Genomics Board, and driving the digital transformation of the NHS. He was also responsible for preparing the health and social care sectors for Brexit In early 2023 James was commissioned by the Government to carry out an independent review of commercial clinical trials in the UK, which was published in May of that year.

James is co-founder and Senior Partner of Newmarket Strategy, a consultancy dedicated to improving access to health innovation by providing strategic advice and technical support to the healthcare, life sciences and health tech sectors. At Newmarket, James provides senior counsel to multinationals, SMEs, investors, universities and charities across health and life sciences, with a particular focus on technology, digital and data.  James is a Life Peer in the House of Lords, Chair of Cambridge University Health Partners (CUHP), a Visiting Professor at the Institute of Global Health Innovation at Imperial College, a Trustee of HDR-UK, a non-executive director of Albion Development VCT plc, and Patron and Strategic Adviser to the Tessa Jowell Brain Cancer Mission. In 2023 James led and published an independent review of commercial clinical trials in the UK for HM Government.

# Fireside Chat Speakers

**Professor Cathie Sudlow, OBE, author of an independent review of the UK-wide health data landscape, Strategic Adviser to Health Data Research UK (HDR UK), Director of the Usher Institute at the University of Edinburgh and Director of the Adolescent Health Study**

Until 2024, Professor Sudlow was Chief Scientist and Deputy Director of HDR UK, and Director of the British Heart Foundation Data Science Centre. She was also the first Research Director for HDR UK in Scotland.

In 2023, Prof Sudlow was commissioned by the Chief Medical Officer for England, the UK National Statistician and NHS England to undertake an independent review of the UK-wide health data landscape. “Uniting the UK’s Health Data: A Huge Opportunity for Society” was published in November 2024, it sets out a bold vision for how the barriers and inefficiencies that currently delay the safe and secure use of health data to improve lives can be overcome, with key recommendations to transform the health data ecosystem.

Over the last 15 years, her focus has been on leading large-scale, collaborative, open-science initiatives that enable a better understanding of the causes and consequences of health and disease across the life course, leading to new and improved approaches to prevention, diagnosis and treatment. From 2020, Cathie worked with NHS Digital (and then NHS England) to develop NHS England’s first secure data environment to hold and enable access for research to linked health data from multiple sources for the whole population of England.
From 2011 to 2019, as Chief Scientist for UK Biobank, she led efforts to follow the health of UK Biobank participants through linkage to national health datasets.

As a neurology specialist doctor with over 30 years working in the NHS, Prof Sudlow’s clinical work has focused mainly on the assessment and treatment of patients with suspected stroke. Cathie is a Fellow of the Academy of Medical Sciences and of the Royal Society of Edinburgh. She was awarded an OBE for services to medical research in 2020.

# Overcoming Data Access Challenges – Lessons from Abroad

This panel opened with a clear message: the UK stands at a pivotal moment in unlocking the full potential of health data for research and clinical trials. The technologies and standards needed to enable scalable, interoperable and efficient data use now exist–and implementation is increasingly feasible.

**Making the Case for E-Source and Interoperability**

Dr Mats Sundgren, Senior Industry Scientific Director, i~HD (European Institute for Innovation through Health Data), set the scene by addressing long-standing barriers and what's changed in recent years. After over a decade of discussion, three key developments have shifted the landscape:

- The quality of electronic patient record (EPR) data has improved markedly.
- Interoperability standards like FHIR and HL7 v2 are now mandated.
- Software can now scale and integrate agnostically across systems.

"Interoperability isn't a buzzword–it's infrastructure," they explained. FHIR, in particular, was likened to a modular vehicle for scalable, future-proofed data transfer.

**International Lessons in Practice**

Drawing on global experience, Joe Lengfellner, Senior Director, Clinical Research Informatics & Technology, Memorial Sloan Kettering Cancer Center, described running over 1,900 oncology trials, where previously fragmented systems made data collection laborious. Now, thanks to better tools and standards, that burden is lifting. "We're finally seeing momentum," they said. "Less manual curation, better data quality, more access."

Others echoed this shift, noting a cultural move from reluctance to readiness. As highlighted by Angela, Fritsche, M.P.A, Administrator and Instructor of Health Care Administration, Mayo Clinic Comprehensive Cancer Cente "We've moved from 'why' to 'why not'–and we're moving faster for patients." The adoption of e-source, they argued, is rooted in trust and transparency, giving patients greater insight into research outcomes.

Crucially, the panel stressed that mandates and policy frameworks are essential to drive uptake: "Without them, this wouldn't have launched."

# Overcoming Data Access Challenges – Lessons from Abroad

**Efficiency Gains and Quantifying Impact**

Panellists detailed the inefficiencies of manual trial data collection–such as double entry–where a single data point might take 3 to 10 minutes to input. In one scenario, automating 10,000 data points saved 5,000 hours of work–multiplied across hundreds of research staff. A recent project at Memorial Sloan Kettering processed 50,000 data points using e-source technology, with overwhelmingly positive feedback from the trial team.

"If we can release this time, we can do more research–faster. That's a profound change," one contributor said.

**Pharma's Role: Standards, Partnerships and Scaling**

From the sponsor perspective, representatives from AstraZeneca and Sanofi described their experience implementing e-source tools. For Rachel Enright, Executive Director, Late Development Oncology Clinical Operations, AstraZeneca , oncology remains their largest and most complex research area. They are currently live in three studies and targeting 30, while working to simplify internal systems and focus on essential data. "This must be a partnership," noted Rachel. "Sponsors and sites need to move rapidly together."

Amy Cramer MMCi, BSN, Clinical Innovation Focus Area Lead, Johnson & Johnson and Founder and Chairman of the Board, Vulcan FHIR Accelerator emphasised that FHIR has transformed the landscape. One panellist described the artificial boundary between NHS care and research as outdated: "It's all healthcare." Regulatory collaboration, including with US agencies, is now enabling more secure, scalable systems.

Still, challenges remain. Data volumes are high, and error risk persists. Adherence to standards and clearer reference ranges were cited as essential safeguards.

**Enabling Innovation and UK Leadership**

Regulatory changes–such as updated FDA guidance on data control–are opening new opportunities. Michel Rider, Global Head of Digital R&D, Sanofi called for the UK to seize this moment by:

- Enforcing robust data standards.
- Requiring sponsor adoption.
- Leveraging expert committees and crowdsourcing to evolve best practices.
- Balancing IP concerns with open innovation.
- Creating a stable data ecosystem for start-ups.

# Overcoming Data Access Challenges – Lessons from Abroad

“There’s a tremendous opportunity. E-source isn’t just possible–it’s already working,” as highlighted by Michel.

**The Road Ahead: Faster, Integrated Trials**

The session concluded on a hopeful note. With e-source, study durations could be shortened by up to three months. Even single-site adoption has measurable impact. Within two years, several panellists predicted, full e-source implementation will be standard in major trials.

**Audience Reflections**

The Q&A highlighted a broader concern: whether deeper issues in R&D itself need reform, beyond standards alone. In response, panellists pointed to the persistent challenge of scaling innovation across the NHS, with outdated infrastructure and fragmented systems still creating friction. Nonetheless, the consensus was that momentum is growing–and with it, the real possibility of systemic change.

# Session Speakers

**Amy Cramer MMCi, BSN, Clinical Innovation Focus Area Lead, Johnson & Johnson and Founder and Chairman of the Board, Vulcan FHIR Accelerator**

Amy Cramer is the founder and Chairman of the Board for Vulcan, an international organization made up of multiple research community members representing perspectives such as government agencies, technology vendors, patients, sponsors and sites across the globe. Vulcan is dedicated to positively disrupting the research community through the advancement of electronic exchange of data based on standards. She works for Johnson and Johnson Innovative Medicine focused on Health Innovation and Data Acquisition. With a background as a cardiac critical care nurse, clinical research coordinator, certified healthcare quality professional, and clinical research informaticist, she brings a wealth of experience to her current role. Throughout her career, Ms Cramer has worked in various healthcare settings, including community hospitals, independent academic medical centers, world-class academic centers and pharmaceutical corporations.

In addition to her responsibilities at JJIM, Ms Cramer is actively involved in several industry organizations; iHD eSource Task Force, formerly held roles as Vice Co-Chair for the Society for Clinical Data Management eSource Consortium, Health Level Seven Co-Chair Clinical Interoperability Council and Co-Lead for Gravitate's Work Package 5.Ms Cramer holds a Masters in Management of Clinical Informatics (MMCi) from Duke University School of Medicine and actively participates on the Board of Alumni for the Duke University School of Medicine MMCi program.

**Rachel Enright, , RN, CCPE, Executive Director, Late Development Oncology Clinical Operations, AstraZeneca**

Rachel Enright is an accomplished leader in the field of clinical operations, with over two decades of experience in oncology drug development. Starting her career in Mississauga, Canada, she relocated to Cambridge, UK, over 7 years ago.  Rachel has worked at AstraZeneca for over 28 years and currently serves as the Executive Director of Clinical Operations, where she oversees the operational execution of various cancer portfolios within Late Development Oncology. Her expertise spans all phases of clinical development, particularly in small molecule and immuno-oncology compounds, with a focus on GU, head & neck, and paediatric cancers.

# Session Speakers

Throughout her career, Rachel has demonstrated a strong commitment to mentoring and developing high-performing teams, earning numerous accolades including the AstraZeneca CEO award and Canadian Presidential awards for excellence.  Rachel's leadership style is characterized by her strategic thinking, innovative approach, and ability to deliver complex global trials on aggressive timelines and budgets.
Rachel is a Registered Nurse and has continually updated her skills through various courses in pharmaceuticals, oncology, and project management.  Her contributions to the field extend beyond her executive responsibilities, as she is deeply involved in initiatives aiming to improve clinical trial frameworks and operational efficiencies at AstraZeneca.

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**Angela, Fritsche, M.P.A, Administrator and Instructor of Health Care Administration, Mayo Clinic Comprehensive Cancer Center**

Angela Fritsche is the Enterprise Administrator for Clinical Research at the Mayo Clinic Comprehensive Cancer Center (MCCCC) and has over 20 years of experience in academic medical centers and higher education research institutions.

She joined the MCCCC 6 years ago to manage protocol development, study conduct and navigated clinical trials through the onset of the COVID-19 pandemic and great resignation.

During her tenure, MCCCC clinical research has successfully transformed operations including decreasing National Cancer Institute activation timelines and increasing accruals. Ms. Fritsche has a passion for bringing technology and innovation to clinical trials to help accelerate bringing hope to patients across the globe. This includes leveraging EHR to EDC which decreases clinical trial costs, improves first time data quality, and provides data faster to assure patient safety oversight and, hopefully, accelerating approval of clinical trials that show improved patient outcomes compared to standard of care.

# Session Speakers

Ms. Fritsche received a Bachelor of Science in Business Administration – Human Resources Management and a Master of Public Administration with a specialization in Healthcare Administration from West Virginia University, Morgantown, WV. In 2024, she completed a Graduate Certificate in Equity, Diversity, Inclusion and Belonging Leadership at Harvard University, Cambridge, MA.

**Joe Lengfellner, Senior Director of Clinical Research Informatics & Technology at Memorial Sloan Kettering Cancer Center, USA**

Joe Lengfellner brings over 20 years of experience in healthcare IT and clinical research, with a career focused on driving innovation at the intersection of technology and clinical trial operations. A recognized pioneer in EHR-to-EDC integration, Joe has authored multiple publications and case studies highlighting real-world implementations that improve data quality, streamline workflows, and reduce site burden.

As the leader of a 50-person clinical research technology team at Memorial Sloan Kettering Cancer Center in New York City, Joe has advocated for forward-thinking strategies such as decentralized clinical trials, FHIR-based interoperability, and eSource adoption, initiatives that have significantly improved the experience for patients, clinicians, and research staff alike.

Joe also co-founded and leads the Clinical Research Innovation Consortium (CRIC), a collaborative network of leading academic research sites, sponsors, and technology partners focused on accelerating the evaluation, validation, and scaling of digital solutions in clinical trials. Under his leadership, CRIC has become a trusted model for de-risking emerging technologies and aligning the ecosystem around standards and outcomes-focused innovation.

His expertise spans digitized trial design, clinical operations, advanced analytics, and the deployment of eClinical tools that support more efficient and higher quality clinical trials.

# Session Speakers

**Michel Rider, Global Head of Digital R&D, Sanofi**

Michel is Sanofi's Global Head of Digital R&D and is accountable for all applications, data, and AI/ML assets applied to discovery, development, and market support of medicines and vaccines. Prior to this she held leadership roles at GSK and Merck in both business and digital/IT, was management consultant with Accenture, and led a commercial software company focused on digitalizing clinical patient dataflow. She holds a BS in Microbiology and an MS in Management of Information Systems.

**Mats Sundgren, PhD, Sr. Industry Science Director, i-HD**

Mats Sundgren, PhD, MSc, is a distinguished authority in Health Data Strategy, serving both industry and academia. With an impressive career spanning over 37 years in the pharmaceutical industry, Mats has made significant contributions across various domains, including Discovery, Development, Manufacturing, IT R&D, Patents, Clinical Science, and Data Science & AI. His work places him at the forefront of technological innovation in the field. In 2022, following an illustrious 12-year tenure as the global integration lead for Electronic Health Records (EHR) services at AstraZeneca, Mats expanded his professional endeavors.

He now holds several key roles: Sr. Industry Scientific Director and co-founder of the i~HD (European Institute for Innovation through Health Data), Executive Strategic Advisor for IgniteData, which develops a system-agnostic EHR-to-EDC solution for clinical trials, and Chairman of the Board of the Research Foundation IMIT (Institute of Managing Innovation and Technology). IMIT includes prominent institutions such as Chalmers University of Technology, Royal Institute of Technology, Lund University of Technology, and Stockholm School of Business. Additionally, he serves as a Board Member of the Center for Health Governance at Gothenburg University. In July 2024, Mats assumed the role of Scientific Adviser for IOMED, a company specializing in AI-powered technology for healthcare data activation. In March 2025, assumed the role of R&D Strategy Advisor for ZS Associates.

Mats has an extensive portfolio of work, including over 80 publications, books, and patents in Life Science, Economics, and Social Science. His areas of expertise encompass Health Data Science & AI, Clinical Science, Clinical Trials Management, Business Modelling, Innovation & Creativity Management, and Device Development.

# Improving the ability to access and use data: the role of interoperability

It was an honour to chair this exceptional panel discussion at *The Future of Life Sciences*, which brought together a diverse and insightful group of experts to explore how interoperability can unlock the full potential of healthcare data. A heartfelt thank you to our brilliant speakers–Dr Sarah Burge, James McDermott, Dr Janet Valentine, and Dr Joe Zhang–whose candour, deep expertise, and forward-thinking perspectives shaped a rich, thought-provoking conversation. Together, we examined how the UK can turn its ambition for a digitally enabled research ecosystem into reality.

**Opening Reflections: Lessons from 30 Years of Building EHRs**

The session opened with a poignant metaphor from a panelist with three decades of experience developing electronic health records (EHRs):

> "Working in healthcare has often felt like walking down a corridor with a very weak candle."

Early digitisation efforts laid crucial groundwork, but lacked today's tools like natural language processing (NLP). With these, more adaptable solutions might have emerged sooner. Thankfully, the UK avoided the overly complex, fragmented EHR systems of the US and is now well-placed to adopt interoperability standards such as HL7 FHIR.

**The UK Advantage—and the Urgency to Act**

The panel hailed the NHS's longitudinal patient records as a unique global asset for recruitment and real-world evidence generation. However, as Dr Janet Valentine of the ABPI warned, pharma will gravitate to regions with reliable, fast data access utilising data-enabled recruitment services through EHRs. Without meaningful progress, the UK risks losing its edge.

While data-enabled recruitment services such as DigiTrials and CPRD SPRINT show promise, gaps persist. CPRD SPRINT only uses GP data for patient searches, whereas DigiTrials can't access GP data, so neither service is suitable for the vast majority of clinical trials.

Even in advanced sites like Cambridge, challenges with entrenched infrastructure and top-down IT approaches remain. Panelists questioned the widely cited claim that 80% of health data is accessible, emphasising real value lies in harder-to-reach data such as biomarkers and deep phenotypes. "We've put our investment in the wrong place–into AI, without investing in the underlying plumbing."

# Improving the ability to access and use data: the role of interoperability

**HL7, FHIR, and Vulcan: Infrastructure for the Future**

James McDermott, Head of Vulcan at HL7, clarified: FHIR is not a content model but an exchange standard– "a 'railway' that lets structured data travel across systems."
The Vulcan initiative accelerates FHIR's use in clinical research by bringing together global stakeholders. Proper implementation can reduce integration costs and improve trial quality and speed.

**Genomics, Integration, and Readiness**

Dr Valentine spotlighted the UK's untapped genomic potential. Despite a national genomics service, trials face barriers from unclear infrastructure, siloed systems, and absent pathways.
"There's no clear pathway to support genomic clinical trials–and that's a trick we're missing."

The panel agreed: infrastructure–not standards alone–is the limiting factor. Without robust systems to support genomic and biomarker data, the UK cannot realise its vision as a genomics superpower.

**Should the UK Double Down on FHIR?**

The consensus was clear: the UK must fully commit to FHIR, aligning with the US, EU, and others. "Why wouldn't we? It would be ludicrous to do something else."

Yet mandates alone are insufficient. Broader change requires education, incentives, and a shift towards expecting interoperability as standard.
"If FHIR is adopted, it's not just about Epic or big systems. It unlocks opportunities for entrepreneurs to build new products on top of open data."

# Improving the ability to access and use data: the role of interoperability

**Q&A Takeaways: Free Text, Workforce, and Capability Gaps**

In the Q&A, Dr Joe Zhang stressed the need for clinicians to work naturally–often using free text–while still capturing structured data. The issue, he argued, lies not with regulation but capacity:

"Access to clinical data should be a right, not a luxury. But we've not built the teams or invested in capability."

Andrew Morris of HDR UK added that the NHS undervalues technical expertise:

"We need to recognise and pay data experts on par with clinicians. The problems the NHS is trying to solve can't be outsourced–they must be solved from within."

With the right investment and internal ownership, the panel believed major progress could be made in months, not years.

**Conclusion**

The UK boasts world-class assets in health data, infrastructure, and genomics, yet risks falling behind due to fragmentation, underinvestment, and cultural inertia.

Interoperability tools like FHIR are not panaceas, but they form the essential infrastructure for a data-driven NHS.

To lead globally in life sciences and deliver better care, the UK must move from vision to action, starting with infrastructure, talent, and policy designed for true, scalable interoperability.

# Session Speakers

**Dr Sarah Burge, Director of Clinical Integration, Cambridge University Foundation Trust**

Dr. Sarah Burge is a senior leader in translational oncology and data-driven healthcare innovation. As Director of Clinical Integration at the University of Cambridge and Development Lead for the Integrated Cancer Medicine (ICM) Programme, she is at the forefront of a radical transformation in cancer care–where research and clinical delivery are seamlessly aligned.he plays a central role in the development of the Cambridge Cancer Research Hospital, helping to shape a new model of care where research and clinical practice are tightly interwoven.

Dr. Burge brings over 15 years of experience working at the intersection of biomedical science, data integration, and healthcare delivery. Her work focuses on building systems and teams that can take innovations–particularly those in AI and data science–through to real-world clinical use.

At Cambridge, she has led projects ranging from the delivery of major COVID-19 research trials to the development of new data platforms for cancer diagnosis and prognosis. She is responsible for ensuring that scientific advances in integrated cancer medicine are supported by the necessary infrastructure, governance, and clinical engagement to reach patients effectively.

Before joining the University of Cambridge, Dr. Burge worked at the Wellcome Trust Genome Campus, where she led bioinformatics initiatives at both the Sanger Institute and EMBL-EBI, with a focus on RNA biology. She continues to collaborate with a wide range of academic, clinical, and industry partners–including GE Healthcare–to deliver translational impact.

**James McDermott, Head of Vulcan, HL7**

With over 30 years of experience in medical statistics, clinical research, and healthcare data sciences, he has established himself as a pioneering leader and innovator. Currently serving Head of Vulcan where his role focuses on advancing the growth and development of the HL7 Vulcan accelerator initiative. He is also Executive Chairman & CEO at Achieve Intelligence, he specialises in leveraging advanced data analytics and AI to deliver tailored business intelligence solutions, particularly in the healthcare sector. He has founded and lead multiple successful organisations,

# Session Speakers

where he has driven strategic initiatives and transformative projects.

His expertise encompasses leadership and strategic planning, development of innovative business and statistical strategies, and extensive participation in industry conferences. He has a proven track record of empowering SMEs through strategic investment and advisory services, ensuring robust, ethical business foundations.

In addition to his professional roles, he is an active contributor to the academic and professional community, regularly presenting at conferences such as Phuse Connect and Domino Rev4 on topics ranging from design thinking in leadership to advancements in biopharma data standardisation.

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**Steven Tolle, Chief Product & Technology Officer, IgniteData**

Steven Tolle is Chief Product & Technology Officer at IgniteData where he oversees product strategy, development and marketing. He also serves on the advisory board for HLM Investment Partners. He has over 30 years of commercial health care technology expertise in the areas of product management, strategy and business development. Steve has spent his career helping to develop and manage some of the most important themes in health care innovation today, including artificial intelligence, diagnostic imaging/medical devices, electronic health records, population health, managed care and value-based pharmaceutical pricing.

Prior to joining IgniteData, Steve was a General Partner at HLM Investment Partners. Previously, he was Global Vice President for Strategy at IBM Watson Health, where he led strategy and corporate development for the Merge Healthcare medical imaging business unit (acquired by IBM for $1B in 2015). Steve led the effort to move Merge Healthcare into the AI space and played a key role in the successful sale to IBM. Other notable previous roles include Senior Vice President/General Manager at Optum, Vice President of Product Management at Allscripts, and Director of Business Development & Product Management at Pfizer

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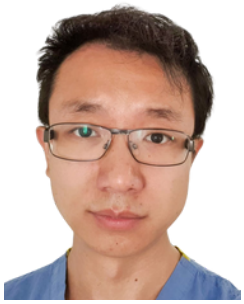
**Janet Valentine PhD, Executive Director Innovation and Research Policy, The Association of the British Pharmaceutical Industry**

Janet has extensive experience in strategic leadership positions in the UK health research and health data research environment. As Executive Director of Innovation and Research Policy at the Association of the British Pharmaceutical Industry (ABPI), Janet is responsible for influencing Government policy to make the UK a globally attractive destination to discover and develop new medicines and vaccines.

Prior to joining the ABPI, Janet was the Industrial Strategy Challenge Fund Director for Data to Early Diagnosis and Precision Medicine at Innovate UK, where she oversaw a broad portfolio of investments in genomics, health data, AI, medical imaging and digital pathology. In her previous role as an Executive Director at the Medicines and Healthcare Products Regulatory Agency (MHRA), Janet led the Clinical Practice Research Datalink (CPRD). CPRD is the UK's largest dedicated health data research service, providing research data services to industry, academia and regulators worldwide. Janet's previous roles include Head of Population Health and Health Informatics at the Medical Research Council and Deputy Chief Executive of the UK Clinical Research Collaboration.



**Dr. Joe Zhang, Head of Data Science at the Artificial Intelligence Centre for Value-Based Healthcare and London Secure Data Environment**

Joe is a specialist doctor and a data engineer/scientist, with more than a decade's experience working in technical programmes across the NHS, academia, and in industry. During the COVID-19 pandemic, he worked as a Senior Fellow in ECMO at Guy's and St. Thomas' Hospital, whilst leading development of national data infrastructure and machine learning tools to support COVID-19 referral pathways.Joe was previously a Wellcome Fellow at the Institute of Global Health Innovation undertaking a PhD in data-centric artificial intelligence, before working at Arcturis Data, building Real-World Data capabilities for supporting external control arm studies.

At the AI Centre and the London SDE, Joe is responsible for the development of multi-modal data lakes across London NHS Trusts, and the application of data science and predictive analytics across a London-wide data ecosystem. His team is pioneering the use of Large Language Models for deep phenotyping of unstructured patient records, opening new doors to precision medicine, medical foundation models, and capabilities for live clinical trial recruitment.

# Closing Fireside: Lord Darzi in Conversation with Lord O'Shaughnessy

The final session of The Future of Life Sciences brought together two leading figures in UK health policy–Lord O'Shaughnessy and Lord Darzi–for a candid and insightful conversation on data, infrastructure, and leadership in the NHS.

Lord Darzi opened by reflecting on a recent eight-week NHS modelling project he led, commissioned to explore productivity, workforce growth, and investment trends across the health service. Despite the tight timeframe, the exercise drew on a vast base of expertise–over 200 analysts from NHS England and DHSC–and combined 335 datasets spanning back to 2000. It was, as he described, a collaborative and focused effort that surfaced both expected and surprising insights.

**"What turned it around was the time. We had just eight weeks. That shaped everything."**

Among the key findings: the NHS workforce has grown by 20% over the period studied, yet productivity has declined. The analysis also revealed that capital budgets are frequently diverted to cover revenue spending, resulting in chronic underinvestment in the infrastructure needed to support modern care.

**"Whatever you do, capital is the answer. In every other industry, capital replaces labour. But the NHS is the only system where labour just keeps growing without the capital."**

# Closing Fireside: Lord Darzi in Conversation with Lord O'Shaughnessy

Lord Darzi expressed concern that no equivalent deep-dive had previously been undertaken. The data was available–it simply hadn't been used to its full potential. The modelling also highlighted substantial variation in performance across Trusts, showing that while challenges are widespread, examples of best practice already exist within the system.

The conversation then turned to antimicrobial resistance (AMR), an area where Lord Darzi is deeply involved through the Fleming Institute. He underscored the critical role of data in improving diagnostics, tracking resistance patterns, and shaping effective interventions.

**"Data changes behaviour. It helps us predict resistance, identify pathogens, and improve diagnostics."**

In response to a question on how to turn evidence into lasting change, Lord Darzi emphasised the need for stronger leadership, long-term infrastructure investment, and a commitment to embedding data use across the system. He closed with a reminder that the UK's efforts have broader implications.

**"Yes, we want to improve UK health infrastructure. But we also have a duty—because if we get this right, we can help many others. The UK has a unique opportunity to lead."**

The session offered an honest look at the current state of NHS data use and a compelling case for investing more deeply in the research, tools, and leadership required to do better.

# Session Speaker

**Professor the Lord Darzi of Denham OM KBE PC FRS, Paul Hamlyn Chair of Surgery and Co-Director, Institute of Global Health Innovation, Imperial College London**

Professor Darzi is the Paul Hamlyn Chair of Surgery and Co-Director of the Institute of Global Health Innovation at Imperial College London. He is a Consultant Surgeon at the Imperial College Hospital NHS Trust and Royal Marsden NHS Foundation Trust. Professor Darzi is Chair of the NHS Accelerated Access Collaborative and Chair for the Pre-emptive Health & Medicine Initiative at Flagship Pioneering, United Kingdom. In 2024, at the request of the Secretary of State, he completed an Independent investigation of the NHS in England.

Professor Darzi is also the Executive Chair of the Fleming Initiative, an innovative programme under the patronage His Royal Highness the Prince of Wales, to address the rising burden of antimicrobial resistance worldwide through an inter-disciplinary approach.
He is a Fellow of the Academy of Medical Sciences and the Royal Society, Honorary Fellow of the Royal Academy of Engineering and Past President of the British Science Association.

In 2002, Professor Darzi was knighted for his services to medicine and surgery, and in 2007 was introduced as Lord Darzi of Denham to the United Kingdom’s House of Lords as the Parliamentary Under-Secretary of State for Health. He has been a member of His Majesty's Most Honourable Privy Council since 2009 and was awarded the Order of Merit in 2016

# Thought Pieces

# Eliminating Double Data Entry in Clinical Trials

**Angela, Fritsche, M.P.A, Administrator and Instructor of Health Care Administration, Mayo Clinic Comprehensive Cancer Center**

Clinical research coordinators play a vital role in the smooth running of clinical trials, yet the processes they rely on have long been burdened by inefficiencies–particularly when it comes to data access and entry. Until recently, many teams were forced to manually duplicate information from electronic health records (EHRs) into sponsor-mandated electronic data capture (EDC) systems. This practice has been time-consuming, error-prone, and increasingly untenable as trials grow in complexity and volume.

**The Challenge: Manual, Repetitive, and Risk-Prone Data Handling**

Historically, patient data required for clinical trials was first entered into the EHR–either in the form of clinical notes or research notes–and then re-entered manually into the EDC system via electronic case report forms (eCRFs). These forms vary widely between studies, as does the design and interface of the EDC platforms that house them. As a result, coordinators have had to refamiliarise themselves with different systems, data structures and field locations for each new study they support. The result: inefficiency, cognitive burden, and a high risk of human error.

**The Solution: EHR-to-EDC Technology**

This landscape is beginning to shift, thanks to the implementation of EHR-to-EDC technologies. These tools identify and extract the relevant data directly from the EHR, map it to the appropriate fields in the eCRF, and present it to the coordinator for verification. This reduces the need for manual searching and duplicate entry.

Instead of navigating through EHR records and copying data point by point, coordinators are now verifying that the correct information has been automatically pulled and aligned with the protocol–saving time, reducing mistakes, and elevating the coordinator's role to one of oversight and validation.

**Cultural Transformation and Efficiency Gains**

Beyond operational improvements, this shift has had a profound impact on organisational culture. Study teams are

# Eliminating Double Data Entry in Clinical Trials

now embracing eSource tools as not just a convenience, but as a means of improving both patient care and trial oversight. By automating routine data tasks, coordinators are freed to focus on higher-value responsibilities, including patient interaction and protocol adherence.

Data is also reaching the EDC systems more quickly, providing real-time insights to clinical teams and enhancing oversight of patient safety. This change supports better decision-making and a stronger overall trial infrastructure.

**Policy Recommendations for the UK**

To enable similar advances across UK research sites, several policy shifts are recommended. First and foremost, there should be national enablement of digital source data capture in clinical research. This would reduce the need for physical storage space, simplify record retention, and allow for more efficient remote monitoring.

Furthermore, the UK should mandate the adoption of mature interoperability standards–specifically FHIR (Fast Healthcare Interoperability Resources).

Standardising the way health data is structured and exchanged will unlock faster access to both current and historical medical information, improving trial readiness and efficiency nationwide.

# Reimagining Clinical Trial Data Access: Lessons from MSK

**Joe Lengfellner, Senior Director of Clinical Research Informatics & Technology at Memorial Sloan Kettering Cancer Center, USA**

Electronic health records (EHRs) are essential to seamless clinical care and billing but historically have not been optimized for clinical trials, and interoperability has been a persistent challenge. As a result, accessing patient data for clinical trials, such as populating an electronic data capture (EDC) system, is often manual and error prone. At Memorial Sloan Kettering Cancer Center (MSK), nearly 400 clinical research coordinators are responsible for manually transferring data from our EHR to the various EDC systems used by different trial sponsors.

We've been working to shift this data entry paradigm at MSK for several years, and I see my colleagues at other research sites starting to do the same. Our previous approaches involved writing custom code and using various data extraction techniques to move data directly from the EHR into sponsor systems. While these early attempts showed success in small pilots, scalable solutions across multiple trials have remained elusive, until recently.

This is now changing with the accelerated adoption of FHIR (Fast Healthcare Interoperability Resources) in the U.S. This has enabled a new class of technology providers, EHR-to-EDC solutions, to mature and be implemented more readily by both research sites and sponsors. These solutions allow for automated, structured, and secure data transfers, replacing repetitive manual data abstraction.

Within MSK, there's growing excitement about our ability to scale this technology across our full trial portfolio. We're seeing both improved efficiency in data entry and a marked increase in data quality. Just as importantly, our research coordinators prefer using this technology to manual data curation. Supporting job satisfaction is critical, especially in a role as demanding and complex as that of the research coordinator. It's a high-stress position, and anything that reduces repetitive work and cognitive load helps retain talent and reduce burnout.

One of the primary drivers of EHR-to-EDC adoption in the U.S. has been regulatory mandates requiring EHR vendors to support FHIR. I would strongly advocate for

# Reimagining Clinical Trial Data Access: Lessons from MSK

similar policy requirements in the UK. FHIR is already in use across many domains, it's a mature, scalable standard ready for broader implementation.

The more broadly this data standard is adopted, the more EHR-to-EDC technology will thrive, and the more clinical trial sponsors will embrace and scale it.

Ibelieve capabilities like this will soon become key differentiators for pharma. Sponsors will prioritize regions with this infrastructure when deciding where to run their most important and time-sensitive trials.

# Getting the UK's data infrastructure right is not just about the technical

**Janet Valentine PhD, Executive Director Innovation and Research Policy, The Association of the British Pharmaceutical Industry**

**Beyond the Technical: It's about the culture and it's about people**

Despite the current interest in the potential benefits of sharing NHS electronic health records (EHR), the technical ability to do so is not a new phenomenon. In the 1980s, GPs were the first to cotton on to the immense benefits of analysing disease trends in their patients' EHR. Since then, the volume of GP data available for research has grown from several dozen GP practices to over 30% of the UK population, resulting in thousands of research publications.

In Wales, GP data is routinely linked to hospital and socioeconomic data for research purposes. The Welsh government saw the value of understanding the health of its population and has invested in the SAIL databank for decades. Secondary care EHR has been used in research for decades in Scotland, including the first study demonstrating the value of using EHR for long term follow up of clinical trials participants. The Nordic countries pride themselves on their linked health and socioeconomic population data which are used globally for research.

Because of the critical importance of tracking the population during the COVID-19 pandemic, the UK government took the decision to make a raft of EHR data available for research which previously had not been possible to access. Yet today these data are once again inaccessible, and researchers still don't have access to comprehensive English GP data and other essential datasets such as hospital prescribing data.

Why is this? The reasons are many and complex and include a historical cultural preference to build infrastructure first and consult users later, which has inhibited progress.

# Getting the UK's data infrastructure right is not just about the technical

The recent government announcement of up to £600 million funding, in partnership with the Wellcome Trust, to establish a Health Data Research Service (HDRS), is a significant and positive step. This commitment, demonstrating leadership from the top, will be necessary to unblock not just the technical but the cultural barriers which to date, have prevented data sharing for research. This will require bringing healthcare professionals on board, so they don't have to accept liability for data sharing, dispelling misinformation and educating patients and the public why research using EHR benefits their healthcare and wellbeing.

Adopting a user centred design from the outset will be critical to the HDRS' success, ensuring, with appropriate safeguards in place, that what is delivered is what researchers want. It will be important to learn from UK research data resources that already deliver for commercial and non-commercial researchers worldwide, to avoid wasting effort in starting from scratch. With these factors in place, the HDRS offers a real opportunity to get the UK's data infrastructure right, through strong leadership and by tackling technical and cultural challenges head on.




# Get Involved


# Join us next year

The Future of Life Sciences convened senior leaders from across the NHS, government, industry, and academia, alongside international voices from Europe and the US. Designed to be focused and impactful, the event created space for honest conversations, practical insights, and cross-sector collaboration on some of the most persistent challenges in health data.

The intimate scale was key to its success–big enough to bring diverse perspectives into the room, yet small enough to allow for meaningful exchange. Networking was more than a formality; it sparked real momentum and a shared sense of purpose. Delegates told us they left feeling energised, better connected, and clearer on what needs to happen next.

We're already planning for next year. The format will remain deliberately tight-knit and high-level, with even more opportunities to contribute to the discussion–whether as a speaker, sponsor, or participant. If you're working at the intersection of life sciences, healthcare, data, and research, and want to help shape the future of the UK's data-driven life sciences ecosystem, we want to hear from you.

To express interest in attending, speaking, or supporting the event, please contact:

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Be part of the next conversation. Help turn insight into action

# About Us

# About Newmarket

Newmarket Strategy is a dedicated healthcare strategy and market access consultancy, bringing a range of technical knowledge and policy insight to complex challenges across healthcare and life sciences.

Our team of experts includes a former Minister, the longest serving Adviser to a UK Health Secretary, the UK's leading expert in navigating HTA processes, NHS England's former Commercial Medicines Director, national NHS leaders of independent sector commissioning and elective care recovery, an expert in the field of digital health and software as medical device, as well as experienced analysts and consultants.

We work with several major provider organisations including major NHS trusts, major pharmaceutical companies, the UK's largest primary care operator and world-class research institutions. We also work with an array of digital health providers – covering products, services, and digital therapeutics – bringing innovative solutions to the health and life science sectors.

# About

# IgniteData

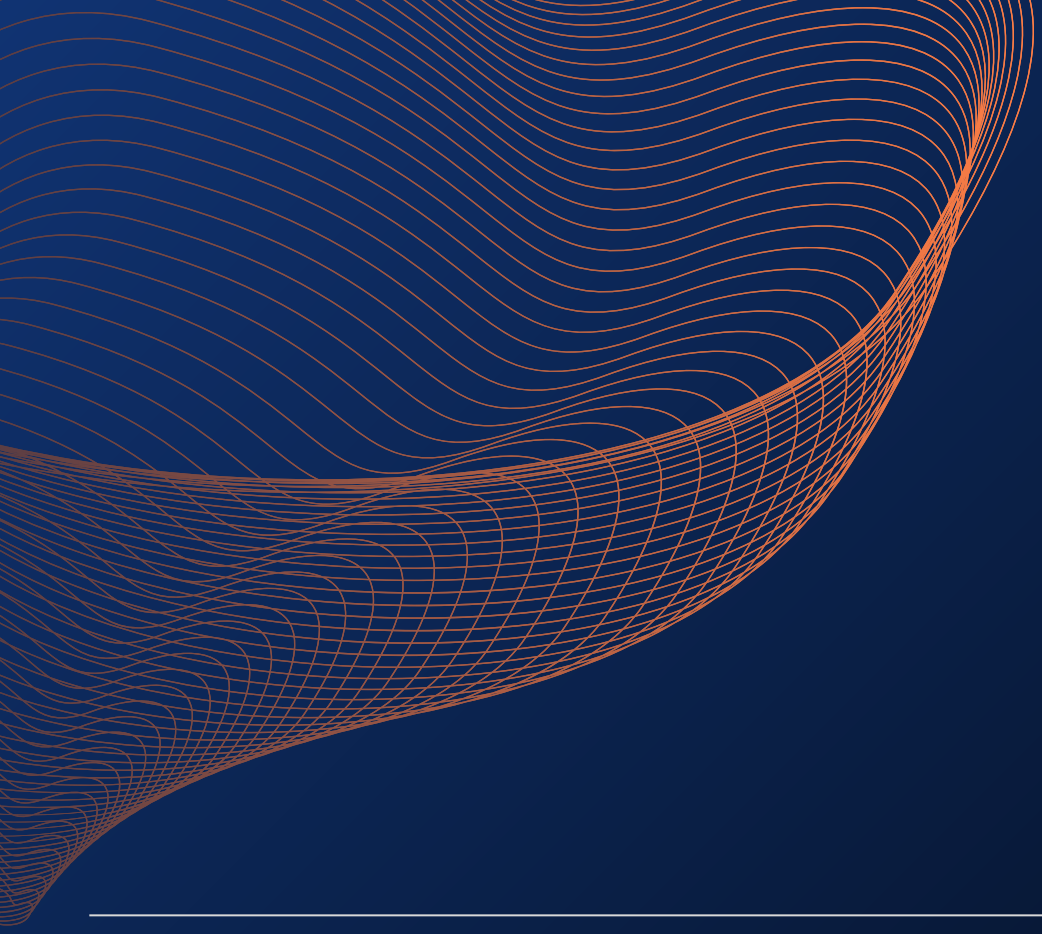
IgniteData is a leading innovator in clinical research technology, transforming how hospitals and research sites transfer patient data for clinical trials. Our cutting-edge Archer technology streamlines data connectivity, reducing inefficiencies and accelerating the delivery of life-changing treatments to patients.

Our team brings together experts in clinical research, data security, and healthcare technology, working alongside global pharmaceutical leaders and top-tier research institutions.

We partner with 75% of the top comprehensive cancer centers, operate across four continents, and maintain 99.999% data accuracy–ensuring research teams can focus on discovery rather than data management.

We collaborate with research organizations, hospitals, and industry leaders to modernize clinical trials, upholding the highest standards of trust, security, and efficiency. Through our commitment to innovation and operational excellence, we are redefining study data interconnectivity and shaping the future of clinical research.

**Learn more at www.ignitedata.com.**



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