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Genomics England and IQVIA Delivering the future of genomics in partnership

Public Policy Projects

Sir John Chisholm
Chair, Genomics England

Foreword

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Genome sequencing has the potential to save lives by identifying genes that cause illness as well as developing and targeting treatments. In doing so, this will generate unprecedented amounts of clinical data; much of which we are yet to fully understand.

That's why the recent collaboration between Genomics England and IQVIA is to be welcomed. By combining Genomics England's detailed genomic and clinical data on 70,000+ people with IQVIA's experience of data analytics and clinical data management, it can revolutionise how we understand – and ultimately treat – illness and disease.

Since our foundation in 2013 Genomics England has been at the forefront of genomic innovation; from working with partners to speed the process of genomic mapping whilst reducing the costs, to developing a bespoke storage environment capable of managing vast quantities of genomic and clinical data.

Our partnership with IQVIA is the next step on that journey. This collaboration will allow more researchers than ever – from academia, industry, charities – to access de-identified data and create custom clinical-genomic datasets to conduct research. This will provide deep insights into both patients and disease, which in turn should speed the development of targeted treatments.

We are now beginning to see the first generation of precision medicines enter the market, targeted at patients with specific genomic tumour aberrations and certain rare diseases. The development of such treatments would not be possible without our rapid advancement in understanding of the human genome.

I am excited about the future of global healthcare innovation, and I believe genomics will be at the heart of this advancement. But for this to be a reality we have to utilise the data we are generating, and we look forward to partnering with IQVIA to do so.

Tim Sheppard
Senior Vice President and General Manager, Northern Europe, IQVIA

Foreword

At its heart, IQVIA is a company driven by advancing human health. We do this by conducting clinical trials of new medicines across the globe, but also by using breakthroughs in insights, technology and human intelligence to help medical and scientific advances benefit patients.

Technology is at the heart of what we do. IQVIA integrate data, analytics and healthcare expertise to enable decision making and to drive collaboration. In the UK, we receive data from all NHS Trusts and in return provide feedback such as medicines optimisation tools, patient level costs and clinical coding services. We also use AI algorithms to find undiagnosed patients with Hepatitis C and rare disease and to identify under-treated patients.

Genomics is a growing branch of healthcare, with an increasing demand for data. To meet the demands of the genomic data revolution, IQVIA is collaborating with Genomics England to link clinical data with genomic data. This world leading collaboration will liberate this data to be utilised by medical researchers, which has the potential to transform how clinical research is done for the benefit of patients, life sciences companies and the wider UK economy.

Drawing insights from clinical-genomics datasets is part of the future fabric of real-world research, and IQVIA is delighted to be a pioneer in this evolving field. By conducting deep analysis into these complex datasets and facilitating genomically enabled clinical trials we aspire to play our part in accelerating the discovery of precision therapies and advancing human health.

Executive summary

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What is Genomics?

Genomics has the potential to transform patient outcomes. By mapping a person's DNA and comparing it to a database of DNA maps, it is possible to identify the genes that causes disease, and potentially design targeted treatments.

Genomics is a rapidly evolving branch of science. In 2003 scientists sequenced the first human genome, and in December 2018 Genomics England announced they had achieved their ambition of mapping 100,000 genomes in just four years, with a new goal of five million genomes mapped in the next five years. Technology is moving so quickly that whilst it once took thirteen years and £2bn to sequence a genome, it now takes two days and costs £1000.[1]

This is a revolution in medical science. Doctors have always tried to personalise treatment, but in reality they have had to match symptoms with available treatments, in the full knowledge the patient is likely to experience side effects. Genomics will allow us to predict who is likely to develop a disease and how an individual will respond to treatments.

Why is this Interesting: The Genomics Data Market

"The market for genomic data continues to accelerate"

It is estimated the global genomics market is worth around $15bn in 2017, set to grow at a CAGR of approximately 10 per cent between 2017 and 2024.[2] Alongside this, the market for genomics data continues to accelerate. In 2018 it is worth over $4bn to the drug discovery and development market. This is set to grow to $5.8bn by 2022.[3]

The first genomics medicines are now reaching patients; with 41 per cent of treatments approved by the United States Food and Drug Administration (FDA) in 2017 considered 'personalised'.[4]

Who uses Genomic Data?

"High profile partnerships in the pharmaceutical industry demonstrate the importance of Genomic data"

Over the last five years many of the global pharmaceutical leaders have partnered with genomics companies, including 23andMe, Ancestry, Biobank, Regeneron and others to utilise their data in drug research.

National governments also see the benefit of genomic research, and there are multiple collaborations between pharma companies and government research bodies to sequence genomes and attract research. In the United States, the National Institute for Health (NIH) is partnering with eleven pharmaceutical companies to identify and validate biomarkers for cancer therapies. This includes $215m of funding as part of the Cancer Moonshot Initiative.[5] In Finland, the FinnGen Study for complex disease genomics - which is a collaboration between Finnish scientists and seven pharmaceutical companies - aims to genotype and analyse 500,000 genomes by 2023.[6] In Saudi Arabia the Saudi Human Genome Project is a ten-year project to find the genes responsible for the genetic disease which impact the Kingdom by sequencing 20,000 people.[7]

Who are the Partners: Genomics England & IQVIA

Genomics England is responsible for whole genome sequencing in the United Kingdom. With 100,000 genomes now sequenced; the ambition is now to sequence five million genomes in the next five years.

IQVIA is a world leader in global health data with one of the largest and most comprehensive collections of healthcare information in the world. The tools it develops allows companies and researchers to interrogate this data to advance science.

What is the Genomics England-IQVIA collaboration?

"To meet the demands of the genomic data revolution, IQVIA and Genomics England are collaborating to link clinical data with genomic data"

The collaboration between Genomics England and IQVIA will develop a platform which will connect clinical and de-identified genomic data to accelerate treatment advancements for patients. This alliance will enable faster and more efficient drug research, more robust evidence to support treatment value and greater access to personalised medicines.

Using IQVIA's E360™ platform, researchers will have privacy-protected, technology-enabled access to Genomics England's patient-consented, de-identified data to create custom clinical-genomic datasets and run leading-edge analytics on genomics and observable traits.

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What is the Impact of the Collaboration?

"This collaboration has the potential to improve health outcomes by speeding research, targeting focus and reducing costs."

The UK has a world leading genomics dataset which can be used to stratify patients, improve drug development, identify biomarkers and enable researcher access to samples. Together, this will result in better healthcare outcomes for patients:

Precision Trials: A molecule for the treatment of pancreatic cancer has been granted US FDA Orphan Drug Designation and is currently being trialed in patients as a result of Genomics England's provision of genomic sequencing and longitudinal follow up for UK study patients. This has not only speeded up the molecule's progression through testing, but reduced trial costs by between 30 and 50 percent due to better targeting of patients.

Patient Identification: In very rare conditions, such as nephronophthisis (NPHP) it can be hard to identify patients. Genomics England helped a pharmaceutical company identify twelve previously undiagnosed patients with homozygous NPHP1 deletions. Of these, at least nine had chronic kidney disease with presentations consistent with NPHP. By identifying these patients the healthcare system was able to better treat their disease, but also analyse HES data to better understand disease history. Ultimately, this finding can be used to develop treatments for the condition.

Environment for Research: Collaboration with Genomics England also enables a safe environment for research, with secure data documentation, tools analysis and robust workflow and collaboration tools to allow integrated working from multiple sites and locations.

What are the benefits of the Collaboration?

"Genomic data is a critical element to transform clinical research and Healthcare delivery"

Combining IQVIA's leading real-world technologies and services experts with Genomics England's de-identified patient datasets, network and infrastructure to generate, organise, and enhance genomic data, can make the United Kingdom one of the most attractive places for life sciences companies to invest.

This collaboration will put the UK at the forefront of being able to offer genomically-enabled clinical trials. By using genomics, researchers can identify the right patient, reduce costs and speed timelines; all of which make the UK a destination for investment.

Benefits for Individuals
Genomic data interrogation should speed up the process of medicine research, by enabling identification of drug targets, as well as easier identification of patients who could benefit from treatment. Under certain circumstances, the collaboration will also enable UK patients to have whole genome sequencing as part of a clinical trial.

Benefits for Life Sciences Companies
Medicine development is a long and costly process, with a low success rate. This collaboration will allow researchers to accurately identify and validate drug targets thereby reducing the failure rate and predicting costly off-target reactions.

Benefits for UK Plc
A healthcare ecosystem which encourages and supports genomic research - and has the tools to facilitate such analysis through the Genomics England-IQVIA collaboration - will make the UK a competitive location for life sciences investment.

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What is Genomics?

Genomics is the study of an individual's genome. A genome is the complete set of a person's DNA; which itself is the chemical compound that is the basis for all living organisms. Almost every cell in the body contains a complete copy of the three billion DNA pairs which make up the human genome. DNA contains all the information needed to build the human body; and each of the 20,000 genes in the human genome code for an average of three proteins.[8]

Everyone's genome is different. 99.8 percent of our DNA is the same as other human beings, but it is the 0.2 per cent of variation that make us unique. Much of it is perfectly healthy – the difference between blue and brown eyes – but sometimes that variation can cause disease.

Genomic medicine works by mapping an individual's DNA and comparing it to a database of DNA maps to identify the genes which maybe causing disease. Considering there are around 20,000 genes in each person's genome, and three billion pairs of letters in an individual's genome, identifying the single variant which causes disease can be challenging.

Most human illnesses have some basis in our genes. For some disease – such as Down's Syndrome or sickle cell anaemia – the gene has been identified. However, for many diseases, including some rare diseases, the variant gene or genes that causes illness have not been identified. In cancer, the tumour cells have a different genome to the healthy cells. Even for those diseases which are not solely genetic there may be a genetic element as well as an environmental one, with the environmental factors triggering a genetic susceptibility.[9]

By mapping as many genomes as possible – from both patients with disease and healthy patients – it is possible to see patterns. These gene patterns - alongside medical records and other diagnostic tests – can be used to identify whether people might become ill, and whether a treatment might be suitable. The goal of genomics is to identify the gene variants which cause disease so that a more accurate diagnosis can be provided, and ultimately develop therapies which can precisely target the variant gene or genes.

Key UK Achievements in Genomics

100,000 Genomes

13 Genomic Medicine Centres and...

85 NHS Trusts within them are involved in recruiting participants

70,000 Patients and family members

1,500 NHS staff (Doctors, Nurses, Pathologists, laboratory staff, genetic counsellors)

21,000 Petabytes of data. 1 Petabyte of data would take 2,000 years to play on an MP3 player

2,500 Researchers and trainees from around the world

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Genomics and Rare Diseases

Genomics England estimates that there are between 5,000 and 8,0000 rare diseases in the UK, affecting around three million people (5% of the population). Around half of those with a rare disease will be given a genomic diagnosis. The 100,000 Genomes Project focused on 1,200 disorders with diagnostic unmet need after usual care. The disorders included in the programme have been nominated by the NHS, researchers and industry.[10]

It is estimated that patients living with rare diseases visit an average of 7.3 healthcare professionals before receiving an accurate diagnosis, and the mean length of time from symptom onset to accurate diagnosis is 4.8 years.[11]

Genomics and Cancer

Cancer affects four in ten people during their lifetime and there are 365,000 new cancer cases per year.[12] In all cases, cancer is caused by mutation in critical genes which then multiply, causing a tumour. The tumour grows as the abnormal cells multiply. In cases of germline mutations these variants are inherited, such as the BRCA1 and BRCA2 genes which lead to an increased risk of breast and ovarian cancers. Somatic mutations can be caused by environmental factors, such as damaging UV rays. By comparing genomes from both these forms of cancer with a healthy genome it is possible to identify – and then target – the affected genes.

UK Government and Genomics

Genomics England was announced by then Secretary of State for Health and Care Rt Hon. Jeremy Hunt MP during the 65th anniversary of the NHS celebrations in July 2013. Its goal was to deliver the 100,000 Genome project, which aimed to sequence 100,000 whole genomes from NHS patients with rare diseases and common cancers. Genomics England is the central coordinator of whole genome sequencing in the UK. It oversees sample and clinical data collection at Genomic Medicine Centres, storage, extraction, sequencing, interpretation and reporting.

Objectives of Genomics England:

- To bring benefits to patients;
- To create an ethical and transparent programme based on consent;
- To enable new scientific discovery and medical insights;
- To kick-start the development of a UK genomics industry.[13]

In December 2018 Genomics England announced it has achieved its objective of sequencing 100,000 genomes.

In October 2018 the new Secretary of State for Health and Care Rt Hon. Matt Hancock MP announced an expanded role for Genomics England with new goals for UK genomics:

- Expansion of the 100,000 Genomes Project to see 1m whole genomes sequenced by the NHS and UK Biobank in five years.
- From 2019, the NHS will offer whole genome analysis for all seriously ill children with a suspected genetic disorder, including those with cancer. The NHS will also offer the same for all adults suffering from certain rare diseases or hard to treat cancers.
- Sequence 5m genomes in the UK, within an unprecedented five-year period.

According to the Second Life Sciences Sector Deal, Government commitment has already generated significant interest and potential new investment to the UK with several companies and charitable organisations expressing an interest in partnering on these projects.[14]

In addition, Genomics England has announced it will undertake detailed development work on a new service to enable genomic volunteers to pay for a personalised report on their unique genetic makeup. This anonymised data will then be made available to researchers and scientists.

Genomics England is funded by the National Institute for Health Research and NHS England. The Wellcome Trust, Cancer Research UK and the Medical Research Council also funded research and infrastructure for the 100k Genomes Project.

The Genomics Market

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The era of genomic medicine has arrived. Genome-based research has already resulted in improved diagnostics and some new therapies. Over 250 medicines are now approved by the Food and Drug Administration (FDA) in the United States for use based on a patient's genetics.[15] Within the next few decades it is highly likely that gene therapy will become the norm, with treatments tailored to an individual's genetic make-up.

Despite this progress, it takes on average 10-15 years for a medicine to move from the bench to the bedside[16], and this could be considerably longer for some genetic treatments. Currently, there are some gene therapies, diagnostics and pharmacogenomic tests available, and this number is rapidly expanding:

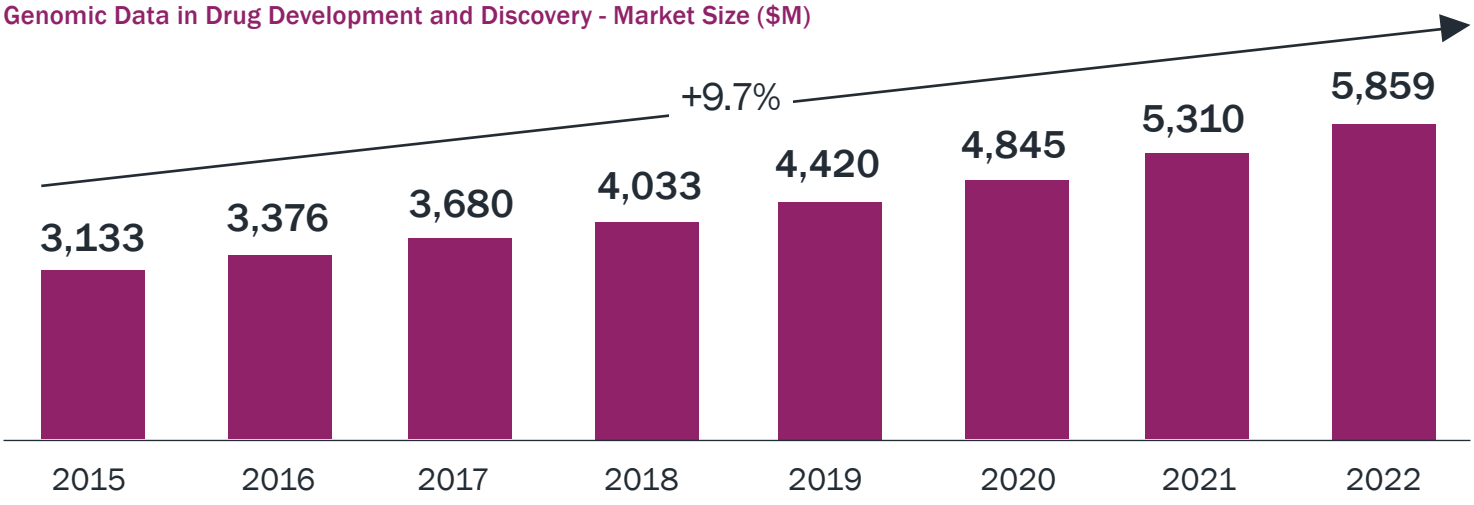
Treatments: In 2017, sixteen of the forty-six New Molecular Entities (NMEs) approved in the United States – as well as three gene therapies – were genomic medicines.[17] Nine of the sixteen were oncogenomic treatments for cancer.

Screening and Diagnostic Tests: Many hundreds of genetic tests are now available in the UK via the NHS,[18] with this number continuing to grow as more genes are identified as being linked to - or increasing the risk of - disease.

Pharmacogenomics: Increasingly, information about a patient's genetic make up can be used to tailor drug therapies, reducing adverse reactions. As approximately 1 in 16 hospital admissions in the United Kingdom is linked to a reaction to a medicine[19], better understanding of how patients will react so that treatment can be tailored and could result in better outcomes for the patient. Such treatment is now routinely available in Australia, Norway and Canada.[20]

It is estimated the global genomics market is worth around $15bn in 2017, set to grow at a CAGR of approximately 10 percent between 2017 and 2024.[21] Alongside this, the market for genomics data continues to accelerate. In 2018 it is worth over $4bn to the drug discovery and development market. This is set to grow to $5.8bn by 2022.[22]

Genomic Data in Drug Development and Discovery - Market Size ($M)



With the establishment of the Genomic Medicine Service, the UK is aspiring to maintain its world-leading position in genomics research. The objectives of the service are:

- Enabling a quicker diagnosis for patients with a rare disease;
- Matching people to the most effectiveness medications and interventions, reducing the likelihood of an adverse drug reaction;
- Increasing the number of people surviving cancer because of a more accurate and early diagnosis and more effective use of therapies.[23]

This will bring benefits not only for patients, but also the wider economy, as it will increase the attractiveness of the UK as a destination for life sciences investment. Life Science companies have already identified the importance of genomics to their businesses with some high profile collaborations, most notably in oncology, where tissue-agnostic therapies have attracted significant research funding.

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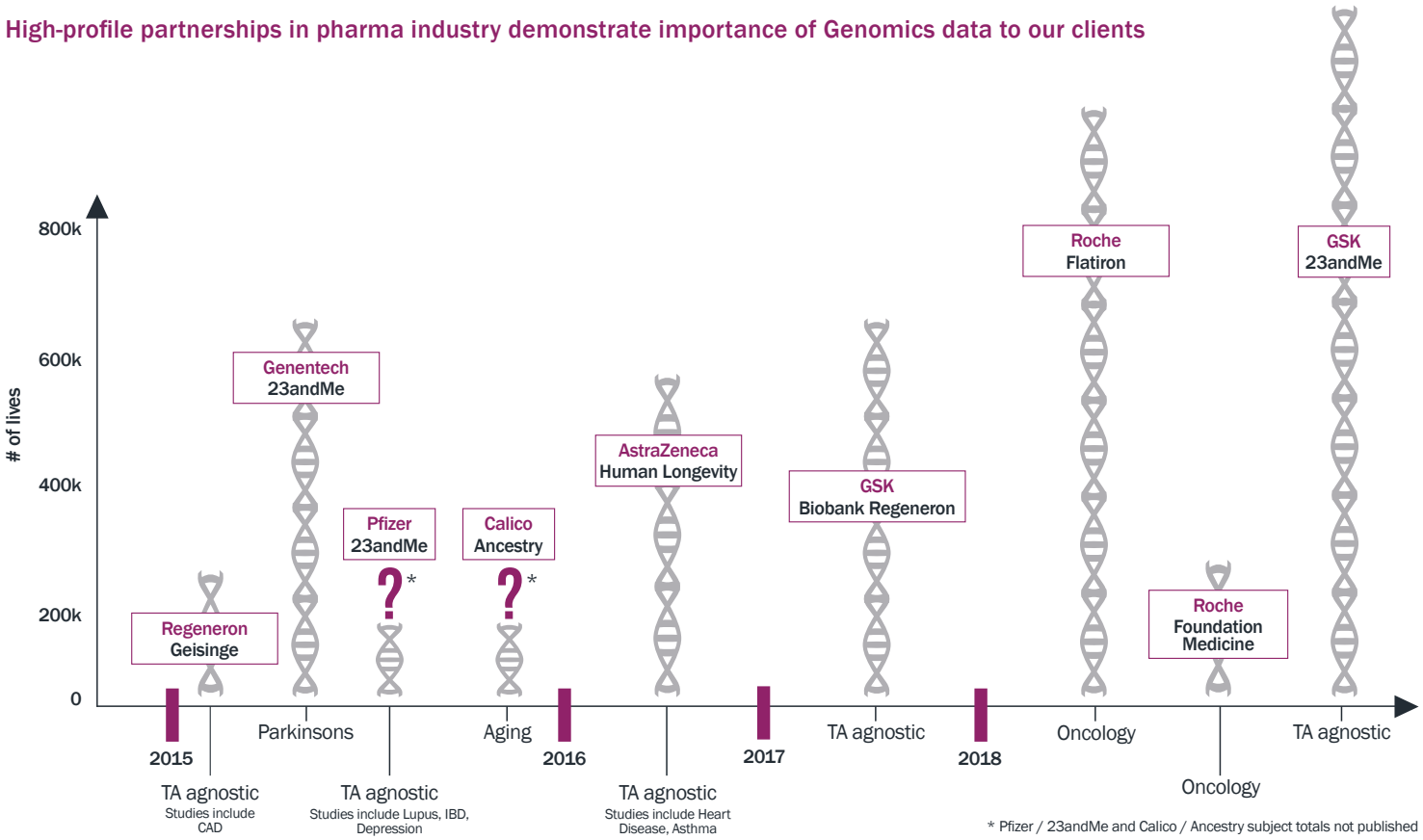
High-profile partnerships in pharma industry demonstrate importance of Genomics data to our clients



It is not just the UK that recognises the importance of genomics, both to patients and the wider economy. This is a highly competitive sector, in which countries are competing to attract investment.

United States: The National Institute for Health (NIH) is partnering with eleven pharmaceutical companies to identify and validate biomarkers for cancer therapies. This includes $215m of funding as part of the Cancer Moonshot Initiative.[24]

Finland: The FinnGen Study for complex disease genomics - which is a collaboration between Finnish scientists and seven pharmaceutical companies - aims to genotype and analyse 500,000 genomes by 2023.[25]

Saudi Arabia: The Saudi Human Genome Project is a ten-year project to find the genes responsible for the genetic disease which impact the Kingdom by sequencing 20,000 people.[26]

The UK Government must continue to invest and support this field of research if it wants the UK to remain a world-leader.

The Genomics Market

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In response to the need for robust, future proofed systems to manage this data and make it available for research Genomics England and IQVIA have recently announced a collaboration to advance healthcare through the appropriate use of clinical-genomic data. By using IQVIA data management tools combined with Genomics England datasets the ambition is to enable faster and more efficient research, which in turn should lead to more treatment options for patients. This collaboration has three strands:

1. Feasibility Research: This enables partners (primarily pharmaceutical and biotech companies, but also research organisations and not-for-profits) to access and interrogate Genomics England's de-identified clinical and genomic datasets using IQVIA's E360™ Platform. This will allow them to quickly assess the usability of the data for research projects and run leading-edge analytics on patient and disease traits.

2. Analytical Consultancy Services: When a specific research question requires further interrogation and analysis of the de-identified patient data, IQVIA, with Genomics England support, will carry out analysis for customers for specific subsets of Genomics England's clinical and genomics datasets. This could include:

- Burden of Illness
- Treatment Pathways Studies
- Comparative Safety/Efficacy Studies
- Drug Discovery
- Drug Target Identification
- Drug Repurposing
- Health Economics and Outcomes Research
- Genome Wide Association Studies (GWAS)
- Pharmacogenomic (PGx) Event Detection
- Companion Diagnostic (CDx) Development
- Clinical Trial Interpretation/Analysis

This analysis will help advance precision medicine and patients' access to novel therapies – with the goal of delivering the right drugs to the right patients at the right time.

3. Genomically Enabled Clinical Trials: The collaboration facilitates genomically-enabled clinical trials, with the UK at the forefront. Possible trial patients can be identified from Genomics England datasets, and for trials with a UK investigator site there is the option of having a whole genome sequence performed on these patients in parallel to the clinical trial. It would then be possible to add the clinical trial data into Genomics England's platform to enable the life sciences company and/or IQVIA to analyse the linked clinical trial data, the genomics data and the Patient Associated Data for these patients. This could be particularly beneficial for rare diseases where patient numbers are small and enrolling enough patients to demonstrate efficacy can be challenging.

Benefits of the Genomics England & IQVIA Collaboration

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This collaboration is vital in helping the UK maintain its place at the forefront of genomic research. It will benefit not only individuals, but also the wider UK economy and the life sciences companies who choose to utilise this new collaboration.

Benefits for Individuals

Individuals with some genetic disorders have significantly reduced life expectancy and poorer quality of life. This collaboration could not only enable a patient to have genome sequencing as part of a clinical trial, but it will also allow for significant health data interrogation, which could provide further information on health conditions or possible treatment options.

In very rare conditions, it can be difficult to identify patients and hard to diagnose disease. Genomic sequencing and genome research can enable faster and more accurate identification. This will not only result in better treatments, but also allows for mining and analysis of current datasets, such as the NHS Hospital Episode Statistics (HES), to identify other symptoms, biomarkers or disease history.

Genomic research can also lead to more accurate targeting of medicines to those patients who will benefit. A 2016 NHS England report concluded that "key pharmaceutical interventions are effective in only 30–60 per cent of patients due to differences in the way an individual responds to and metabolises medicines".[27] By targeting medicines it should be possible to improve that efficacy rate, and ensure only those who can benefit receive a medicine, which brings improvements to both the NHS funding the treatment and, most importantly, the patient.

Benefits for Life Sciences Companies

The UK is the single biggest integrated health system in the world, with NHS records dating back to 1948 giving a unique data set, ripe for interrogation. By combining the information which can be taken from medical records with the Genomics England dataset and IQVIA interrogation tools it will be possible to get answers to a range of research questions.

Access to such information is vital for life sciences companies as they develop new treatments. An environment which encourages such research - and has the tools to facilitate such analysis - will make the UK a competitive location for life sciences investment.

Evidence suggests that using genomic sequencing to identify patients for inclusion in a clinical trial can reduce trial costs by 30-50 per cent. Alongside this, better quality data could help reduce drug failure rate. Medicine development is a long and costly process, with a low success rate. If genomic research can accurately identify and validate drug targets it would reduce the failure rate and possibly predict harmful off-target reactions. The clinical success rate for medicine development could be increased, thereby reducing development costs, and ultimately the price paid by the health system.

Benefits for UK Plc

The Life Sciences sector is a significant contributor to the UK economy, generating £64bn of turnover and employing more than 233,000 scientists and staff.[28] The Government has identified the life sciences as a key sector the UK economy in a post-Brexit world,[29] however 44 per cent of participants in a recent IQVIA survey[30] believe that Brexit will make the UK less attractive for product launches. As pharmaceuticals in a globally harmonised industry, retaining attractiveness to multinational companies will be challenging.

The 2018 American Pharmaceutical Group (APG) Global Insights Survey questioned US life sciences senior leader on their views of the UK, and 86 per cent agreed that uncertainty over Brexit is affecting global decisions about future investments in the UK.[31] However, many identified access to high quality real world data as an attractive factor when making investment decisions.

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Case Study: Genomics England Discovery Forum

As members of the Genomics England Discovery Forum companies have access to selected, de-identified whole genomes and clinical data from the Genomics England dataset. In return, all discoveries have to be shared with Genomics England's science team as well as all the other Forum members, guaranteeing the quickest possible developments for patients. As a result, two forum members - Alexion and BioMarin - have identified previously undiagnosed patients with severe conditions.

Nephronophthisis (NPHP) is a childhood genetic disorder affecting primarily the kidneys. It's rare (around 1 in 60,000 births) and very serious, usually resulting in kidney failure by the age of 15. It is responsible for 15 per cent of cases of childhood end-stage renal failure – with no treatment currently available to prevent this.[32] Using Genomics England's dataset, Alexion has identified 10 undiagnosed patients, recruited as part of the 100,000 Genomes Project's rare disease programme, who carry the gene deletion causing the disease. These findings have been shared with Genomics England and fed back to the patients' NHS clinical teams. This is an exciting first step in identifying the cause of the illness, which aims to lead to further research and treatment.

CLN2 disease is a very rare inherited disorder caused by mutations in the TPP1 gene and one of a group of life limiting conditions called Batten Disease. The first symptoms strike after the age of 2, with symptoms typically emerging in children between the ages of 2 and 4. CLN2 is one of a group of disorders collectively known as Batten Disease and can lead to seizures, muscle twitches, vision loss, intellectual disability and behavioural problems.[33] Around 30 to 50 children live with the condition in the UK, and life expectancy is around 10 years. Currently, there is no cure or life-extending treatment for CLN2.[34]

Biopharmaceutical company, BioMarin, is another Discovery Forum member focused on rare disease patients. It has identified one patient recruited into the 100,000 Genomes Project for a condition unrelated to CLN2, but who carries two pathogenic mutations of the TPP1 gene. Moving forward, BioMarin intends to engage the UK's National Institute for Health and Care Excellence (NICE[35]) and NHS England[36] on the use of its cerliponase alfa treatment in the NHS.[37] Ultimately, it is hoped that work from BioMarin and others, supported by evidence from the Genomics England database, will bring clinicians more options in the treatment of CLN2.

One Piece of the Puzzle

Genomics England and IQVIA have taken a significant step with their wide-ranging collaboration, which will put high quality genomic data in the hands of researchers who can use it to better respond to complex challenges around illness and disease. However, this is just one element of the ecosystem needed in order to retain the UK's position as a world-leader in genomics. Alongside important innovations such as the IQVIA-Genomics England collaboration the UK Government should:

Generation Genome: Implement in full the recommendations of Dame Sally Davies Report Generation Genome.[38] There has been significant progress, including a national network of genomics services and making data accessible – but this valuable report should be revisited and its recommendations reviewed.

Life Sciences Strategy: Implement in full Sir John Bell's Life Sciences Industrial Strategy, which sets out a clear path to a strong life sciences ecosystem.[39]

NHS Commissioning: For genomic research to become a routine part of healthcare, the Government must ensure systematic application of genomic data and the use of genomic research in the management of NHS patients, including routinely sequencing tumour samples.

Genomic Medicine Service: The Government must continue to fund and support the recently launched Genomic Medicine Service, to ensure continued progress in this area, as well as equity in access to treatment and services across the UK.

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Patient and Public Education: This is a fast paced and highly complex branch of science; however steps must be taken to continue to educate patients and the public about the importance of genomic research in tackling illness, and the use of data for research via secure and anonymised datasets.

Access to Treatments: There continued to be significant UK taxpayer investment into research into genomic conditions, and whilst this is welcomed, it must be matched by investment in access to these treatments, so that UK patients can benefit from any medicines developed from this research. Access to innovative medicines in the UK remains low and slow when compared with other European countries,[40] and it vital that UK patients can access the medicines that have been developed using UK research investment and data.

About Genomics England

Genomics England, a company wholly owned and funded by the Department of Health and Social Care, was set up to deliver this flagship project which has now sequenced 100,000 whole genomes from NHS patients. Its four main aims are: to create an ethical and transparent programme based on consent; to bring benefit to patients and set up a genomic medicine service for the NHS; to enable new scientific discovery and medical insights; and to kick-start the development of a UK genomics industry.

About IQVIA

Formed through the merger of IMS Health and Quintiles, IQVIA is headquartered in the USA. It has more than 55,000 employees operating in more than 100 countries.

IQVIA offers a broad range of solutions that harness advances in healthcare information, technology, analytics and human ingenuity to drive healthcare forward. It enables companies to rethink approaches to clinical development and commercialisation and to innovate with confidence, as well as accelerate meaningful healthcare outcomes. Its insights and execution capabilities help biotech, medical device and pharmaceutical companies, medical researchers, government agencies, payers and other healthcare stakeholders who tap into a deeper understanding of diseases, human behaviours and scientific advances, in an effort to advance toward cures.

As a human data sciences company, IQVIA has one of the largest and most comprehensive collections of healthcare information in the world, which includes more than 530 million comprehensive, longitudinal, non-identified patient records spanning sales, prescription and promotional data, medical claims, electronic medical records and social media. This scaled and growing dataset contains approximately 30 petabytes of proprietary data sourced from more than 120,000 data suppliers and covering over 900,000 data feeds globally. Using this data, IQVIA delivers information and insights about more than 85 percent of the world's pharmaceuticals, as measured by 2016 sales. IQVIA's data is widely referenced in the industry and used by governments, payers, academia, the life sciences industry, the financial community and others.

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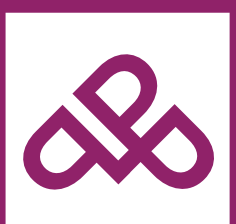

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