

# SAIL DATABANK







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When we concluded last year's Annual Report with the sentence "We anticipate the year ahead will be potentially the most challenging of SAIL's existence" we had no idea how prescience that statement would prove to be! The emergence of the COVID-19 virus in December 2019 rapidly escalated into a worldwide pandemic by March 2020, with the international community engulfed in an unstable and rapidly changing situation, death and infection rates rising exponentially, and societies retreating into lockdown. This global catastrophe led to unprecedented demands for data by government, health organisations and the general public to enable them to track and predict the trajectory of the virus and plan counter-measures.

The SAIL Databank, with its rich data resources and established world-leading technology and

governance structures, was uniquely prepared to address this need, and we are immensely proud of the contribution we have made to the national and international emergency response. Health Data Research (HDR) UK, who monitor and co-ordinate the provision of data for COVID-19 research by Trusted Research Environments (TRE's) across the UK, recognised SAIL Databank as "leading the way across all dimensions, highlighting the benefits of having mature infrastructure in place from the outset."

By June 2020, SAIL Databank was supporting nearly two thirds of all active UK projects focussing on COVID-19, having secured access to sixteen new data sources, and converted nearly half of all enquiries received into live projects, the most urgent of which received data access within five working days of application. In addition SAIL has played a key role in providing intelligence to the Welsh Government's Tactical Advisory Group (TAG) in its COVID-19 response, subsequently feeding into the UK's SAGE (Scientific Advisory Group for Emergencies), as well as providing data to the international research community.

The contribution of SAIL to the COVID-19 response marks an extraordinary culmination to what had already been an outstandingly successful year. Publication of initial findings from a Welsh Government sponsored evaluation of the Flying Start Programme, and the flagship report "Born Into Care" both utilised SAIL data to assess the impact of public service interventions on the health and wellbeing of children and their families. SAIL's involvement in the newly established Health Data Research Hub for Respiratory Health – BREATHE has also been a major achievement and is already proving a valuable alliance in the ongoing fight against COVID-19. As always, and even more so this year, we pay tribute to the extraordinary efforts and talents of the



SAIL team, whose skills, hard work and commitment continue to make SAIL the outstanding success that it is.



The SAIL Databank is partially funded by Welsh Government through Health and Care Research Wales.

The SAIL Databank is a internationally recognised secure repository of data, which provides a key resource to leading research groups within Wales, the UK and internationally. Based at Swansea University, and led by

Professors David Ford, Ronan Lyons and Kerina Jones, SAIL is now in its twelth year of operation and has established itself as one of the best-characterised population databanks anywhere in the world. It contains thirty five health and public service data sources from a wide range of sources including hospitals, General Practices, the education sector and the family justice system. Originally SAIL focussed primarily on data about the population of Wales, but during the last two years it has become a popular and rapidly expanding databank for health and public service data from all over of the UK.

"Wales is a small connected country and our ability to link data anonymously means we shall get even greater value out of that... that is the positive advantage of our SAIL Databank. The need for such a resource has never been greater" Vaughan Gething AM, Cabinet Secretary Health and Social Services

This expansion in data resources has been matched by a 64% increase in numbers of projects supported by SAIL Databank in the last two years. As the COVID-19 crisis accelerated post February 2020, we saw a further doubling of rates of enquiries, around two thirds of which we expect to convert to live projects before the end of 2020. Despite the economic recession, we expect these increased levels of activity to continue for the foreseeable future.

Accredited to the highest industry standards for data security and renowned for its world leading information governance model, SAIL has become a cornerstone resource to the NHS and the Welsh and UK Governments,

"SAIL Databank (Wales) is leading the way across all dimensions, highlighting the benefits of having mature infrastructure in place from the outset" HDRUK COVID-19 Health Data Research Weekly update for SAGE and UKRI/DHSC providing them with essential data to enable the evaluation of services and assess the effectiveness of health and wellbeig interventions. During 2020 SAIL has also been at the heart of the Welsh and UK-wide emergency response to the COVID-19 pandemic, providing data to NHS Wales, Welsh Government COVID-19 TAG, SAGE, local authorities across the UK and a variety of research groups.



The SAIL Databank is a world renowned secure data repository which brings together a variety of information about the UK population. This data is extremely important to research groups within Wales and internationally, who use it to improve public services and to increase health and wellbeing. SAIL data comes from a wide variety of sources; hospitals, General Practices, social care, education and other public service providers. Whenever we access public services such as the NHS, social services or education services, information is recorded about which services we used, why we accessed them and what happened to us as a result. This information has great value and can be used in a variety of ways to improve public services, for example this sort of data may be used to compare different treatments for the same medical condition, to see which treatment produces the best results over time. Welsh Government and NHS Wales also use SAIL data to identify improvements to health and wellbeing caused by services they have provided. This helps them decide if it is worthwhile continuing to invest money in particular schemes, and to check that they are producing the benefits which were expected.

SAIL Databank is recognised as one of the securest research environments in the UK, holding a current ISO 27001 certificate and formal accreditations from UK Statistics Authority and NHS Digital All the data in SAIL is de-identified before it flows into SAIL, via a non-reversible technical process carried out by an independent organisation within NHS Wales, so individuals can never be identified and privacy is fully safeguarded. All requests to use SAIL data are assessed by an independent panel (made up of a combination of data and governance experts and members of the public) who ensure that the research will provide public benefit and that there is no risk to privacy and anonymity.

SAIL is a unique Welsh achievement of which the nation can be very proud. Its technology and security models are

recognised as world leading innovations and have been adopted by over 25 major research platforms worldwide. The data within SAIL allows hundreds of research projects to take place each year, resulting in improvements to health and other public services. This year SAIL has been at the forefront of the response to the COVID-19 pandemic, providing support for over two thirds of all UK research combatting the virus.

From the very beginning of the SAIL Databank, full public involvement was an important priority for us, and it continues to underpin all aspects of our work. We have an extensive public engagement programme, including involving members of the public in our Consumer Panel which help to shape research using SAIL data, and our Information Governance Research Panel which approves every instance of data made available to researchers. For more details about SAIL, and how you can become involved, see our website <u>www.saildatabank.com</u>





The SAIL Databank mission is to provide a safe Trusted Research Environment (TRE) which harnesses populationscaled health and associated data to increase the quality and quantity of research, and support better policy making, practice and citizen health and wellbeing, by working collaboratively with data guardians, academics, members of the public, practitioners and policymakers from Wales, across the UK and internationally.

SAIL has created a world leading resource of linked data, protected by rigorous data governance processes and supported by a unique and extremely innovative technical platform. However the nature of the SAIL mission is such that it is never finished – there is always more which can be done to improve our services and maintain SAIL's position as a world leading research resource. During the last two years we have been focussing on three key development areas, namely;

Supporting more and better research using SAIL Data: This is the heart of the core SAIL service and the work area which the funding provided by Health and Care Research Wales is used to support. Since our establishment, we have increased the numbers of projects which we are supporting year on year, which in turn has led to a sustained increase in the levels of research funding secured by these projects. Between 2018-2020 we streamlined our internal processes to increase efficiency, and this has led to a 64% increase in the numbers of projects supported by SAIL Databank in the last two years.

As the COVID-19 crisis accelerated post February 2020, we saw a further doubling of rates of enquiries, around two thirds of which we expect to convert



to live projects before the end of 2020. These increasing levels of research activity have important economic benefits for Wales, attracting research income, which in turn creates and safeguards jobs.

**Improving data linkage methods and technology:** During the twelve years of SAIL operation a world leading and novel technology platform has been developed, underpinned by substantial database and associated infrastructure, and provides comprehensive data anonymisation, linkage and protection functionality. Over the last two years, this technology (branded UK Secure eResearch Platform (UKSeRP) <u>https://ukserp.ac.uk/</u>) was recognised as being sufficiently advanced to be offered as a package to leading research groups within the UK and internationally, and this was met with immediate interest and engagement by the wider data science community. There are currently 20 separate installations of UKSeRP technology within the UK, and three live international deployments, with further discussions ongoing with a number of interested groups and organisations. The recent COVID-19 pandemic has illustrated the advantages of having a robust infrastructure, capable of making rich linked data available at a moment's notice. We anticipate further uptake of our technology over coming years as organisations rise to the challenges of combatting the pandemic and other public health demands.

Acquiring new and more comprehensive data sources to support research: In previous Annual Reports we have described our ongoing work programme to increase the numbers of data sources available within SAIL. For the last two years we have focussed on responding to Welsh Government's increased recognition of the need to 'join up' public services data about the population of Wales, to enable researchers to identify and study how a wide and complex range of factors interact to affect people's health and wellbeing.

During the past year we have had considerable success in acquiring additional health and other public service data, led

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SAIL helped researchers secure a total of £32,428,282 funding between April 2018 and February 2020.

This has created or secured 33 new jobs within the research / data science community.

This figure does not take into account the increased research activity post February as a result of COVID-19.

by demand from researchers using SAIL. By February 2020 we had acquired Local Authority data from the 'Supporting People' Programme and also three new education data sources - HESA Student Record data, HESA Staff Record data and HESA Destinations of Leavers from Higher Education (DLHE) Record data. The Children and Family Court Advisory and Support Service (CAFCASS) Cymru, CAFCASS England data, Welsh Government Flying Start project, Looked after Children and Children Receiving Care records have been loaded into SAIL, and agreement has been signed for Support and European Social Fund Monitoring data.

We have also negotiated access to key health data sources including The Millennium Cohort Study data from the Centre for Longitudinal Studies, pathology test results from the Welsh Laboratory Information Management Service (LIMS) and Welsh Maternity Indicators data. We have also received the initial two data sources relating to respiratory health as part of our collaboration with BREATHE – The Health Data Research Hub for Respiratory Health. More respiratory data sources will follow as part of the development of the platform over the next twelve – eighteen months.

"Good government policy that solves social and economic problems and improves lives needs good evidence. The work using administrative data for research here in Wales has been UK-leading. I want to encourage others throughout Wales and the UK to realise the benefit of access to data in a secure, robust and ethnical manner. Glyn Jones, Chief Statistician for Wales After February 2020, the onset of the COVID-19 pandemic required greater quantities of data with more frequent updates, and SAIL's established infrastructure and governance models meant that we were able to respond in an agile and responsive way. To meet the requirements of government, the NHS and academic collaborators to support the emergency response, we have negotiated more a frequent set of data flows from NWIS for core data, and have also accelerated the acquisition of key data sources such as Office for National Statistics (ONS) 2011 census data and a range of COVID-19 related data. It is anticipated

the response to the pandemic will also lead to the acquisition of a number of new data sources which we hope to acquire to SAIL for use in intelligence generation and research. In addition, research ready data assets such as the COVID-19 multi-morbidity e-cohort data will be utilised to respond to the pandemic.



\*Impact of COVID-19\*

SAIL has been at the forefront of the Welsh and UK COVID-19 emergency response planning efforts since their inception. Demand for data was unprecedented, with 95 urgent COVID related enquiries received and 16 new data sources acquired within the first two months of the pandemic alone. In response, a single virtual team consisting of SAIL, HDR UK and ADR Wales team members was formed to maximise efficiency. All Welsh Government TAG & SAGE requests were serviced by a single overarching team of Swansea based data scientists, with a "One Wales" approach from the start <a href="https://popdatasci.swan.ac.uk/news/one-wales/">https://popdatasci.swan.ac.uk/news/one-wales/</a>. A number of other requests were directed via BREATHE to encourage collaborative working and reduce duplication of effort. All emergency projects were expedited, being processed through our full governance processes within a 48 hour timeframe. Thanks to the extraordinary efforts by the SAIL team and our IGRP panel members, SAIL has supported more COVID-19 planning and research activities than any other Trusted Research Environment within the UK.

### ZOE - COVID-19 Symptom Tracker

SAIL has formed a flagship collaboration with King's College London, health technology company ZOE and BREATHE to make data from a public 'symptom tracking' app more widely available. Regular downloads of anonymised data from the app are securely delivered through BREATHE for dissemination to the research community via SAIL's secure infrastructure. The data can also be linked with other COVID-19 or more general data sources held within SAIL, to provide additional insights and enable a greater range of research to be undertaken.

Prior to the establishment of national track and trace programmes, the data has been used to inform the 4 nations' emergency COVID committees, providing detailed insight into participant-reported symptoms of COVID-19 across the UK. This information can help to identify spikes in infection rates and enable targeted countermeasures such as local lockdowns or increase testing to be implemented. BREATHE has provided support to the effort through its national network of academic partners, and is working closely with Kings College and other leading scientists

to identify patterns and feedback intelligence which will aid the fight against COVID-19.

Lead researcher Professor Tim Spector from King's College London, said "Accurate real-time data is essential if we are to beat this disease." Professor David Ford from SAIL Databank at Swansea University Medical School, added, "SAIL Databank has been providing researchers the NHS, government and from Universities secure, responsible access to data for over a decade. We are very proud to be involved in this project, which has collected extremely important data to help us all understand the bewildering range of symptoms associated with this awful virus. Through this, and many other parallel initiatives, SAIL is doing whatever it can to make data work hard to address the challenges of COVID-19"

Lives Lost – New study suggests those with COVID-19 who lose their lives, even with underlying health conditions, die much sooner than otherwise expected. The increase in global deaths due to COVID-19 has been widely reported, but media emphasis on 'underlying health conditions' has created an impression that many of these people would have died soon anyway. New research led by Dr David McAllister with colleagues from Glasgow and Edinburgh Universities, Public Health Scotland and the Scottish Public Health Observatory, challenges this view.

Using more than 850,000, anonymised, individual patient records within SAIL Databank the team examined possible associations between age and survival rates against an index of comorbidities. It was estimated that the number of years of life lost was 13.3 for men and 10.9 for women, and in all the study's models the years of life lost remained high at over 5 years, regardless of high counts of multi-morbidity and even among older age groups. This research seeks to provide evidence to policy makers of benefits of shielding identified vulnerable groups, which could help strike a balance as lockdown measures are relaxed.



## Adolescent Mental Health

Professor Ann John, Professor in Public Health and Psychiatry at Swansea University has been conducting a programme of research into the mental health impact of COVID-19, supported by SAIL. Reflecting on her recent paper published in The Lancet Psychiatry, which highlights an urgent need to recognise and tackle the harmful impacts of the COVID-19 pandemic, Professor John commented "Nobody doubts there will be mental health effects of the lockdown ... For many this will be focussed around health anxiety and loneliness but we may also see rises in online gambling, cyberbullying, home drinking, domestic violence and relationship breakdown. Combine these with the economic hardship and bereavement that many are experiencing and it becomes obvious that we must act now to protect the population's mental, and well as, physical health. This means practical advice but also new ways of delivering support and care. We know the impact on mental health will not be experienced equally in our society - people in more deprived households and areas or who are already vulnerable tend to be more at risk. We need to ensure that whatever we do, we don't make those disparities wider but consciously move to address them."

One of the ways in which Professor John herself is addressing the impact of COVID-19 in young people is via the Adolescent Mental Health Data Platform (ADP) which is she leads. The ADP, supported by SAIL, is actively engaged in research to:

**RECOVERY** – In early 2020 the UK New and Emerging Respiratory Virus Threats Advisory Group (NERVTAG) advised that several possible treatments for COVID-19 should be evaluated, including Lopinavir Ritonavir, Interferon β, corticosteroids, and Remdesivir. These groups also advised that other treatments will emerge in the future that require evaluation. SAIL is supporting a project led by Professor Richard Haynes, Oxford University which responds to this call. Paying tribute to the rapid response received from SAIL, Professor Haynes said "RECOVERY is a high-priority public health trial investigating treatments for adults hospitalised with COVID-19. It has been set up very rapidly and has already recruited its first 100 patients in a week, including over 30 in Wales."

> *"I cannot speak highly enough of my experience in using SAIL"* Dr David McAllister, Glasgow University

- Identify mechanisms (e.g. coping strategies and preventive interventions) to support vulnerable groups during
  pandemics;
- Identify interventions that can be delivered under pandemic conditions to reduce mental health issues and boost wellbeing;
- Developing guidelines for public bodies and media organisations on keeping young people individuals informed and promote adherence to advice while preventing over-exposure and mitigating the effect of viewing traumatic content.

**COVIDENCE UK** – With the backing of SAIL Databank at Swansea University's Medical School, a new research study, led by Queen Mary University London in collaboration with Health Data Research (HDR) UK, King's College London, The London School of Hygiene and Tropical Medicine, The University of Edinburgh and Queen's University Belfast, is looking for volunteers to help combat the pandemic now and in the future. The project will help scientists to understand why certain people appear to be at greater risk.

Professor Ronan Lyons, co-director of the SAIL Databank, said "We are delighted that people in Wales will have an opportunity to take part in this ground-breaking research. It will rapidly test whether a number of non-pharmaceutical interventions can reduce the number of people suffering from serious COVID19 infections."

To sign up for this study, go to <a href="https://www.qmul.ac.uk/covidence/">https://www.qmul.ac.uk/covidence/</a>



A new £2.1m research study investigating the risks of COVID-19 on Black, Asian and Minority Ethnic (BAME) healthcare workers has been launched, after higher proportions of associated deaths within these groups were recorded. National ONS data shows that people from minority ethnic groups, particularly South Asian and Black and African Caribbean communities, are up to four times more likely to die from COVID-19, however the reason for this increased risk is not known. Dr Manish Pareek, Associate Clinical Professor at the University of Leicester, and study lead, commented "Even taking into account factors such as deprivation, household structure, age and gender, ethnicity is still is an important predictor of getting infected and having adverse outcomes."

A stakeholder group of major national organisations including the General Medical Council, Royal College of Nursing, the Nursing and Midwifery Council, General Dental Council, NHS Employers and the BAME Professionals' Association will help to conduct the research and provide evidence to policymakers so that decisions can be made in near real-time.

**Professor David Ford, Director of SAIL Databank, said,** "We are pleased and excited to be supporting this very important study. Our role will be to support the construction of a fully de-identified but linked data of over two million people. This resource, assembled for the very first time, held securely and under strong governance, will be capable of providing important new insights into how COVID-19 has affected BAME healthcare staff across the UK."

Commenting on the announcement of UK-REACH, **Chief Medical Officer for England and Head of the NIHR**, **Professor Chris Whitty, said:** "With evidence showing that people from Black, Asian and minority ethnic backgrounds are more severely affected by COVID-19, it is critical that we understand what factors are driving this risk to address them effectively".

**Science Minister, Amanda Solloway, said:** "COVID-19 has had an enormous impact on all of our lives, but sadly we have seen that people from Black, Asian and minority ethnic backgrounds are disproportionately affected by this terrible disease. There is an urgent need to better understand the complex reasons behind this. These new projects will enable researchers to work directly with ethnic minority groups to improve our evidence base and,

"The SAIL Databank is a valuable asset in supporting our understanding of how COVID-19 is impacting on the health and wellbeing of people in Wales. We have actively worked alongside and encouraged collaboration with SAIL Databank, to build on the strength of expertise available here in Wales." Dr Rob Orford, Chief Scientific Adviser for Health, Welsh Government crucially, save lives."

Health Minister, Lord Bethell, said: "I am deeply concerned by the disproportionate impact of this horrible virus on some minority communities. We need to find out what's causing this, so we can stop these deaths. These research awards will give Britain's scientists resources they need to answer the urgent questions behind these disparities so we can address the root causes and save lives."

## Data Research Alliance and Workbench

UKSeRP technology, developed within the SAIL Databank environment will underpin the new International COVID-19 Data Research Alliance and Workbench. The International Alliance is an independent consortium of leading life science, philanthropic and research organisation uniting to respond to the COVID-19 global pandemic by supporting support the rapid development of therapies. Convened by Health Data Research UK, it will draw on expertise and work in partnership with the established UK Health Data Research Alliance, to align members to a common set of principles and standards for the ethical and responsible use of data for public benefit. The founding members of the International Alliance bring their collective data assets, expertise and funding, and including the Bill & Melinda Gates Foundation, Minderoo Foundation, Wellcome, African Academy of Science, HDR Network Canada, Genomics England, and the Infectious Disease Data Observatory.

The Workbench technology, delivered by Scottish firm, Aridhia, and supported by SeRP, will provide a set of tools that allows scientists to discover, access and analyse global multi-dimensional data whilst respecting confidentiality and privacy to develop an efficient approach to working across boundaries, essential to achieving a rapid response to COVID-19 and future pandemics.

Professor David Ford, Director of SAIL Databank and SeRP, said, "We are delighted that Swansea University's Secure eResearch Platfrom (SeRP) is providing the 'Adaptor' technology to this important collaboration. Working with Aridhia, we will deliver the means by which independent, well governed, data repositories can participate in large scale federated research studies enabled by the Alliance, without having to move their data out from their local control.

### Controlling COVID-19 through enhanced population surveillance and intervention (Con COV): a platform approach

Funded by DHSC/UKRI and led by Professor Ronan Lyons, this project brings together a specialist research team made up of representatives from Welsh Government, Public Health Wales and academia which will to integrate multiple sources of data within the SAIL Databank. The project will: 1) provide detailed insight into the evolving pandemic in the general population, vulnerable groups and diverse settings (health care workers, social care workers, care homes and schools);

2) support and undertake evaluations of the effectiveness of adopted counter measures as these evolve;

3) rapidly inform policy and practice decision makers; and

4) communicate effectively with the general public.

The project also includes funds to support further associated research, requirements for which will become apparent as the work of the group develops. Each week the project will provide a report to the Welsh Government COVID-19 Technical Advisory Group (TAG) and UK Government's SAGE; this will help inform evidence based strategies to control the virus, safe guard the general population and assist in bringing the UK out of lockdown.





### **Developing Collaborative Partnerships**

SAIL is a key partner in a £4.6m UK wide consortium to develop the BREATHE platform, which will use data to advance the development of new treatments and innovation in care delivery for conditions such as asthma,



chronic obstructive pulmonary disease and respiratory infections, that will benefit the NHS, patients and industry. SAIL will provide the data hosting environment, the data access and information governance framework for researchers and will also play a significant role in data acquisition. BREATHE is one of only seven prestigious HDR UK data hubs and competition for the funding was extremely tough. SAIL's state of the art data hosting and management facilities were identified as one of the key

factors considered by the funders in making the award, demonstrating SAIL's growing effectiveness at leveraging research funding for flagship national and international collaborations.

Professor Aziz Sheikh of the University of Edinburgh and Director of BREATHE said: "I'm delighted that BREATHE will be working closely with colleagues at Swansea University to transform the UK's respiratory health. As a long-term admirer of the outstanding SAIL Databank, I am very pleased that we will be able to draw on its considerable expertise in securely and responsibly managing patient data for public benefit."

A new research report 'Born Into Care: One thousand mothers in care proceedings in Wales', published by Nuffield Family Justice Observatory (Nuffield FJO), has revealed that pregnant women living in Wales - who are risk of their babies being removed from their care in the first year of life - are more likely to have had mental health problems compared to other pregnant women.

The study, led by researchers at Swansea University, working with

colleagues from University of Lancaster, also challenges the assumption that mothers who become involved with children's services avoid or delay interaction with antenatal services - with almost two-thirds (63 per cent) having made contact by the end of the first trimester of pregnancy.

The research was carried out by the Family Justice Data Partnership, a collaboration between Lancaster University and Swansea University, with CAFCASS and CAFCASS Cymru as integral stakeholders. It is

funded by the Nuffield FJO, providing it with groundbreaking analysis about the family justice system.

It is the first project to link family court records to administrative, maternity and health data in Wales, and was made possible by analysing core family justice and linked data sources in Swansea University's SAIL Databank, where the availability of the CAFCASS data in the SAIL Databank opens up a range of research possibilities to better understand, provide evidence and ultimately improve lives of those involved in the family justice system. "Welsh policy makers and practitioners require an evidenceinformed picture of families ... to tailor services more closely to their needs, and to make the best decisions". Dr Lucy Griffiths, Nuffield Family Justice Observatory

Nuffield

**Family Justice** 

Observatory



### **Supporting UK and International Research**

SAIL is providing support to the BEACHES (Built Environments And Child Health in WalES and AuStralia) project, joint funded by the UK Research and Innovation's Medical Research Council and Australia's National Health Medical Research Council (NHMRC), joins up academic expertise from Wales and Australia. The three-year project will combine evidence and analysis from Australia and the United Kingdom to further our understanding of the impacts of built environments on population health, including understanding any differences between the two countries.

Data collected from more than one million children will be analysed to help understand how built environments can contribute to physical activity and childhood obesity, and how to overcome this challenge to create family-friendly environment for healthy living. The collaboration brings together experts from institutions including Population Data Science and the College of Engineering at Swansea University; as well as Australian institutions, led by Telethon Kids Institute, including The University of Western Australia, Curtin University, Queensland University of Technology and Monash University.

> "SAIL is a vital component of the BREATHE programme, combining an established secure data holding environment with specialist data science experience and skills" Chris Orton, Programme Manager, BREATHE Data Research Hub for Respiratory Health

**Multi-morbidity National Implementation Project:** SAIL data is being used to underpin Heath Data Research (HDR) UK's Multi-morbidity National Implementation **Project** and SAIL Director Professor Ronan Lyons is one of the key project co-ordinators.

The health service is currently struggling to treat greater numbers of patients with more than one disease or condition (multi-morbidity). Multi-morbidity has been measured in lots of different ways for different groups of people making it hard to know just how big a problem it is. This project will use data across four nations (including SAIL) to find out more about what diseases and conditions are found together, how they develop as people age and also which cause the most problems for people and the health service. This will allow researchers, health care workers and policy makers to better plan how to deliver care to people with various types of multimorbidity with public engagement throughout.

### Working with industry

An observational study of INR control according to NICE criteria in patients with non-valvular atrial fibrillation-The SAIL Warfarin Out of Range Descriptors Study (SWORDS) This study, published in the European Heart Journal, marks the culmination of a five year collaboration between SAIL Databank, academics at Swansea and Cardiff University and Bristol Myers Squibb Pharmaceuticals Ltd to examine poor anticoagulation control in patients with non-valvular atrial fibrillation. It aimed to quantify numbers of patients with poor INR control and describe associated demographic and clinical characteristics. It concluded that 43.0% patients had at least one of the NICE markers of poor INR control and that female gender, age ( $\geq$ 75), excess alcohol, diabetes heart failure, ischaemic heart disease and respiratory disease were all independently associated with all markers of poor INR control.





2020 will always be defined by and remembered for the global COVID-19 pandemic, which caused unprecedented levels of change in our lives, our workplaces and our communities, and it is clear that coronavirus will continue to exert a significant influence for the foreseeable future. We are immensely proud of the contribution we have made to the UK Emergency Response to the pandemic and also the support we have been able to provide to the many research groups investigating the wide ranging impacts of the virus and seeking treatments and interventions to address these. We stand ready to continue this fight into next year and beyond, and the additional data resources which we have secured during the past four months will further increase our capacity to provide value to COVID-19 related research efforts.

One unexpected effect of SAIL's involvement in the COVID-19 response was an increased recognition of the quality of our infrastructure and governance structures, and our Directors and other members of the team are increasingly in demand as strategic advisors in setting the national and international strategy for data management. We are excited to continue to pass on our experience and to make a positive contribution in this area in the coming years.

In an open letter sent to the UK Information Commissioner, Chief Medical Officer of the UK, and UK data providers, and signed by 374 signatories, SAIL Databank has been highlighted as an exemplar data access system in an otherwise disparate UK data landscape.

Since 2018 SAIL has focussed on the establishment of collaborations with key partners such as BREATHE, the Family Justice Data

Partnership, Health Data Research UK, the Adolescent Data Platform and the Administrative Data Research Programme. As described in this year's Annual Report, these partnerships are beginning to produce some excellent, high impact research outcomes, but all are still in their infancy. We look forward to working with our Data Science partners even more closely during the forthcoming year to maximise the potential benefits from

"The SAIL Databank continues to achieve additional standards to assure it's Trusted Research Environment, upholding the confidentiality and security of vital health and administrative data used for research in the public interest." Ashley Akbari, HDR UK (Health Data Research UK) Wales and Northern Ireland linking health and other public service data for public benefit. Whilst we continue to expand our reach into the wider UK and international community, we remain committed to the Health and Care Research Wales Research Groups and the wider researcher communities within Wales with who we have such fruitful long standing relationships.

2020 – 21 looks set to be a challenging year, with the twin threats of COVID-19 and economic recession looming. Nevertheless we are confident that we can make even more of a contribution than before and we look forward to doing so.

