

| Project Name | Earliest Start | Project Description |
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| Parental transmission of type 1 diabetes | 20/08/2022 | Type 1 diabetes is a lifelong, incurable condition associated with many possible complications, especially if blood sugar levels are poorly controlled. Children with a family history of type 1 diabetes are at increased risk of type 1 diabetes. However, the risk is twice as high if the child's father has type 1 diabetes compared with if the mother has type 1 diabetes. The reasons for this are unclear. Approach: Using data from large datasets, we will explore the impact of environmental factors on the risk of type 1 diabetes in children of mothers and fathers with type 1 diabetes. We are particularly interested in whether children of mothers with poorly controlled type 1 diabetes during pregnancy, who are exposed to higher blood sugar levels, might be less likely to develop type 1 diabetes. Expected impact: Understanding factors that increase the risk of developing type 1 diabetes may help us identify strategies to reduce the likelihood of children at high risk of type 1 diabetes developing the disease |
| DECODE: Data-driven machine-learning aided stratification and management of multiple long-term COnditions in adults with intellectual | 20/07/2022 | About 1 in 100 people are identified as having intellectual disabilities. Of these, about two-thirds have two or more longterm health problems, known as multiple long-term conditions (MLTCs). Sometimes these conditions can be delayed or prevented through lifestyle changes, such as diabetes and heart problems. For other conditions like epilepsy, better management can improve the quality of life. We want to use computer programs, called machine learning, to learn more about MLTCs in people with intellectual disabilities. We will find out which conditions are more likely to occur together and what happens over time. This information will help us to develop a new joined-up model of care for people with intellectual disabilities and MLTCs. Our research combines healthcare information (data) and what we hear from experts. The experts include experts by experience (people with intellectual disabilities and their carers) and professional experts. 1. Healthcare |
| Leaving a pupil referral unit: Exploring the transitions and post-16 destinations of care experienced young people across Wales | 18/07/2022 | Over three years, the fellowship will explore the educational experiences and trajectories of care experienced young people in Wales, who have been excluded from mainstream school. Specifically, it will focus on young people who are in their final year of compulsory schooling and attend a pupil referral unit (PRU). Four PRU sites across Wales will take part in the study, and young people from these settings will be engaged with at three different points - 1) during their time at the PRU; 2) at the beginning of their first year in a new destination; 3) and once more, 12 months later. Professionals who are involved with supporting these young people will also be interviewed about their roles and practices. Alongside this qualitative work administrative data will be collected through the linking of Welsh datasets. This work will provide an overview of how many care experienced young people in Wales have been excluded over a five year period, and spent |
| The inequalities in the patterns of needs for carers and cared for people receiving support from local authorities across Wales | 11/07/2022 | The Networked Data Lab (NDL) programme includes five NDL partners: The Aberdeen Centre for Health Data Science which includes NHS Grampian and the University of Aberdeen; Imperial College Health Partners, Institute of Global Health Innovation, Imperial College London, and North West London CCGs; Liverpool CCG, Healthy Wirral Partnership and Citizens Advice Bureau; Leeds CCG and Leeds City Council; and NDL Wales which is comprised of Public Health Wales, Digital Health and Care Wales (DHCW), Swansea University and Social Care Wales. As part of the programme, each lab has been tasked with conducting a project to improve data access/quality in the lab/local area. Our data development proposal is to increase access to linked local authority social care data in Wales, focussing on unpaid carers. Unpaid carers provide informal and unpaid care to family, friends and neighbours. Carers are a key group in the social care |

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| Sunproofed: A Mixed Methods Evaluation of Sun Safety Policies in Primary Schools in Wales | 22/06/2022 | Why this project: Skin cancer is the most common cancer in the world. In Wales, skin cancer rates have risen by 63% since 2005 and dermatologists now spend 50% of their time treating skin cancer. This means they cannot spend as much time on other conditions and people with other skin diseases are suffering. Skin cancers are divided into melanoma and keratinocyte (non-melanoma). For melanoma, 86% of cases can be prevented through less exposure to the sun's ultraviolet radiation (UVR). Studies show that children who are badly sunburned are more likely to develop melanoma skin cancer when they are older. With the Welsh Government recommending that people do more to prevent future health problems, preventing skin cancer is now more important than ever. Children spend almost half their time at school playing and learning outdoors, and one way to prevent skin cancer is to teach children at school how to protect themselves from UVR. A sun safety |
| Transforming healthcare data with graph-based techniques using the SAIL Databank | 03/05/2022 | Persons diagnosed with multiple diseases or health conditions are multi-morbid. Understanding this population and multimorbidity is an important concern for public health to ensure health services are designed for managing and treating multimorbidities collectively, rather than focusing on individual diseases separately as per the current model. Identifying diseases which occur together is a complex analytical challenge, methods and computational resources that are able to handle this complexity need to be developed and rigorously tested so that any policy recommendations and service reconfiguration proposed is based on robust evidence. A novel mathematical method developed in SAIL uses graph based techniques which identifies sets of diseases that occur together. This project will investigate graph based methods further and test the usefulness of these techniques to the NHS by comparing with other analytical techniques and validating |
| Is school absenteeism harmful to education and labour market outcomes? | 30/04/2022 | Adverse childhood experiences, such as school absenteeism, can carry into adulthood. However, the long-term consequences for educational attainment and labour market outcomes are not fully understood. Frequently absent students miss out on classroom learning and developing key dispositions crucial for future success. This project examines whether school absenteeism is negatively associated with individuals' educational attainment and labour market outcomes. Additionally, it investigates whether psychosocial dispositions (e.g., self-esteem), behavioural dispositions (e.g., risky behaviour), and aspirations (e.g., educational) can explain the association between absenteeism and educational attainment. It will further consider the role of these dispositions and children's educational attainment in explaining the association between absenteeism and labour market outcomes. Finally, we will analyse whether the |
| The effects of air pollution on mental health | 06/04/2022 | Rationale: Previous, literature has found a potential association between mental health disorders and exposure to air pollution. However, additional, high-quality research is necessary to confirm this association and the other factors that could affect it. Since the prevalence of mental disorders are increasing, which could be potentially linked to air pollution. Therefore, finding risk factors such as air pollution which could be reduced is necessary to decrease the financial and societal burden caused by mental health conditions. Impact: The creation of a peer review article has the potential to encourage an increased understanding of this topic more widely in the public health sector. This as well as the linkage of data in SAIL to air pollution has the potential to put pressure on policy makers worldwide to inform legislation and policies to improve air quality. This may result in cleaner air as well as overall improved health now and for future generations |

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| Trauma Evaluation Analysis and Research Cymru (TEAR Cymru) | 01/04/2022 | <p>On the 14th September 2020, the South Wales Trauma Network went live; prior to this there was no adult and paediatric network serving the population of South Wales, West Wales and South Powys. A trauma network consists of a Major Trauma Centre (MTC), with a number of Trauma Units (TUs) and Local Emergency Hospitals (LEHs), and rehabilitation services. The trauma network ensures rapid transfer of patients who are most severely injured from the scene of an incident or other hospitals to the MTC, in order to benefit from timely and efficient specialist care.</p> <p>Care continues closer to home or in the community once specialist care is completed. Care closer to home is generally facilitated through rehabilitation. It should be recognised that major trauma</p> |
| MSc Health Data Science student teaching, assignments and dissertation projects | 22/03/2022 | <p>This project will be used by students on Swansea University's MSc Health Data Science to undertake one or more of: a small project on the data-modelling techniques, a short machine-learning exercise and, most significantly, one of a variety of final dissertation projects. The assignments and dissertation project theme(s) will be designed to facilitate students learning to use a Gateway environment, developing an analysis plan, selecting data to form an analysable dataset, and utilising techniques in machine learning and epidemiology. They will investigate the modelling of cardio-pulmonary and respiratory diseases of both infectious and non-infectious origin from the perspective of medicine, wellbeing and/or public health. The same core datasets will be used for all projects. The modelling and machine-learning taught-module projects will be the same for all students and will be carefully defined by the module co-ordinators. The aim of these projects is to</p> |
| BREATHE Dataset Curation | 16/03/2022 | <p>Interstitial lung disease (ILD) and Chronic Obstructive Pulmonary Disease (COPD) are chronic respiratory disease that cause substantial disability and deaths. Studies on ILD and COPD frequency and associated impact and costs have tended to provide high level national snap-shot pictures. Whilst these have been useful, we need to understand how these considerations are changing, both at a national and a small-area level (e.g. Health Board, Lower Super Output Area (LSOA)), to inform national/local health policy and planning. Traditionally, health data has been managed by computer experts. However we now need doctors trained in informatics to supply useful ILD and COPD data. Our researchers will have access to a large amount of recent anonymised ILD and COPD data (e.g. GP visits, admissions, medications). A large dataset of ILD and COPD patients will form an observatory which can be regularly updated. This will initially be</p> |
| Healthcare utilisation and intermediate outcomes in patients with blunt chest wall trauma following discharge from the | 04/03/2022 | <p>Injuries to the chest (blunt chest trauma) accounts for over 15% of all trauma admissions to Emergency Departments worldwide. The most common causes of injury include falls from a standing height (>2m), high velocity falls (>2m), road traffic accidents, assaults and sporting injuries. Over 1500 patients presented to the Emergency Department in Morriston Hospital in 2019 with blunt chest wall trauma. Difficulties in the management of blunt chest wall trauma patients in the Emergency Department are becoming increasingly well recognised in the literature. Longer-term complications after blunt chest wall trauma have been investigated. In a recent study, chronic pain was reported by 64% of patients, and disability by 67% of patients. Currently in most hospitals, patients are simply discharged home with no follow-up care. The majority of patients are discharged directly home from the Emergency Department or Urgent Care Centre (previously called a</p> |

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| STRETCHED (STRategies to manage Emergency ambulance Telephone Callers with sustained High needs – an Evaluation using | 16/02/2022 | The project is part of a larger study into people who make frequent calls to ambulance services. Over recent years, increasing numbers of 999 calls to ambulance services have presented challenges in providing timely and appropriate response. A small number of people call 999 a lot, and are classified by ambulance services as 'Frequent Callers' if they call more than five times a month, or 12 times in three months. The needs of these callers are not being met through traditional 999 responses. They don't always have a medical problem which will require urgent help, and there may be a better way for their needs to be met without them having to phone 999. One approach to meeting the needs of people who are making high use of the 999 service is case management. The case management approach means the person is referred to a team from different agencies - including social services, primary care (GP), community mental health and the |
| Predicting lower back pain | 14/02/2022 | The prevalence of spinal pain and associated risk factors in Wales: a population-based study. In a recent Global Burden of Disease Study, Wu et al. (2020) identified spinal pain as the leading cause of years lived with disability across all regions of the globe. Notwithstanding, its impact on quality of life, spinal pain has increased by 50% over the last 25 years (Hartvigsen et al., 2018; Buchbinder et al., 2020) and indirectly contributes to premature mortality and declining life expectancy (Gallaway et al., 2017). Spinal pain has also been linked to several common comorbidities, most notably cardiovascular disease, obesity, diabetes, cognitive decline, and neurodegeneration associated with Alzheimer's Disease (Rundel et al., 2017; Ramanathan et al. 2018; Williams et al., 2018). If left untreated, chronic spinal pain may also be responsible for accelerated brain ageing and neurodegeneration (Williams et al. 2018), as evidenced by lower grey |
| Wolfson Centre for YPMH - Workstream 5 - Aim 2 | 11/02/2022 | This project will form part of the Wolfson Centre for Young Peoples Mental Health in Wales as part of one of five closely interlinked work stream packages focused on understanding how to prevent depression and anxiety, understanding more about what happens to young people as they go into adulthood and to provide the right support for these individuals. This part of the project (aim 2) will focus on studying the utility of artificial intelligence tools to identify the risk of negative outcomes in children and young people with depression, such as substance misuse, self-harm, suicide and trajectories to other severe mental illnesses over time. Vitally, we will pair these tools with traditional epidemiological methods to validate their results and make sure they are clinically relevant. |
| TIME: Take home naloxone Intervention in Multicentre Emergency settings | 08/02/2022 | People who take opioid drugs such as heroin can overdose. The number of people who die this way is increasing; which has tragic consequences for families, friends and communities. Naloxone is a drug that can reverse the effects of opioid overdose. Emergency ambulance staff and doctors in the Emergency Department regularly administer naloxone. But some people die before they reach emergency medical services. There are schemes in the UK and internationally where naloxone is given to drug users to administer to others in an emergency. This is called 'Take Home Naloxone' (THN). But we don't know whether THN saves lives. There are some concerns that it could encourage risk-taking behaviour i.e. the drug user feeling that they have a "safety net" and can take a higher dose. We will carry out an initial study to see: 1) whether it is possible for ambulance paramedics and Emergency Department staff to give out THN kits to drug users they see, and; 2) if we |

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| COVID-19 CANCER ATTITUDES AND BEHAVIOUR STUDY (CABS) | 03/02/2022 | During the COVID-19 pandemic, people may not be aware of the importance of seeking early medical help for signs of cancer or taking up screening, when available, to diagnose cancer sooner. In addition, some people may not want to be referred to a hospital for diagnostic tests due to fear of catching coronavirus in the healthcare setting. COVID-19 may also affect whether people take part in healthy behaviours that can reduce the chances of getting cancer. These factors may lead to more cancers occurring, and more cancers being diagnosed at a late stage when treatment may be less successful. Over 18 months, we will carry out a large study to measure cancer attitudes and behaviours in adults aged 18+ across the UK. We aim to include adults from a range of different backgrounds including people from a Black, Asian or minority ethnic background and those who live in disadvantaged communities as data suggests that they may have been |
| Subclinical hypothyroidism effects on clinical outcomes | 03/02/2022 | Subclinical hypothyroidism (SCH) is a thyroid gland problem that is identified through blood tests. Doctors decide whether a patient has SCH based on their hormone levels - in this case, increased Thyroid Stimulating Hormone (TSH) and normal thyroxine (T4). Past studies on the long-term effects of having SCH have given mixed results, such as whether or not it raises the odds of getting heart disease and strokes. It is also not clear whether receiving treatment by replacing thyroid hormones using drugs makes these outcomes less likely. The best method to learn of the effects of SCH and its treatment would be through large trials in which patients are chosen at random. However, few people have taken part in past trials, so it has been hard to apply those results to others. It is also very costly and complex to run a trial. This study proposes to analyse electronic health record data in the same way these trials are done. We will also use machine learning methods to |
| Machine learning on risk factors for prediction of renal damage | 01/02/2022 | Chronic Kidney Disease (CKD) is a health disorder where the function of the kidney progressively declines. It is a prevalent disease that affects people of around 8-16% worldwide, and 35% of elderly aged 65 or above. There is currently no cure and only slow-down measures are available. CKD is costly to treat and poses a big challenge in an ageing population. There are four stages of CKD. Once a patient situation advances to later stages, risk of death increases exponentially. Late-stage patients often suffer from weekly dialysis, and/or long wait for kidney transplant. It is a big lifestyle changes to the patients. Objective of this proposal is to contribute to the early discovery of CKD. This would benefit patients and society alike, enabling early targeted treatment and psychological support. Furthermore, it would lead to a healthier population by raising the awareness of CKD (e.g. among NHS) and long-term economic benefits (e.g. reduced |
| The indirect impacts of COVID-19 on the sexual and reproductive health of women in Wales | 17/01/2022 | A presentation will be made to the SAIL Consumer Panel on the direction and scope of the research, the data being used and the analysis plan. It is important to engage directly with groups of interest which includes women of reproductive age and health professionals in the reproductive and maternal health field. In order to do this, we will liaise with women and health professionals within the Swansea Bay health board. Our public engagement will be expanded to include qualitative research in the form of interviews and focus groups to gain knowledge of women's and health professionals lived experience throughout the COVID-19 pandemic. Engagement will start at the beginning of the project and will be maintained throughout the duration of the project. It will help us explore new perspectives and research angles, inform the direction of the research, and raise public discussion, interest in and contribution to knowledge generated and its |

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| Extending the Hughes Abdominal Repair Trial: Long-term Follow-Ups by Routine Data (exHART-FURD) | 13/01/2022 | Bowel Cancer UK estimate that there are approximately 42,000 new diagnoses of bowel cancer each year in the UK, with surgery being the most common treatment. Surgery undertaken to treat colorectal cancer frequently leads to the development of a hernia within the abdomen around the line used in operating on the patient. This complication, known as an incisional hernia (IH), is often painful, reducing the quality of life of those suffering from them; it can also be expensive to treat, often requiring further surgery. It is of considerable benefit to patients to determine the extent to which alternatives to current standard surgical techniques offer better treatment. The Hughes Abdominal Repair Trial (HART), which opened to recruitment in 2014, is a large randomised controlled trial of the Hughes technique of stomach wall closure as an alternative to standard surgical practice, reporting on rates of incisional hernia at one year and over two years postsurgery. In this project |
| A Multinational project looking at anti-psychotical medication risk of developing Glioma, subsequent treatment and clinical outcomes in | 05/01/2022 | Gliomas are the most common malignant brain tumour. Survival remains poor, reflecting a lack of advancement in treatment options. Medications that exert effects on brain chemicals affecting behaviour, mood, thoughts, or perception are known as 'psychotropic' medications. These include for e.g. those used for the treatment of mental illness, such as antidepressants for the treatment of depression and antipsychotics for schizophrenia. Accumulating evidence in mice suggests these medications, may protect against glioma. Recent studies in humans using clinical data, including by our team, have found that the use of antidepressants and other such medications may reduce the risk of glioma. However, the number of patients with glioma included in this study was relatively small. This is a particular challenge, as glioma comprises many subtypes. This study will therefore investigate three main aims. We will evaluate i) the patterns of |
| Understanding and predicting health and social care utilisation and adverse outcomes | 05/01/2022 | More people in the UK are living to be very old. It is predicted that the number of people aged 85 years and over in the UK will double by 2043. This will make it increasingly difficult for the National Health Service (NHS) and social care services to meet people's needs, and so we need to identify who is most in need of care so the right care can be delivered to the right person at the right time. Currently, several tools are used to do this, but they can be less accurate for older people and often focus on individuals rather than looking at the environment in which someone lives. We will create a tool that will help us to predict who is at risk of being admitted to hospital or to a care home, or of dying. To do this, we will use information such as age, sex, and current health conditions (e.g., heart disease, arthritis, depression, and dementia). We will also look at how the household and local neighbourhood environments put people at risk of having health conditions, being admitted |
| STREP - Evaluation of the Sore Throat Test and Treat Service in community pharmacies | 05/01/2022 | Community pharmacies are offering a greater number of services for people who may have an infection. These services aim to rapidly assess, diagnose and treat infection and relieve some of the pressures faced by General Practices. Some community pharmacies are offering a Sore Throat Test and Treat (STTT) service, involving a consultation with a pharmacist that includes an examination and an assessment of the likelihood of a bacterial throat infection (using a validated scoring method). People who are likely to have a bacterial throat infection will have their throat swabbed and tested for the presence of bacteria, and if present, will be treated with antibiotics. There are plans to roll this service out to more community pharmacies. However, before this happens, it is important to know what impact the service has on patients and the NHS. Is the service meeting its aims? Is it safe? What is the impact on antibiotic dispensing rates? The |

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| What are the effects of established glucocorticoid therapy on the risk of adverse COVID-19 outcomes? | 01/01/2022 | Glucocorticoids (GCs, or 'steroids') are used widely as anti-inflammatory drugs in the treatment of diseases such as asthma, chronic obstructive pulmonary disease (COPD) and rheumatoid arthritis. They are also used to replace deficient hormone production in patients with adrenal insufficiency (including Addison's disease and hypopituitarism). Up to 3% of the population will be prescribed steroids each year, a figure which rises to 7% in people over 60 years and 10% in those over 80. This high prevalence represents a public health challenge since serious adverse effects, including diabetes, osteoporosis and cardiovascular disease may be associated with long-term steroid use. Steroids also play an important role in adjusting the body's response to infection, yet patients taking steroids are considered at increased risk of infection because of their effects in suppressing the immune system. The risks, however, may vary according to the type of infection. |
| PROphylaxis for paTiEnts at risk of COVID-19 infecTion (PROTECT-V) | 15/12/2021 | There are several clinical trials of treatments for COVID-19 underway in the UK, but most of these exclude dialysis patients. It is not uncommon for patients with advanced kidney disease to be excluded from clinical trials, due to the complexities of their underlying health conditions, and difficulties finding the correct dose of a drug to be used, if it is removed by the kidneys. However, because kidney failure may increase the risk of contracting or becoming very ill from COVID-19, it is important that treatments are also tested in people who are on dialysis. We have only limited information available to us about how COVID-19 affects dialysis patients, but we suspect that if an infection occurs, symptoms are more commonly seen than in the general public. The PROTECT trial is unique in that it enrolls dialysis patients allowing them to potentially benefit from preventative medications. The focus of this trial is on prevention of disease, rather than |
| Capstone PM-344 - student project - Neurology | 13/12/2021 | This project will be used for students completing their 3rd year project at Swansea University. This is important to develop capacity and expertise in data science, and to improve accessibility to real-world anonymised population-scale 'big-data' for research to students. SAIL is a world-leading trusted research environment and values the principles of learning and development of the next generation of data scientists and researchers, through a managed, secure and supervised approach. This student project theme will be specifically be focussed around epilepsy and important outcomes for people with epilepsy in Wales. Epilepsy is a common neurological condition, affecting around 30,000 people in Wales. People with Epilepsy face many problems apart from seizures including side effects from medication, physical and mental health problems and increased risks of premature death. In this project, the students will look at three specific and important |
| Trends in the Prevalence and Complexity of Children with a Life-limiting or Life-threatening condition in Wales | 30/11/2021 | This study aims to update the information on the prevalence of children living with a life-limiting condition in Wales and to examine how the complexity and stage of the children's condition are related to the service they receive. This will provide information to aid future service planning and delivery. Life-limiting conditions (LLC) are serious health conditions in which the child's life may be shortened. It was estimated that 3,200 children (0 – 19 years) lived with an LLC in Wales in 2009/2010. The estimation is likely to be underestimated when considering current data from England and Scotland showing a markedly increase over the last decade. Children living with an LLC usually have repeated admissions to hospitals and requires healthcare including palliative care for many years. These data are pivotal for service planning and provision. One challenge in the field is the lack of information on the severity or complexity of the child's condition. This could be assessed using key features like the number of health conditions and the use of medical technologies and problem severity by children's clinical stages. |

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| The impact of variation in colonoscopy quality on the risk of future advanced colorectal polyps or cancer | 16/11/2021 | A colonoscopy is a camera examination of the large bowel (colon) often performed as part of bowel cancer screening programmes or for symptoms such as changed bowel habit or bleeding. Deciding whether a patient needs further colonoscopies after their initial procedure will depend on the findings. If polyps are identified, the decision regarding follow up procedures is mainly governed by their number and size. There are several clinical guidelines with advice on this but there is little consideration regarding other factors that may affect the need or timing of surveillance which has significant implications for the patient and health service. Colonoscopies performed through bowel screening are closely monitored to assure quality and safety. The individuals performing the procedures are regularly assessed to ensure these standards are met. One of these parameters are the number of polyps they detect as this reflects a thorough examination of the |
| Measuring mental health problems across an integrated child health system, together with associated risk factors: towards developing early | 15/11/2021 | This project will use linked administrative data from health, education and social care to measure the levels of mental health risk and the rates of having a mental health problem across Wales. We will use these calculations to test if it is possible to develop algorithms that enable us to predict which young people acquire mental health problems. To do this we will carry out the following steps: (1) Measure the frequency and levels of a range of risk factors linked to developing mental health problems. We will see how these vary across Wales. Risk factors to be tested include specific demographic information, adverse childhood experiences (ACEs), patterns of service use, school attendance and attainment, among others. The project will also seek to map the prevalence and distribution of different mental health problems and risk factors (including ACEs) so that the needs of the population can be compared to local service provision, and service gaps identified. (2) Explore the relationship between the presence of risk factors and developing a mental health problem. We will see if these relationships vary across |
| Asthma and COPD Audit Programme (NACAP) | 01/11/2021 | Information on asthma and COPD care is required for the National Asthma and Chronic Obstructive Pulmonary Disease (COPD) Audit Programme (NACAP) Wales primary care project. This project looks at the care received by, and management of, people with asthma and COPD by general practices (GPs) in Wales. It compares the care and management against national standards and guidelines to make sure all patients receive the best care possible. All patients over the age of 35 with a diagnosis of COPD and all adults, children and young people with a diagnosis of asthma in Wales are included. The National Asthma and COPD Audit Programme (NACAP) primary care project involves the collection of information relating to asthma and COPD patient care and management from Wales general practice (GP) computer patient records. This means that information on asthma and COPD patient care is extracted (pulled) from general practice (GP) record systems and does not involve the practices submitting any data manually. The National Asthma and COPD Audit Programme (NACAP) has carried out two |
| HEAL-COVID | 07/10/2021 | This study will assess several different treatments that may be of benefit in reducing or preventing the complications that patients with COVID-19 are reporting after their acute illness. The aim of the study is to develop treatments for COVID-19 that reduce the longer-term death and disability. We propose a large, multi-centre clinical trial designed to assess whether several different treatments are better than the current “standard care” (the best available evidence-based treatment). The study is designed to learn from ongoing existing National Institute of Health Research studies looking in-depth at the issues experienced by patients with COVID-19. Patients will be randomly assigned to treatments or standard care. There will be no placebo, therefore patients will be aware of which therapy arm they have been allocated to. The presence of more than one treatment in the trial will ensure that a majority of patients will be offered an active treatment. Information will be collected from their routinely collected health records (mortality and subsequent hospitalisations) to minimise the burden on study |

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| neoWONDER: Neonatal Whole Population Data linkage to improve lifelong health and wellbeing of preterm babies | 01/10/2021 | 15 million babies (1 in 10) a year, are born premature before 37 weeks; most require care in specialist neonatal units. In the UK, neonatal services cost the National Health Service (NHS) around one billion pounds a year and is the fourth most expensive specialised service. This investment has improved rates of survival, but some babies will have disabilities and later life complications, such as heart disease and diabetes. These adverse consequences have implications for health, education and social service providers, and warrants more research focus to identify interventions that lead to improved outcomes without longer-term harm. Unfortunately, most studies have evaluated only short-term outcomes that occur prior to discharge, such as brain ultrasound findings, rather than long-term functional outcomes, such as the ability to walk, that are more meaningful to patients and families. A major reason for the lack of long-term data is the complexity and cost of |
| Pathways to Co-Occurring Psychiatric Disorders and Morbidity in Autistic Spectrum Disorder | 30/09/2021 | Autism Spectrum Disorder (autism) is a long-term condition which affects 1-2% of people. People with autism can have difficulties with social skills and communicating with other people, repetitive behaviour and can have a small range of hobbies or interests. It can affect how people perceive the world. Mental and physical health problems are common in autistic people, but we don't understand why. There are also gaps in this research with some health problems not studied. Research in other mental health conditions like schizophrenia show they can reduce life expectancy by at least 10 years. This project aims to examine whether there are relationships between autism and certain mental health conditions which leads them to be developed in specific patterns. It will also look at the effect of common physical health problems like high blood pressure and diabetes in autistic people compared to the general population. Finally, we will estimate the life expectancy of people with autism to see if it is different to the rest of the population |
| Regression discontinuity to asses medical interventions | 29/09/2021 | Randomized controlled trials (RCTs) are studies where patients are randomly assigned to receive a treatment or not, often under highly controlled conditions and are considered to be the method of choice to test for treatment effectiveness. However, they may not fully capture real-life effects occurring during routine care and lack the long-run perspective necessary to evaluate treatments. This study aims to apply a method called regression discontinuity (RD) to de-identified electronic health record (EHR) data from patients in primary and secondary care settings. Intuitively, RD uses thresholds (cut-offs) in variables that influence whether someone receives a treatment or not (e.g., blood pressure above 160/100 mmHg). By "zooming in" around the threshold, it can be assumed that people just above and just below the threshold are similar to each other and can, thus, be compared in the same fashion as treated and untreated patients in a clinical trial. The method could potentially be applied widely in clinical medicine because clinical decisions are frequently (at least partially) based on such |
| Project Acorn | 27/09/2021 | In order to fully appreciate the project and its impact it is important to look at the overall aims and ambitions of SPRYT and then look at how this project fits into this overall picture The Problem The national health services (NHS) lose over 1Bn GBP per annum due to patients missing appointments. The cost to the healthcare system of missed appointments does not consider the cost to the patient of missed diagnosis and treatment. The no show rate for screening and referrals ranges between 30 and 50%. The reason for missed appointments varies from a fear of finding out that they have a serious medical problem to forgetting they have an appointment booked. SPRYT Solution (3 Stages) 1) Artificial Intelligence (AI) is applied to predict no-shows providing clinical staff with actionable insight as to which patients have a high probability of non- attendance 2) Our appointment scheduling assistant enables patients to book or reschedule appointments as well as ask questions directly via whatsapp. communication is bi-directional and can be initiated by the healthcare system. 3) We are incorporating behavioural |

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| Depression and anxiety illness course and clinical outcomes in children and young people | 13/09/2021 | This project will form part of the Wolfson Centre for Young Peoples Mental Health in Wales as part of one of five closely interlinked work stream packages focused on understanding how to prevent depression and anxiety, understanding more about what happens to young people as they go into adulthood and to provide the right support for these individuals. This part of the project will focus on depression and anxiety in children and young people. Depression and anxiety have major long-lasting health and social function impacts for many. More unusually it can be linked to repeated depression, serious mental illness or suicide. It is very difficult for doctors to make judgements about risks for individuals, especially for young people. This project hopes to help by learning about what affect the course of depression, anxiety and other mental disorders, and suicide/self-harm. We will look for the things that predict what happens to young people with depression and anxiety over time, like those that affect the likelihood of future mental disorders, self-harm and suicides. |
| Mental health and self-harm in prisoners in Wales, an e-cohort study | 07/09/2021 | This work will focus on mental health and self-harming behaviours of the male prison population in Wales in 2019 and also whether these men die younger both during and after release from prison. We will explore the risk factors that lead to selfharming behaviours and mental health illnesses, such as whether on remand or not, past history of mental illness/ self-harm behaviour, type of prison, type and length of sentence and substance use. We aim to investigate the rates and proportions of mental health diagnoses (e.g. learning difficulties, ADHD, ASD, conduct disorder, bipolar disorder, schizophrenia and other psychotic disorders, eating disorders, PTSD and anxiety diagnoses/symptoms, self-harming behaviours, alcohol/drug misuse) and make comparisons to non-prisoners (from the general population with comparable age and sex in Wales). We will also evaluate trends in these rates over time using linked data from the SAIL database. |
| What is the incidence of lymphoedema following cancer surgery and can we predict who will get it | 05/09/2021 | Our aim is to identify the number of patients who develop swelling (Lymphoedema) following cancer surgery in Wales and describe their characteristics (e.g. age, sex, cancer location and extent and type of surgery). Presenting a picture of these patients may help to develop a 'prediction' tool in the future to identify which patients may be more likely to develop Lymphoedema. This information will improve understanding of which patients may need more support and Lymphoedema monitoring. Improvements in cancer treatment mean that patients are surviving longer. One side effect of cancer surgery that involves the lymph nodes is Lymphoedema. This can cause uncomfortable symptoms and affect quality of life. Around 20% of patients undergoing cancer surgery develop Lymphoedema. Lymphoedema requires constant self-management and lifelong treatment and has lots of complications including cellulitis (skin infection). We will carry out this work using |
| IMproving Prophylactic Antibiotic use for Recurrent urinary Tract infection (IMPART) | 01/09/2021 | The aim of this research is to improve the use of long-term antibiotics used to prevent urinary tract infections (UTIs) in patients who have recurrent UTIs. This project will generate new evidence about the risk of antibiotic resistance in patients who take long-term antibiotics. This information will aid the development of a decision aid that will facilitate shared decision-making between patients and clinicians on the management of recurrent UTIs. This information will aid the development of a decision aid that will facilitate shared decision-making between patients and clinicians on the management of recurrent UTIs. UTIs are very common in women, affecting 10-13% each year. Further infections following treatment are common. Approximately three percent of those affected will develop recurrent UTIs, which are defined as two UTIs in six months or three in 12 months. The main treatment for recurrent UTIs are long-term antibiotics which have been shown to be effective. The concern is the development of antibiotic resistance but the effect of long-term antibiotics on resistance is unknown. Methods The project |

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| Understanding Society (the UK Household Longitudinal Study): Linkage to Welsh health and education records | 01/09/2021 | Understanding Society - the UK Household Longitudinal Study (UKHLS) - collects annual survey data from households and their occupants across the UK. It is a multi-purpose, multi-topic study, built on the successful British Household Panel Survey (BHPS) which ran from 1991-2009 and had around 10,000 households in it. Understanding Society started in 2009 and interviewed around 40,000 households, including around 8,000 of the original BHPS households. The Study is based at the Institute for Social and Economic Research at the University of Essex. The UKHLS research team wishes to supplement the survey data with other routinely collected datasets and has requested consent from participants to link to health and education records. To achieve this, we wish to extract data from SAIL regarding consented participants from Wales, and for these data to be removed from SAIL, linked to UKHLS participant records at Essex on a secure server, and for the subsequent linked data to be deposited in an anonymised format at the the UK Data Service (UKDS) from where it can be made available for secure |
| Validating HF detection algorithms | 31/08/2021 | Heart failure (HF) is a chronic, progressive condition in which the heart cannot pump enough blood to meet the body's metabolic needs. This proposed data application is for the real world validation and calibration of an algorithm predicting the risk of outcomes in HF patients. Heart failure is a leading cause of hospital admissions in older patients in the UK, with the average age at diagnosis being 77, equating to 5% of all emergency admissions, these emergency department attendances continue to rise year on year adding pressure to the already busy health system. HF is also the primary cause of death and disability throughout the world, and as advancing age is a distinct predictor of in-hospital mortality and complications in HF, the prevalence and incidence of HF are predicted to continue to rise as the population ages. Timely diagnosis and management of HF is critical, but identification of patients with suspected HF can be challenging, especially in primary care. Finding targeted treatment for high and low-risk patients is critical for efficient treatment strategies, both concerning health outcomes and |
| COVIDENCE/CORON AVIT | 24/08/2021 | The COVIDENCE UK Research Study was developed in response to the outbreak of coronavirus (COVID-19) to look into how lifestyle factors might influence the risk of catching COVID-19, the severity of symptoms, speed of recovery and any longer-term effects on health. People aged 16 and over from all parts of the UK and from all walks of life are being asked to provide some baseline information about their lifestyle and health using an online questionnaire. They are then contacted once a month to check if they have developed symptoms of coronavirus infection or if they have attended a hospital for treatment. The data they provide will be linked to their health records (GP, Hospital, Covid-19 Test & Vaccine data, Deaths) to allow the study team: 1. To learn more about risk factors for coronavirus infection in UK adults 2. To find out how quickly people recover from coronavirus infection, and whether there are any long-term complications of this illness 3. To evaluate the impact of coronavirus infection on the physical and mental well-being of the UK population 4. To establish a database of people who may be |
| Looked after Children in the youth justice system: A mixed methods feasibility study | 23/08/2021 | This research builds on a proof of concept study conducted by the applicant, Dr Helen Hodges which took information from the risk assessment process in youth justice to create mathematical models which enabled the probability of further offending behaviour to be considered over time. Typically, what would be expected is that as a youth offending team works with a young person who has offended and the various interventions put in place reduce the likelihood of further offending to a negligible level. However, it is recognised that having offended, around four out of ten young people go on to offend again, with different rates for boys compared to girls, for different age and ethnic groups, and their history of prior offending. The proposed research seeks to explore why there are differences in this trend, and in particular, why care experienced young people appear to fair worse than their peers who have never been looked after. This responds to concerns raised by Lord Laming and David Lammy MP about the overrepresentation of care experienced young people and those from BAME |

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| PROBAT - Probiotics and the prevention of atopy in infants and children | 17/08/2021 | <p>We are proposing to exploit the new research networks established by the Wales Office of Research and Development (WORD) to answer a crucial research question and address a major public health issue: allergic disease in childhood, such as asthma and eczema.</p> <p>No-one fully understands why childhood asthma and eczema have become so common. Authorities suggest that environmental changes are responsible. It has been noticed that the increase in these conditions co-occurred with the introduction of antibiotics. Some research suggests that children who take antibiotics in their first two years are at increased risk of asthma and eczema. To explore the possible links between prescribed antibiotics and these conditions, we propose to examine the medical records, both electronic and paper, in general practice and hospital of a cohort (group) of children who have joined our existing study. This study is investigating the use of probiotics to prevent eczema.</p> |
| Using AI and machine learning to track the longitudinal primary to critical care disease trajectory | 17/08/2021 | <p>Our project aims to use state-of-the-art artificial intelligence techniques to identify people in the community (patients registered with a primary care practice) at-risk of future serious acute illness. We hope to identify people at an early stage to reduce critical illness and hospitalisation. We will use routinely collected general practice and outpatient data, linked to inpatient hospital records, to generate predictive models for future hospital admissions. The machine learning techniques that we will use are specifically designed to handle data that is collected sporadically and changes over time - medical data being a prime example! In addition to precisely measured data (such as weight and blood test results) we will incorporate information about an individual's patterns of interaction with healthcare. For example, if a person is needing to consult their GP on a more regular basis, this may indicate worsening overall health. We will model a number of distinct disease trajectories including a focus on COVID-19 disease. Our goal is to allow healthcare staff to intervene early to avoid future admissions.</p> |
| PROBAT update | 16/08/2021 | <p>Altering the infant microbiota (the population of microorganisms that reside within or on the body), can potentially provide long-term benefits to the child. Probiotics are defined as "live microorganisms which when administered in adequate amounts confer a health benefit on the host." (WHO, 2001). The beneficial effects of probiotic supplementation on the consumer's health, have been shown in a number of robust clinical trials. However, often, such studies have weaknesses, including a short trial of probiotic supplementation (i.e. supplements were not supplied for a substantial amount of time) and/or a short follow up period on consumer's health, after probiotic supplementation has ended. Therefore, the amount of evidence for or against the use of probiotics to enhance gut health is limited and requires further analysis to truly determine the effects probiotics have on human health. In 2005, a clinical trial (PROBAT), was undertaken to determine the effects that supplementation with probiotic bacteria would have during late pregnancy and early infancy, on the presence of allergic diseases (such as</p> |
| Endocrine-modulating medications and conditions and clinical outcomes in gynaecological cancer patients | 06/08/2021 | <p>Gynaecological cancers of the endometrium (or womb), ovaries and cervix make up a significant burden of cancers diagnosed in females worldwide, and account for over 1 million cases every year. Among all gynaecological cancers, ovarian cancer has the poorest survival rates, with less than 43% of patients in the UK surviving at least five years after diagnosis. Five-year survival rates for endometrial cancer are 75% but is significantly worse in those diagnosed with advanced disease (e.g. 15% for stage 4) and in those with more aggressive cancer subtypes (e.g. 50% for serous type). Just over 60% of women diagnosed with cervical cancer in the UK survive more than 5 years after diagnosis, despite cervical cancer screening programmes being in place for over three decades. Standard-of-care treatment for gynaecological cancers often involves removal of all or part of the reproductive organs, which presents challenges for younger gynaecological cancer patients who wish to have children. Given that the incidence of gynaecological cancers are increasing in premenopausal women, there is an urgent need for</p> |

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| <p>Report on diagnosis of neurodevelopmental disorders including treatment, prescribing and usage of neurodevelopmental</p> | <p>05/08/2021</p> | <p>Neurodevelopmental disorders like attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) can affect a child's behaviour, memory or ability to learn. In a previous report for the Welsh Government, we found that although there was no rise in the number of people being diagnosed with ADHD between 2003 and 2013, prescriptions for ADHD medication did increase. In our last report, we found that prescriptions for ADHD medications for those aged 15 to 18 years grew more than other age groups. Building on the previous report, we will investigate individuals, up to the age of 24 with different neurodevelopmental disorders such as ADHD and ASD between 2009 and 2020. Trends for the number of individuals diagnosed with neurodevelopmental disorders, the number of prescriptions for medications that they receive and the amount of contacts they have had across different services will be investigated to assess any possible change over time. We will look at educational outcomes and compare that to the rest of the population to see if there is any difference in attainment</p> |
| <p>CovPall-Connect. Evaluation of the COVID-19 pandemic response in palliative and end of life care: Connecting to boost impact and data assets</p> | <p>03/08/2021</p> | <p>Our research hopes to assess the palliative care response to Covid-19. In a project called CovPall we surveyed medical and nursing professionals about how they have managed and changed the way they work during Covid-19. We also collected information on patients' symptoms and their management. We want to use national data to boost findings from CovPall. We hope to allow use of CovPall data for other research. We will assess how the response to Covid-19 affects a number of factors</p> |
| <p>Real world, long term outcomes of the impact of invasive and non invasive diagnostic modalities on coronary artery disease</p> | <p>13/07/2021</p> | <p>According to World Health Organisation (WHO) data, coronary artery disease (CAD) remains the leading cause of death globally, causing 16% of all death in 2019, rising by more than 2 million to 8.9 million deaths since 2000. Those figures highlight the need to intensify the global focus on preventing and treating cardiovascular diseases. One critical measure is modifying core health behaviours (smoking, physical activity, diet, and weight) and risk factors (cholesterol, blood pressure, and glucose control) that contribute to cardiovascular health and significantly impact the prognosis of CAD. In addition, early detection of CAD has been a key goal for decades to allow appropriate targeted treatment. Historically the first line of investigation for CAD has been the exercise tolerance test (ETT). ETT is a non-invasive, well-established, and relatively cheap test. ETT works by inducing physiological stress (exercise) to reveal any coronary obstruction. Although practical, ETT is not 100% accurate and can only detect true coronary disease in 7-8 out of 10 cases. Moreover, the results can be challenging to interpret in the</p> |
| <p>The inequalities in the patterns of needs for mental health illness and crisis for children and young people in Wales</p> | <p>12/07/2021</p> | <p>The project is commissioned by Networked Data Lab (NDL) programme funded by the Health Foundation, under taken in NDL Wales (led by Public Health Wales in partnership with Digital Health and Care Wales, SAIL Databank and Social Care Wales).</p> <p>As Welsh Government and partners look towards responding to the impact of the COVID-19 pandemic, the Review of the Together for Mental Health Delivery Plan 2019 to 2022 included ensuring that all people in Wales have access to appropriate mental health support. A better understanding of the impact of recent challenges on the presentation for mental ill health amongst children and young people, and longitudinal differences across societal groups is needed to help inform future action. This project aims to understand trends in the presentation of mental health crisis events and support for children and young people in Wales. We will use routinely collected health care</p> |

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| Rates of Cancer in autoimmune disease in the SAIL Databank | 12/07/2021 | <p>Our immune system guards against germs like viruses and bacteria. When it senses these foreign invaders, it sends out an army of fighter cells to attack them. The immune system normally can tell the difference between a foreign cell and our own cells. An autoimmune disease is a condition when the immune system mistakenly attacks the body: the immune system mistakenly believes a part of the body to be a foreign cell and attacks. It can attack one organ (for example, Type 1 diabetes attacks the pancreas, and Multiple sclerosis (MS) attacks nerve cells in the brain), or the whole body (such as Lupus). Doctors don't know what causes autoimmune diseases. Some autoimmune diseases have been linked to a higher cancer risk, specifically to certain types of cancer depending on which type of autoimmune disease a person has. Recent drugs for cancer activate the immune system to fight the cancer and doing so sometimes cause autoimmune diseases. This implies that there may be a relationship between cancers and autoimmune conditions, especially if certain cancers are associated with different autoimmune</p> |
| Analysing the effects of variation in access rates amongst patients groups in Wales and a Time Series study of the benefits of specialist Real World healthcare resource utilisation for CFTR modulators using the sail databank and UK CF registry in Wales | 01/07/2021 | <p>The Welsh Health Specialised Services Committee (WHSSC) want to demonstrate value for money and equity of access for the interventions it commissions. This takes the form of measuring the benefits that secondary care receive from investing in WHSSC for some of its commissioned therapeutic or diagnostic interventions.</p> <p>The work would estimate the reductions on hospital beds, outpatient and general practice (GP) appointments the interventions achieve. By using the same metrics for each intervention a comparison between different interventions could be made highlighting those that most benefit Health Boards. For each of the interventions the plan is assess whether there is a drop in admissions for patients in the condition group relating to the intervention before and after the intervention takes place. In addition the effects of the length of stay attributable to the</p> |
| COVID-19 Symptom Tracker – Cabinet Office | 06/06/2021 | <p>In the UK, approximately 10,500 people have cystic fibrosis (CF), one of the most common life-threatening genetic diseases. In recent years, precision medicines called CF transmembrane conductance regulator (CFTR) modulators have been developed to treat people with CF. They work through targeted effects on CFTR processing and function and are specific for certain CF-causing gene mutations. Clinical trial research has clearly demonstrated the benefits of CFTR modulators in treating cystic fibrosis (CF); however further real-world evidence is needed to better understand their impacts on health care resource utilisation in clinical practice and over longer time intervals than trials typically allow, and to estimate the associated costs/economic burden. This project seeks to investigate health care resource utilisation among CF patients prior to and following initiation of CFTR modulator treatment, using linked data from the UK CF</p> |
| | 03/06/2021 | <p>There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. The project objective is to monitor symptomatic testing uptake and analyse how this differs by demographic groups and region. This involves frequent monitoring and reporting of:</p> <ul style="list-style-type: none"> - Number experiencing COVID-19 symptoms - Number taking COVID-19 test - Number with positive COVID-19 test results <p>With demographic breakdowns, e.g. by age, sex and ethnicity, at UK, national and LSOA levels</p> |

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| The Older People's Built Environment and Timely Care Health e-Study | 25/05/2021 | Healthy ageing is the promotion of positive health and wellbeing in older people and is an extremely relevant and important issue due to the impact it can have at an individual and government level. One of the main aspects of healthy ageing indicated by the World Health Organisation, is how people interact with their surroundings and local environment. However, the relationships between an individual's surroundings and the risk to preventable adverse social care and health outcomes is largely unknown. We aim to analyse two common outcomes that may be influenced by an individual's surroundings are care home admissions and falls. These outcomes are also known to incur significant costs to the NHS, local authorities and government. The risk to the outcomes may also differ depending on if someone has a dementia diagnosis and the associated financial costs are increased. |
| Myocardial Infarction and Stroke Subsequent to Urinary tract infection (MISSOURI) | 20/05/2021 | This research aims to find out whether the chance of having a heart attack or stroke is greater after a urinary tract infection (UTI). We know from prior research that the body's response to an infection may interfere with blood flow to the heart or brain causing heart attack or stroke. Prior research has also found that the chance of having a heart attack or stroke is greater following a respiratory tract infection. However, prior research has not fully explored the relationship between UTI and heart attack or stroke. Answering this question is important because UTI is common and if it increases the risk of heart attack or stroke, we need to think of ways to prevent these events. This may be possible using simple medications such as aspirin, which could be taken for the duration of an infection. To answer this question, we will link anonymised data from primary and secondary care sources already held in the SAIL Databank, with urine test data processed by NHS laboratories. We will not recruit individuals or identify individuals from the data. Using these existing data means we can answer this question. |
| Linkage of children's social care and health and education data in Wales: exploratory analyses | 28/04/2021 | The CASCADE (Children's Social Care Research and Development Centre) Partnership aims to produce world-class research focused on improving children's social care. One of the work packages includes developing the capacity to link children's social care and existing health and education data in Wales. The aim of this project is therefore to: a) Undertake exploratory analyses of routinely collected local authority social care data currently held in SAIL to explore the characteristics of Children Looked After (CLA) and Children Receiving Care and Support (CRCS) in Wales, and to examine their health status and education outcomes. This will provide insight into how the care system is working; better understanding of the pathways of children and families through social care services in Wales; and their outcomes beyond their involvement with the care system. b) To undertake some methodological work on the social care datasets held within SAIL, such as the development of syntax to facilitate the build of research-ready datasets for other researchers. c) Through access to the data to advise on the |
| How can NCS healthcare data be connected with wastewater surveillance of COVID-19 in a privacy preserving fashion | 21/04/2021 | COVID-19 is a serious disease caused by a virus called SARS-CoV-2. To protect communities, we need to find out how many people have this virus, and who they might infect. Most people get tested when they start to feel ill. However, some people never feel ill when they're infected with the virus. But they can pass it on to their families without knowing. We're developing new ways to identify how many people have the virus but don't have symptoms, so we can protect communities. Fortunately, traces of the genetic material of the virus can be found in the poo of everyone who is infected, even if they don't feel ill. The poo travels through the sewerage network to sewage treatment centres in your local area. Here, samples of the sewage are taken to measure the amount of genetic material it contains. This allows us to estimate how many people in the community are infected. We want our estimates to be as accurate as possible. We therefore need to compare them with information |

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| Understanding the mental health and wellbeing needs of shielded children or children living with shielded patients, before and during the COVID-19 | 13/04/2021 | Studies show that children’s mental health and wellbeing has been badly affected by public health interventions to minimize the spread of the COVID-19 virus. However, so far no studies have looked into mental health in the group of children who were advised to shield or who live with someone who was advised to shield. This project aims to understand the mental health and wellbeing needs of children aged 2–19 in Wales who were shielding or were living with someone who was shielding, before and during the COVID-19 pandemic. We will summarise the number of children who were given a diagnosis or prescription relating to anxiety (including attachment disorders and post-traumatic stress disorder), depression, self-harm, sleep disorders, eating disorders or substance abuse before the pandemic, during the period of shielding, and after the period of shielding, and compare these numbers with a group of children who were not advised to shield or were not living in a household with a shielded patient. We will also explore whether certain children were more or less likely to have received care for each |
| Addressing inequalities in ‘Children in Need’: A population linkage study to inform policy | 08/04/2021 | Across the UK, in recent years, there has been an increase in children being referred to social services and being taken into care. This increase can be seen particularly in more disadvantaged areas, but the reasons for this are unclear. Long term health and educational outcomes for these children are on average worse than for the general population and supporting these children represents a major expenditure at local authority level. In this project we aim to better understand the reasons why more disadvantaged children are more likely to be referred to social services. We also aim to better understand the consequences of being referred to social services, having a child protection plan and being taken into care, on children’s health and educational outcomes. We plan to use this knowledge to identify populations of children who are more likely to end up being taken into care and who are likely to have poorer outcomes, and to develop better policies and practices to support these children. This will help plan timely interventions that can prevent the need for contact with social services |
| BREATHE – ResMed | 15/03/2021 | ResMed pioneer innovative solutions that treat and keep people out of the hospital, empowering them to live healthier, higher-quality lives. Their digital health technologies and cloud-connected medical devices, transform care for people with sleep apnoea, and other chronic diseases. To improve the health of people with obstructive sleep apnoea (OSA) then better understanding is required of the healthcare utilisation pathway for this population. The feasibility part (Phase 1) of this project is to identify OSA patients using Welsh routine health data and to describe the OSA care pathway. OSA coding expertise will be sought from within the BREATHE network of clinicians to advise the Analytical Team in identifying the codes used to define the OSA cohort. In the full pathway mapping part (Phase 2), these findings will be applied and extended to Scottish and Welsh routine data to compare pathways between countries in terms of type and frequency of activity, and estimated pathway cost. ResMed have relationships with clinicians, patients and patient organisations in the field of OSA. However, we |
| ICODA: iPOP (Driver Project 2) | 11/03/2021 | In the international Perinatal Outcomes in the Pandemic (iPOP) Study, we will seize the unique opportunity offered by the COVID-19 pandemic to answer urgent questions about perinatal health. In the first two study phases, we will use population-based aggregate data and standardized outcome definitions to: 1) Determine adverse perinatal outcomes (rates of preterm birth, low birth weight, and stillbirth) and describe changes during lockdowns; and assess if these changes are consistent globally, or differ by region and income setting, 2) Determine if the magnitude of changes in adverse perinatal outcomes during lockdown are modified by regional differences in COVID-19 infection rates, lockdown stringency, adherence to lockdown measures, air quality, or other social and economic markers, obtained from publicly available datasets. We will undertake an interrupted time series analysis (ITSA) covering births from January 2015 through July 2020. The ITSA is a method of statistical analysis involving tracking a long-term period before and after a point of intervention (in our case the first lockdown) to |

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| The Relationship Between Cancer and Kidney Disease | 01/03/2021 | There have been tremendous advances in treatments for cancer in recent years. In particular, chemotherapy is now much more sophisticated and used to treat over a quarter of people diagnosed with cancer. Survival from cancer has therefore doubled in the UK over the last 40 years. However, there is a cost of surviving cancer: people are more likely to live with long-term health conditions. Furthermore, long-term health conditions can be both a cause of cancer and an effect of cancer treatment. People with long-term health conditions may be less likely to present to their doctor with symptoms of cancer, or these symptoms may not be investigated in the same way as in people who do not have long-term health conditions. This could lead to later diagnosis and treatment of cancer in people with long-term health conditions. Although new treatments are always tested in clinical trials, these trials often exclude people with chronic health conditions. The trials therefore do not give us a complete understanding of how well these treatments perform in real people, and whether the treatments have unanticipated side |
| Association between epilepsy and anti-epileptic drugs and risk of intracranial aneurysms | 01/03/2021 | A subarachnoid hemorrhage (SAH) is bleeding in the space between the brain and the surrounding membrane (subarachnoid space). Bleeding results from the rupture of an abnormal bulge in a blood vessel in the brain. This abnormal bulge is called an aneurysm. An SAH is a severe type of stroke and it occurs in relatively young people; the mean age is 50 years.. Although SAH is relatively rare constituting only 5% of all strokes, it has a major impact due to its devastating effects; 1/3 of patients die (~17,000 persons/yr in the EU) and 1/3 remains dependent on help. Some of the risk factors for aneurysms and SAH are well understood, but they only explain part of an individual's risk which suggests that there are other, unknown risk factors for the disease. Insight in these risk factors will provide potential new treatment options and may lead to the prevention of SAH. In a recent genetic study on aneurysms and SAH we found a potential link of the disease with epilepsy/anti-epileptics. However the reasons for this link are unclear. Therefore, we aim to investigate the association between the diagnosis of epilepsy |
| Establishing the impact of COVID-19 on the health of domiciliary care works in Wales and understanding | 18/02/2021 | Domiciliary Care Workers (DCWs) are employed in both public and private sectors to support adults at home. Support varies but often includes personal care, which demands close contact between DCW and the person being supported. People working across the care sectors in England and Wales have experienced higher rates of death involving COVID19 infection. Social care workers, in both residential and domiciliary care settings, have been particularly badly affected, with rates of death involving COVID-19 approximately double that for health care workers. We do not fully understand the full impact on domiciliary care worker mortality, how COVID-19 has affected worker health more broadly, and the risk factors that contribute to these. The ONS mortality data relies on occupational classification, missing for many individuals reported as dying with some COVID-19 involvement. In Wales and other devolved nations, all DCWs working with adults have to register with a regulatory body. The population of DCWs in Wales is therefore known, and can be linked to health data held in the SAH |
| Nish – Covid national initiative | 17/02/2021 | Policy relevant research remains critical to understand and address the Covid-19 pandemic. Chronic health effects of infection, particularly as new variants emerge, remain poorly understood. Data on the short-and medium-term, health service impact, safety and effectiveness of vaccine and of different vaccination strategies are urgently needed. The breadth of national linked electronic health records (EHRs), combined with the depth of representative, generalizable longitudinal population studies, places the UK in a unique global position to address continuing and emerging pandemic related questions. This work is part of a national UK initiative across the 4 nations to compare and contrast; 1) health record data linkage for longitudinal population studies, 2) a co-ordinated analyst resource to interrogate these datasets rapidly and efficiently. This work provides underpinning resource to support a team of high calibre analysts (data scientists, software engineers, statisticians), to interrogate existing data to provide rapid, accurate and policy relevant outputs. The longitudinal studies across the |

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| Factors influencing dementia progression | 12/02/2021 | The individual experience of living with dementia can vary enormously from person to person and symptoms may progress at different rates and in different ways for each person. The aim of this study is to understand what factors affect the progression of dementia and how they influence the key time points on the dementia patient's journey, including hospital admissions, transfer to care home and death. This is important because if we know what makes some patients with dementia more likely to be admitted to the hospital or move to a care home sooner than others, we can provide patients and their carers with a better prediction of what to expect during the course of their disease. Even more importantly, the knowledge of the individual risk factors of disease progression will allow us to develop interventions to prevent some of the unnecessary hospital stays or delay the time to care home admission by supporting patients better in their own homes. Latest figures suggest one in four hospital beds are occupied by people with dementia – and 20 per cent of these admissions are due to preventable |
| The dynamics of frailty in older people: modelling impact on health care demand and outcomes to inform | 09/02/2021 | Older people who have complex health problems are often described as frail. People who are frail are more likely to find it difficult to deal with small changes in their health or circumstances. This means that, when they get ill, the effects are worse than for other people. Until recently, it was difficult to provide care for frail older people because it was hard to identify people who were frail without an assessment by a consultant. This meant that frail older people were not always receiving the care they needed. Better care for frail older people has become a priority for the NHS. It will improve their health and quality of life and it will also help the National Health Service (NHS) to use its resources more efficiently. It is now possible to use a tool called the electronic Frailty Index (eFI) to identify all the frail older people in a General Practice (GP) primary care from their routine data. This will allow GPs to offer services designed for the frail older people in their practice. However, the GPs and local health NHS services need to know more about their frail older patients and what sort of health and care services they need |
| REHEARSE – Study (Assessment of Remote Heart Rhythm Sampling Using the AliveCor Heart Monitor to Screen for Atrial Fibrillation): Long- | 09/02/2021 | Disruptions in heart rhythms such as conditions like atrial fibrillation [AF] (causing high heart rate) increase the risk of a person suffering from a stroke (blockage of the blood supply to the brain). This can lead to a lower quality of life or death. It is already possible to identify people who may be at risk of developing AF but it can be difficult to diagnose whether they actually have it. This is because AF can occur without the patient noticing it or if they do have symptoms the AF has passed before they see their GP. We have recently shown that if you give people at risk of developing AF a device that allows them to record their heart rhythms for 1 year (twice a week or more if they feel symptoms) at home you are more likely to identify those with AF compared with those who continued with normal care. In addition, we also found that those with the recording device were less likely to have a stroke or other related event in the year following the study than the routine care group. We want to extend this follow-up period to see if this difference continues between the two groups. To do this we will link the study data to the |
| COVID-19 Symptom Tracker - Impact Evaluation of Test and Trace | 09/02/2021 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. This project is looking to evaluate the impact Test and Trace has had in order to implement better decisions regarding Test & Trace going forwards |

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| Understanding the Cost of Health Inequality in Wales | 02/02/2021 | Health status of an individual is greatly influenced by socio-economic, behavioural and environmental factors. People from deprived areas might be more likely to visit GP services and less likely to visit specialist healthcare service than those from least deprived areas. This can have huge cost implications to the NHS Wales in delivering health services. However, the cost of healthcare services incurred to the different section of the population in Wales have not yet established. This study aims to identify the social patterning of different health service uses and estimating the annual and life-time costs of health inequality to the NHS Wales. This findings will help the NHS Wales to efficiently allocate healthcare resources among different sections of the Wales populations. We will use different health service use data (Hospital Inpatient, Outpatient, Emergency, Critical Care, Primary Care GP and other community health services) and integrate the cost information to estimate the average and total annual cost of health inequality to the NHS Wales. The cost of health inequality will be estimated by areas of |
| Sub-project for 0911 Multi-morbidity | 02/02/2021 | See project 0911 for more details. |
| Population Segmentation and Risk Stratification across Cwm Taf Morgannwg | 28/01/2021 | Population Health Management seeks to understand patient populations, groups or clusters by characteristics related to their need and use of health care resources. This can help Primary Care Clusters and General Practitioners (GPs) to decide how best to use limited time and resources to deliver anticipatory and pre-emptive care for patients. Segmenting the population based on a range of factors can identify groups by their holistic need and ability to benefit from anticipatory care. What is population segmentation and risk stratification? • Population segmentation is grouping the local population by what kind of care they need as well as how often they might need it. • Risk stratification means understanding who, within each segment, has the greatest risk of having a significant health event or is at most risk of deterioration. Why is it important? • Current systems of health & care categorise populations by: (1) the disease conditions they have, or (2) the |
| How have parental risk factors affected the changing care rates in Welsh local authorities? | 28/01/2021 | Children's social services are facing challenging times, with the numbers of children in care increasing year on year. These numbers have been increasing since the mid-1990s but the reasons why are not clear. There are also huge variations in the rate of care entry across different Welsh local authorities. There has been speculation about possible reasons but almost no direct research on the issue. The rise could be associated with changing problems in society. Alternatively, it may be due to the way local authority social service departments respond to family problems. This project aims to unpick some of the reasons why the numbers are increasing. It will do this by looking at the sorts of problems that the adults living with children before they go into care have, to see whether this has changed over the years between 2003 and 2019. It will use local authority data on looked after children, and Welsh demographic data to look at the adults in the |

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| <p>Recurrent Care Proceedings in Greater Manchester – a Quantitative Study</p> | <p>25/01/2021</p> | <p>The Department for Education awarded funding to spread and scale across Greater Manchester (GM) innovation projects delivered by Rochdale, Stockport, Wigan and Salford in 2014-16 that focused on vulnerable adolescents, complex families and preventative help and edge of care work. One of the four projects is Salford's "Strengthening Families". The programme aims to reduce the number of children going into care and prevent mothers from getting into the cycle of repeat removals. It is an intensive specialist programme for pregnant women who are pre 20 weeks gestation who have previously had a child, or children, taken into care and where their unborn child risks being removed at birth following social worker assessment and legal proceedings. It provides holistic and intensive interventions for five years, trying to break intergenerational cycles of harm and trauma. The model is now been adopted and adapted in other GM local authorities and a Community of Practice has been formed for GM authorities to facilitate collaboration and the sharing of learning and challenges as authorities begin or</p> |
| <p>Understanding the relevance of markers in rare disease</p> | <p>25/01/2021</p> | <p>To date, there are over 7000 different rare diseases that afflict millions of individuals in the World and are responsible for the deterioration of physical health, mental health, and socioeconomic conditions. These conditions remain a mystery, with around 26% of rare disease patients not surviving beyond the age of 5, suggesting a gap in the literature with no formal diagnostic criteria nor a known cure. Thus, there lies an urgent need to build knowledge on the clinical profile of these conditions and to reduce the patient's time to diagnosis. The initial focus of this study is on a disease known as Fabry (E75.21), a rare metabolic disorder affecting multiple body systems. The condition may lead to heart disease, kidney disease, strokes, and weakness, numbness and pain, usually in your hands and feet, in addition to several other problems. It can cause serious implications in women as well as men. The symptoms of a classical Fabry patient include painful extremities (acroparesthesia), a characteristic rash (angiokeratomas), and abdominal symptoms; in the non-classical form of the disease, these features</p> |
| <p>Administrative Data Agricultural Research Collection (AD ARC)</p> | <p>20/01/2021</p> | <p>Agriculture is currently facing a range of challenges. There is concern about the potential impact of both economic and environmental change on farm household incomes and on the health and well-being of farming households. Additionally, the long-term impact of both Brexit and the COVID-19 pandemic provides new impetus for this work. This project aims to add the human dimension to statistics about farming activities by creating an anonymised agricultural data resource to generate new evidence. We will use data linking to bring together existing public sector datasets on agriculture and farm businesses at an individual level with the Population Census and Annual Population Surveys. This core agricultural dataset will then be further linked to data relating to health and education to create the AD ARC data resource. The focus of the research is to better understand the demographic, health, education and economic characteristics of farm households associated with different types and sizes of farm businesses. Additionally, research will investigate relationships between farm family characteristics and</p> |
| <p>BRIAN (Brain tumouR Information & Analysis Network)</p> | <p>21/12/2020</p> | <p>The Brain Tumour Charity is the UK's largest dedicated brain tumour charity, committed to fighting brain tumours on all fronts. At The Brain Tumour Charity we have built an app and associated database called BRIAN (Brain tumouR Information & Analysis Network). BRIAN allows those affected by a brain tumour to share their healthcare records with researchers, record information about their treatments & quality of life, and view aggregated data insights on others' experiences, through a secure app launched in September 2019. The database behind BRIAN combines national brain tumour datasets that The Charity has obtained from NHS Digital and Public Health England with patient-entered data. This data is used to generate the insights in BRIAN which are intended to help better inform brain tumour patients about their condition, the patient pathway, treatment options and the incidence of brain tumours. At present, although we have patiententered data for brain tumour patients treated in Wales we have no data from the official healthcare data providers in Wales, only data from English institutions</p> |

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| Indicator or Indication: Psychotropic medication as a proxy measure of mental ill health | 21/12/2020 | Measuring population mental ill health is difficult and current, commonly used indicators are not perfect. Hospitalization and suicide rates, though easily accessible, often represent extreme mental ill health manifestations and acute distress, whereas a larger proportion of the population with poor mental health receive outpatient or community services that are often only captured in surveys. Surveys are subject to a range of biases and often fail to capture those most at risk of poor mental health, the isolated and those with subthreshold diagnoses. Administrative data research across the world frequently uses prescribed psychotropic medication as an indicator of mental health, e.g. anti-anxiety medication equates to anxiety and antidepressant medication equates to depression. Whilst these medications are predominantly prescribed for the treatment of mental ill health they are occasionally prescribed for other indications, e.g. antidepressant medications can be used for pain relief, fibromyalgia or enuresis. It is vitally important to understand the accuracy of this method in identifying individuals with |
| COVID-19 Symptom Tracker – DHSC Track and Trace Programme | 03/12/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. This project will use data gathered from the Test and Trace app and CIS alongside data from other sources such as the ZOE app data in order to test different statistical analyses to produce more representative and robust inferences for local level populations in order to guide policy decisions |
| Dementia risk prediction by clinical and environmental characteristics | 01/12/2020 | Around the world there are more than thirty six million people who have dementia, and every year nearly five million more people are diagnosed with dementia. The most common cause of dementia is Alzheimer’s disease (AD), with more than half of all new cases being caused by AD. Of those cases, about 1 in 20 is before the age of 65, which is what is referred to as earlyonset Alzheimer’s disease (EOAD). The reasons why a person might get AD are very complicated. About a half to three-quarters of the variability in whether a person will get AD is because of their inherited genes. For people diagnosed with EOAD their genes cause more than 90 to 100% of the reason. Although we have detected a lot of the common genetic links with AD, we don’t know about all of the genetic links yet in the development of this disease. There is a lot of debate about why it is that we have not yet discovered every genetic link, but we think that it is probably to do with the way that our environments interact with our genetic code. In the past decades there have been a lot of advances in our medical understanding of |
| Investigating whether in utero exposure to maternal medication is associated with adverse pregnancy outcomes and | 30/11/2020 | Prescribing medicines to pregnant women are avoided wherever possible because some medicines can affect the development of, and cause harm to, the baby in the womb. However, sometimes medication cannot be avoided because it is required to treat short or long term conditions during pregnancy. Harmful effects on the baby, which are immediately obvious at birth, have been reported for many medicines. Less is known however about the type of longer term harm a medicine may cause the baby in the womb, which may only be obvious in later years, particularly when the child starts school. Wales records national health and education data including information on births and other maternity events, subsequent pregnancy and child outcomes, prescriptions received, diagnoses recorded in GP practices, hospitalisations, deaths and school outcomes. Records for the same mother and subsequent records for the same child can all be linked together enabling novel research to answer such questions. Our team aim to investigate the association between specific medications taken during pregnancy |

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| The current state of inequities in healthcare provision | 27/11/2020 | Over recent decades, there has been considerable evidence that those living in areas of high socio-economic deprivation suffer from multiple disadvantages in terms of accessibility and utilisation of healthcare. The Inverse Care Law describes the situation where the people who are most in need of healthcare are those who have the least access to it. The Inverse Care Law was first described was almost 50 years ago. Today, tackling avoidable healthcare inequities is still a major priority and concern for healthcare commissioners. This work will investigate whether people living in more deprived areas in Wales have the same access to health care compared to those living in less deprived areas. We will look at a variety of measures including differences in access to screening services; vaccinations; prescriptions; hip replacements; GP consultations and place of death to identify any differences. The measures will take account of underlying differences in the population groups such as age, and the differences will be evaluated using standard statistical techniques to ensure that any differences are more than |
| COVID-19 Symptom Tracker – Cardiff and Vale UHB | 27/11/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. The SAIL anonymised data will feed two main projects, which are already active and running and represent an important part of Cardiff and Vale Health Board’s covid response: 1) A COVID nowcast model to inform our Ops planning team about what to expect in terms of hospital demand. 2) A Regional Surveillance Dashboard, which has been developed in cooperation with Adult Social Care, Public Health Wales and Cardiff and Vale local authorities, and informs operational and strategic covid response workstreams within the regional partnership and |
| Understanding health needs of shielded patients before and during COVID-19 Pandemic | 16/11/2020 | This project aims to understand health and wellbeing needs of people who shielded during the COVID-19 pandemic in Wales before and during the pandemic. There are two main working packages in the project. The first focuses on the interaction with National Health Service (NHS) services including primary and secondary health care usage for all people who were asked to shield, both before and during the pandemic. The second is to understand the mental health and wellbeing needs for shielded children and children living in households with someone shielded. |
| CONCEPTION Amend | 11/11/2020 | The CONCEPTION project is working with 20 EU countries to create sustainable solutions to the problem of uncertainty regarding the safety of medicines use pre-conception, and during pregnancy and breastfeeding: we aim to reduce the current (over) reliance on animal studies and case reports. Comprehensive characterisation of drug-related benefits and harms necessitates information on: fertility rates, pregnancy loss, terminations, congenital anomalies, preterm birth, intrauterine growth (as SGA), complications of pregnancy (hypertension, pre-eclampsia), complications of childbirth and the puerperium (e.g. haemorrhage), neonatal complications (e.g. pulmonary hypertension, hypoglycaemia, discontinuation syndromes), breastfeeding rates, infant and child outcomes, including education performance, long-term conditions, hospitalisations, survival and reproductive success. In addition, the impact of adverse effects of prescribed medicines on reproductive health and childbirth warrant consideration. To answer the question "Is this medicine safe in pregnancy or lactation?" the team aims to compile data |

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| GenOMICC – COVID-19 | 11/11/2020 | Genomics England is partnering with the GenOMICC consortium, Illumina and the NHS to study the genetic code of thousands of patients affected with COVID-19. The aim is to help scientists understand whether a person’s genes may influence their susceptibility to the virus and therefore why some patients with COVID-19 experience a mild infection, while others are affected much more severely. The study is lead by Dr Kenneth Baillie, University of Edinburgh. We propose to study the genomes of up to 20,000 people currently or previously in an intensive care unit with COVID-19, and up to 15,000 individuals who have mild or moderate symptoms. We can then bring the patients’ genome data together with data about their individual strain of the virus, which is being established by the COVID-19 Genomics UK Consortium, for a deeper understanding of the impact of different strains on patients with different genes. The study hopes to gain new insights into why some people are at greater risk of developing life-threatening symptoms, identify treatments which have the best chance of success in clinical trials |
| SCORE-AF (SAIL Comparative Antocoagulation Outcomes Risk Evaluation – AF) | 04/11/2020 | Atrial fibrillation (AF) is the most common abnormal heart rhythm in clinical practice, and hospitalisations because of AF are increasing. Patients with AF have a 5- to 7-fold greater risk of stroke than the general population. Strokes associated with AF also result in more disability and death than non-AF strokes. Blood thinning medicines called oral anticoagulants can decrease the stroke rate by more than two-thirds; however, these medicines can also put patients at increased risk of bleeding. Warfarin has been the most prescribed oral anticoagulant used in patients with AF to reduce the risk of stroke, but it requires careful and very frequent management of the dose in order to be effective. Our previous SAIL studies have shown considerable variation in the effectiveness of warfarin management and how poor management increases the risk of bleeds. Our previous work has also shown that many patients with AF have not been prescribed anticoagulants and these patients are more likely to have a stroke. Since 2012 a newer class of oral anticoagulants known as the Direct Oral Anticoagulants or DOACs have |
| The future of unpaid carers: Understanding their wellbeing needs and support for unpaid carers in Wales | 02/11/2020 | Unpaid carers have made a significant contribution to supporting the most vulnerable before and during the COVID-19 pandemic. Caring can be both hugely rewarding, as well as very challenging . Unfortunately, caring duties fall disproportionately on certain population and social groups. Providing unpaid care can have an adverse impact on the physical and mental health, education, and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. Welsh Government have highlighted that some carers need support both as carers and to maintain their own lives outside their caring responsibilities, supporting life alongside caring. The recent Public Health Wales (PHW) Health Impact Assessment identified unpaid carers as a specific group vulnerable to the direct and indirect impact of COVID-19. Despite the contribution of unpaid carers to population health in Wales, there is a lack of understanding of the true extent and diversity of unpaid carers, the impact of caring on their own health and mental wellbeing, and the longer term impact of caring on |
| COVID-19 Symptom Tracker – National Institute for Health and Care Excellence (NICE) | 28/10/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. - the analysis of this data set will inform the related COVID work undertaken by the institute, with the immediate focus on informing COVID rapid guidelines development. |

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| Millennium Cohort Study (MCS) – SAIL Welsh Linkage for deposit with UK Data Service | 22/10/2020 | The Millennium Cohort Study (MCS) is the fourth of Britain’s world-renowned national longitudinal birth cohort studies. Each follows a large sample of individuals born over a limited period of time through the course of their lives, charting the effects of events and circumstances in early life on outcomes and achievements later on. They help show how trajectories of health, wealth, education, family and employment are interwoven for individuals and vary between them. Where there is consent from respondents for data linkage, their health (for children up to their 14th birthday and parents for all/any time period) and education records (for children up to age 16) will be matched to records in the SAIL Data Bank. The purpose of this linkage is to enrich the data for research purposes and public benefit and to make them more widely accessible so that researchers can apply to access them through the SAIL Data Bank and also through the UKDS. The linked data will be deposited as 'Secure Access' datasets at the UKDS. |
| CovTRANSIT - monitoring and evaluating impacts of COVID-19 Lockdown and exit – from Behaviour Change to Business Activities and | 19/10/2020 | The COVID-19 pandemic is a global public health crisis that is having a profound impact on every area of life and business. Some adapt comfortably, while others are disadvantaged. As the peak of infections is reached, it is important to understand how lifting and re-establishing various measures (e.g., general mobility restrictions, school closures, social distancing, business closures, self-isolation) will translate into behaviours, especially to find the optimal combination of measures at the right time, and to balance these restrictions with aspects of economic vitality. This project aims to improve our understanding of how the public change behaviours during the whole pandemic cycle, how this influences business and the transmission of the virus from individuals to groups and communities. This will inform the emerging impact of lockdown and help recovery and transformation. |
| Understanding the determinants of educational achievement and the association with health and well-being in Wales: | 09/10/2020 | Understanding the factors that potentially influence children’s educational achievement is important as this could contribute to the Welsh Government’s recommendations and policies to tackle inequalities in educational achievement as well as raise educational standards. Health and education data will be linked to the Millennium Cohort Study Data (MCSD) to provide a unique opportunity to explore issues, which have previously been not possible due to a lack of available linked information. This project aims complete an analyses to study children’s educational progress and the association with children’s health, taking into consideration the potential impact of a child’s home, school and neighbourhood environments. |
| Examining associations between complications of pregnancy and incident cardiovascular disease | 08/10/2020 | The proposed project aims to find out if pregnancy-related complications (e.g., diabetes or high blood pressure during pregnancy period) increases the mother’s risk of developing cardiovascular disease (such as heart attacks, strokes, heart failure etc.). Previous research has suggested that women with history of pregnancy-related complications are more likely to develop cardiovascular disease. Documentation of pregnancy-related complications associated with cardiovascular disease may be useful to identify women who should be monitored after pregnancy to increase early detection of cardiovascular disease and to support preventive strategies. We will use anonymised health data that is routinely collected to assess the effect of pregnancy-related complications in increasing the risk of new onset cardiovascular disease (heart attack, stroke, irregular heartbeat or heart failure) in the mother. |

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| Patient flow forecasting/modelling numbers in the Major Trauma Network in Wales | 06/10/2020 | Patient flow forecasting/modelling numbers in Major Trauma Network (MTN) Wales NHS Wales has announced plans for a Major Trauma Network (MTN) in South Wales. The MTN will consist of a Major Trauma Centres (MTC) which will be based in the University Hospital of Wales (UHW) alongside Trauma Units (TU) within each of the six health boards in South Wales. The network was planned to go live in April 2020. Preparations for the MTN used anticipated flow numbers based on data available from the Trauma and Audit Research Network (TARN) database. However comparison of this data with Hospital Episode Statistics showed poor case ascertainment. Also given that currently no MTC exists in South Wales, it is expected that flow of patients will be significantly altered following the establishment of the MTN. Data entry into TARN will be made mandatory for major trauma patients in South Wales and therefore there will be accurate data concerning patient numbers and flow. It would therefore be useful to investigate patient flow before and after the establishment of the MTN and quantify |
| Covid-19 Symptom Tracker - Leverhulme Centre for Demographic Science | 05/10/2020 | How accurately can we predict a positive Covid-19 diagnosis, without a test having been taken? Machine Learning based approaches can -- in theory, and with enough data -- provide diagnoses in scenarios where tests are either unavailable or impractical. Using the Covid-19 Symptom Study (with its millions of anonymised observations) which is hosted on the SAIL platform, we will develop, implement and test a set of algorithms which make this prospect a reality. |
| Patient-centred Care for Fibromyalgia: New pathway Design (PACFIND) | 30/09/2020 | Fibromyalgia is a common condition causing widespread chronic pain, associated with profound fatigue and marked sleep disturbance. Diagnosis and management is complex. Some individuals can wait up to ten years for a diagnosis, involving many general practice consultations and referral to a number of different specialists. The European Rheumatology Association (EULAR) recently published recommendations on how to manage fibromyalgia. Whilst there is considerable evidence on effective treatments, most individuals with fibromyalgia are not receiving timely diagnosis or access to effective treatments. There is almost no evidence on how to organise health services to deliver recommended therapies. Patients feel dissatisfied with current services believing that no-one is willing to take responsibility for their care. We want to provide better services for people with fibromyalgia which ensure: |
| Unintentional Childhood Injury in Wales | 30/09/2020 | This project will assess how common childhood injury is in Wales, identify the risk factors, and investigate the psychological consequences of being injured in childhood. In the first stage of the study we will analyse hospital admission data to determine how common childhood injury is in Wales, and if this has changed over time. The study will describe the patterns of injury according to factors such as age, sex, and deprivation. In the second stage of the study we will investigate risk factors for childhood injury including pre-existing developmental diagnoses (e.g. ADHD and epilepsy), parental mental health, alcohol and substance misuse, and childhood injuries. This will be achieved by linking hospital admission data to GP data for both the child and their parents. To assess the long term psychological consequences of childhood injury, we will use hospital admissions for injury in childhood and GP data for mental health diagnoses later in life. |

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| COVID-19 Symptom Tracker – Bradford Teaching Hospital | 30/09/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work: Modelling work to support the local NHS and city response in terms of critical care bed provision, ward bed provision, and timing of any changes that are necessary to other less urgent clinical work. Coordination of response across cities of Bradford and Leeds, and the local region. |
| COVID-19 Symptom Tracker – NHS Tower Hamlets CCG | 30/09/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. The C-19 Symptom Tracker data will inform local NHS Providers in their planned responses to increases in COVID-19 infection and subsequent hospitalisations. |
| Estimating the social needs of looked after children | 28/09/2020 | Looked After Child (LAC) The term LAC is used to define a child has been placed under the care of the local authority in either a foster care setting, residential unit or can be in the process of being adopted. They are predominantly placed in care setting as a result of abuse or neglect but can also be placed due to other factors such as parental disability or incarceration. Unfortunately, LAC are suggested to experience poorer health and social outcomes; compared to their peers who do not go into the care setting. Situated within these outcomes and current, major priority objectives for government; are the areas of mental health and educational attainment. Research proposes that LAC are four times more likely to have a mental health disorder compared to those not in the care setting (Non-LAC) and nine times more likely to have a special educational need due to emotional, behavioural, developmental and learning difficulties. Several studies have explored the prevalence of mental, neurodevelopmental and behavioural disorders in the looked after population; however, they are often depicted |
| SAIL Databank Conversion to OMOP Common Data Model | 24/09/2020 | The Observational Medical Outcomes Partnership Common Data Model (OMOP CDM) is a standardized format for storing health data from many different sources. Standardization is desirable because it allows easily repeating the same research studies in different locations. This helps increase the robustness of research, as well as allowing data from many different places to be analysed so that there is enough data to study extremely rare conditions and events. Standardized data also allows researchers to share tools and methods across different data sources. The EHDEN consortium has been funded to support the conversion of health datasets across Europe to the OMOP CDM. They have trained and certified Small to Medium Enterprises (SMEs) to be able to perform this conversion, and then provided funding to holders of datasets to convert their data. SAIL has won some of this funding and will commission one of the SMEs to convert a subset of SAIL datasets to this format. The SME will be selected from this pool of approved companies via a competitive procurement process, and we will inform the |

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| Impact of socioeconomic circumstances on risks and life-course consequences of preterm birth: studies into differential exposure | 23/09/2020 | Preterm birth is a significant public health problem, affecting approximately 7% of births, preterm birth is a leading factor in infant mortality, and children born preterm are significantly more likely to have delayed development, poor health, and worse educational outcomes. Preterm birth is increasing in the UK, and pregnant women who are of a lower socioeconomic status are significantly more likely to give birth preterm than more affluent women. Growing up in more disadvantaged socioeconomic conditions is associated with worse outcomes for health and education. Given these children are already more likely to be born preterm, it is evident that outcomes for the children are potentially negatively impacted by this, and it is clear how preterm birth can be an important contributor to the generation of health inequalities. A challenge for this situation is that we do not fully understand the pathways from maternal socioeconomic status to preterm birth, or the relationships between preterm birth and childhood socioeconomic conditions, and their influence on outcomes in later life. This limits the |
| COVID-19 Symptom Tracking Data - Joint Biosecurity Centre | 23/09/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the COVID-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. The Joint Biosecurity Centre (JBC), working with NHS Test and Trace, the Office for National Statistics and Public Health England provides real-time analysis about COVID-19 outbreaks, looking to identify and respond to outbreaks as they arise. The JBC collects and analyses data from an array of sources to understand the drivers of infections and infection rates across the UK, and consequently advise the government on suitable policy responses including local restrictions and other nonpharmaceutical interventions. Separate to this application, JBC has access to local authority-level COVID-19 prevalence estimates from the ZOE app. The purpose of this |
| COVID-19 Symptom Tracker – Liverpool University | 21/09/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is investigating how to abstract data from the App (probably to daily counts of symptomatic individuals in LTLAs) such that it can be combined with data from other sources (eg 111 calls, death data, hospital admissions and test results) to accurately estimate the current extent to which the population in different areas of the UK is infected with COVID-19 and to make accurate forecasts of how this will change in the future. |
| UK-REACH: United Kingdom Research Study into Ethnicity And COVID-19 outcomes in Healthcare workers | 17/09/2020 | COVID-19 has spread rapidly across the world causing significant illness and deaths in many countries. Health care workers (HCWs – those who work in a healthcare setting) are more likely to be exposed to the virus. There is a concern that HCWs from ethnic minority groups may be at increased risk of poor outcomes. It is important that we understand differences in COVID-19 diagnosis, hospitalisation, and death rates between ethnic minority and White HCWs to inform policies to protect the health of these key workers. The UK-REACH programme will address this gap in understanding through a unique large database analysis, to understand if and why ethnic minority HCWs are more susceptible to the virus. |

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| Childcare Offer for Wales - Administrative Data Linking for Long Term Outcomes | 14/09/2020 | The Childcare Offer for Wales (the Childcare Offer) commits to providing 30 hours of government-funded childcare and early education for up to 48 weeks of the year for working parents of three and four year olds in Wales. The Offer is intended to give parents more choice on where they work, how many hours they work, and potentially choose better jobs. The project aims to examine the impacts on recipients (both parents and children) of the Childcare Offer over the longer term. It will seek to quantify (where possible) the extent to which the Offer has contributed towards the above aims, and consider impacts more widely. We will look at a number of outcomes for children who have received the Offer compared to those who did not. Outcomes will include children's educational outcomes such as school attainment, attendance, exclusions, and identification of Special Educational Needs (SEN); rates of A&E, GP and hospital outpatient visits; the reasons for using these services; use of other early years services (e.g. Elving Start, Families First - Welsh Government programmes designed to improve |
| COVID-19 Symptom Tracker – University College London | 14/09/2020 | i-sense EPSRC IRC aims to build a new generation of digital sensing systems to identify and prevent outbreaks of infectious disease, harnessing data science, nanotechnology and engineering (www.i-sense.org.uk). There is an urgent need to map the spread and impact of COVID-19 across the UK. Early detection of local outbreaks is key to protecting populations from disease. i-sense researchers will analyse data from the COVID-19 Symptom Tracker app, which is now used by close on 2m people, in combination with our existing data sets (including search queries and mobility data) to understand the spread of the disease and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. The work builds on our recent breakthroughs in analysis of Google search queries (adopted by PHE for national influenza and COVID-19 surveillance, Lampos et al. arXiv 2020), mobility data (Bennett et al. arXiv 2020) and our recent review of digital technologies in the public |
| COVID-19 Symptom Tracking Data - DAIS | 14/09/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work: - modelling drivers of testing outcomes by location and person characteristics - modelling spatial spread and dispersion of new outbreaks - analysing mobile phone-based movement data. |
| Understanding Self-harm amongst children and young people in care | 08/09/2020 | This project aims to explore self-harm amongst children referred to social care services in Wales. It has been found children and young people in care are more likely to self-harm due to adverse backgrounds and continuing stress. Although there is research on self-harm of adolescents, very little focuses on children and young people in care. This may be due to data access issues as data on children in care have often been restricted. For the first time, data are now available to explore the prevalence of self-harm amongst children and young people in care as well as the potential risk factors influencing the act of self-harm. The research project seeks to address the following research objectives: |

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| COVID-19 Symptom Tracking Data - Cheshire East Council | 03/09/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Comparison of the information given in the Zoe app with other sources of data from local and national sources to see whether it can be used as part of an early warning system to predict increases in cases and to understand better when the Zoe app gives us a different picture to other data sources. |
| PREDICting long-term outcome following admission with AcuTE severe colitis (PREDICATE) | 01/09/2020 | Ulcerative colitis can present rapidly with frequent bloody diarrhoea, causing severe, sometimes life-threatening illness. This is known as acute severe colitis (ASC), and requires admission to hospital for treatment, first with intravenous steroids, followed by more powerful drugs if this fails, and/or surgery (colectomy) if the patient becomes very ill at any stage. Even if the patient gets better, colectomy is often required because of chronic ill health over the next few years. At present it is impossible to predict which treatment will work, and there are concerns that some treatments may have serious long-term consequences such as the development of cancer or life-threatening infections. We collected clinical and survey data from a cohort (around 1500 patients) of acute severe colitis patients throughout the UK. All patients had survey and clinical data collected at baseline, and consented to long term follow up of their routine data. We would like to follow up the Welsh patients (around 80-100 patients in total) from the cohort to explore the mortality rate and look at their resource use, procedure and |
| Evaluation of real world effectiveness and safety of new diabetes drugs: a meta-analysis and collaboration | 31/08/2020 | There are many new medications used to treat diabetes which have come on the market in recent years. Clinical trials can evaluate broad safety and effectiveness for people who are eligible for a trial. However, some side effects are often only seen when the drug is given to large numbers of people. In addition, patients recruited to clinical trials often are healthier than the typical population and often are not on many other medications at the same time. People with diabetes in the general population are often on many more drugs than would be acceptable for a trial participant. This means side effects associated with being on other medications will be missed in a trial and only become apparent in studies looking at populations. This study aims to bring together the medical records of people with diabetes who are treated with new drugs in 6 European countries. We will examine side effects and effectiveness in the 'real world'. Using data from 6 countries will enable us to detect rare side effects and to see who the medications work best for by enabling us to have the numbers to look at subgroups within the |
| COVID-19 Symptom Tracker – Makerere University | 31/08/2020 | The insufficiency of COVID-19 testing infrastructure is a global phenomenon, but it is more prevalent in developing countries such as Uganda, where there is a dearth of requisite resources (equipment, test kits, testing centers/facilities, and personnel). Currently, testing resources have been focused on high-risk demographics (cross-border truck drivers, air travelers/returnees) and their contacts. As of August 20, 2020, only 333,667 samples have been tested, of which some are repeat/follow-up tests for the same subjects. This is a drop in the ocean for a country of over 40 million people. Recently, there has been a surge in community transmission and COVID-19 deaths. To contain community transmission, there is an urgent need for an efficient, rapid, and widely available method to screen for COVID-19. The major goal of our work is to develop a robust mobile application for pre-emptive screening for COVID-19, that utilizes machine learning models trained on anonymized clinical data from confirmed COVID-19 patients. This will be followed by evaluation studies among COVID19 patients in a |

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| To investigate whether hormone replacement therapy in women diagnosed with common cancers alters their risk of cancer-specific | 21/07/2020 | Hormone replacement therapy (HRT) is widely used and has proven benefits in women with menopausal symptoms. The role of oestrogen in cancer development and progression is complex. Recent studies have suggested HRT could be protective in women with melanoma, colorectal and liver cancer. In contrast, there have been concerns that HRT could accelerate cancer progression in women with lung, bladder, gastric, and brain cancer. Consequently, some researchers have recommended against using HRT in women with these cancers. However, epidemiological studies have not investigated the survival of women using HRT after diagnosis of most cancers and therefore the safety of HRT use in cancer patients remains unclear. |
| Machine Learning for Discovery of Patient Journey-Wide Phenotypes and Colorectal Cancer Stratification | 21/07/2020 | The project will use multiple data sources found in SAIL to produce a robust prognostic tool for stage II/III (two and three) colorectal cancer patients, based on existing work completed to develop the tool using a patient cohort of 661 in Northern Ireland. Variables similar to those in the Northern Ireland cohort will be identified in SAIL to generate an comparable Welsh cohort. The purpose of this cohort is to validate the prognostic tool's performance on patients from a separate healthcare system and population, providing evidence of the tool's wider applicability. The exact SAIL data required will be identified by mapping variables using standardised codes. The proposed work with SAIL data will then involve two stages: 1. Analysing the similarities and differences between the Northern Ireland cohort (outside of SAIL) and Wales cohort (inside of SAIL). 2. Identifying if the prognostic tool can provide high-quality prognostic predictions for the Wales cohort (inside of SAIL). |
| Effects of withdrawal of inhaled corticosteroids in patients with COPD: a national population cohort study in Wales | 17/07/2020 | Chronic obstructive pulmonary disease (COPD) is a chronic lung disease characterised by limitation in airflow to the small airways of the lungs. People with COPD experience chronic cough, wheeze, sputum production, and breathlessness. Deterioration in symptoms and lung function is slowly progressive over time. People with COPD can also experience sudden "flare-ups" of their symptoms, termed exacerbations. These exacerbations are often treated with antibiotics and corticosteroid tablets, and if severe can lead to admission to hospital. In Wales, in 2018, there were 73,922 people registered with their GPs as having COPD, and the numbers of people living with COPD are rising. Patients with COPD rely on inhalers to be able to live as fully as possible, and so it is important for healthcare workers to understand the best option of inhaler for their patients. |
| Classifying Neurodegenerative Disorders for Clinical and Research purposes | 17/07/2020 | Neurodegenerative conditions involve a progressive worsening in the function of the brain. They include conditions such as dementia and Parkinson's disease. Neurodegenerative conditions are getting increasingly common in the UK as the population ages and they carry a high social and healthcare burden. In most cases there are no definitive diagnostic tests for the neurodegenerative disorders and their diagnosis relies on the interpretation of history, examination findings, some investigation results and progression with time. It can be very difficult sometimes to distinguish between Alzheimer's disease and other forms of dementia (such as Lewy body or Fronto-temporal dementia) and Parkinson's disease and other forms of Parkinsonism (such as Progressive Supranuclear Palsy or Multiple System Atrophy). This can lead to a diagnostic delay, increased patient anxiety, delay in receiving treatment or even incorrect treatment being given. Patients with an incorrect diagnosis can also miss out on trials of new treatment and incorrect support from the appropriate |

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| Maternal pre-pregnant body mass index and risk of spontaneous preterm delivery | 13/07/2020 | Babies who are born preterm (before 37 completed weeks of gestation) have an increased risk of dying in their first year and of a range of health and developmental problems, both short and long-term. Previous studies have suggested that mothers who are either underweight or overweight either before or in early pregnancy are more likely to have a baby who is born preterm. However, it is not clear exactly at what thresholds - in terms of the mother's body mass index (BMI) - the risk increases or whether the thresholds vary from country to country. Although overweight and obesity are increasingly common, fewer women are underweight. It is therefore necessary to use large-scale datasets on mothers and their babies to answer these questions. This study aims to use anonymised datasets from several countries to find out what the optimal BMI range is order to minimise the risk of preterm birth. These findings will help inform the advice given to women <i>planning on having a baby</i> |
| Factors affecting Pathology reference ranges in the Welsh population | 13/07/2020 | Pathology departments are obliged to ensure the reference interval (also known as "normal ranges") quoted on test reports are accurate. This is vital to enable correct test interpretation. Otherwise, abnormal results may be missed and normal results may trigger unnecessary investigation and patient concern. However, many ranges are historic and not based on good quality evidence from the local population. Many factors known to affect "normal" results, e.g. age, gender, ethnicity, are not well characterised. This project will assess reference ranges based on analysis of retrospective routine laboratory data. This data may be affected by e.g. concurrent disease or by medications, so the project will attempt to define appropriate criteria for setting such ranges. For example, high platelets are known to cause raised serum potassium results - it would be of use to characterise the scale of this effect, not only to confirm whether patients with high platelets should be discounted when setting "normal" ranges, but also to aid interpretation of potassium when a patient is known to have raised platelets |
| COVID-19 Symptom Tracker – CMO NERVTAG | 13/07/2020 | COVID-19 is an emerging disease and there is still a lot to learn. It is essential we harness the wealth of data available to help inform government decision making to optimise our response. This data is one such repository which could allow analyses which are otherwise not possible. The initial goals of the project fall into two broad areas: 1. Mapping the spread of infection There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close to 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. 2. Understanding clinical predictors and symptomatology The New and Emerging Respiratory Virus Threats Advisory Group (NERVTAG) advises the government on the threat posed by new and emerging respiratory viruses. They have provided critical advice throughout the epidemic |
| Clinical Impact of Post-Vaccination Era Measles in Wales | 07/07/2020 | Measles is a highly contagious viral disease. Before vaccines were introduced, the UK would regularly experience over half a million cases, in bi-annual outbreaks, with common complications and an expected death rate of 1 in every 1000 cases. A series of vaccines and campaigns beginning in 1968 all but eradicated measles in the UK. However, vaccination levels must be kept extremely high to keep the disease at bay. This level is about 95% for measles, to produce what is known as 'herd immunity' in the population. In 1998, a media scare occurred, and the measles vaccine (MMR) was claimed to have a link to autism in children. Although the scientific paper was immediately discredited, and ultimately withdrawn, vaccination of children declined rapidly in response. Within only a few years, many studies in many countries had shown that there was no substance to the claim, but the vaccination rates remained worryingly low. The |

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| Analysing antidepressant prescription duration in Welsh GP practices to monitor depression management and address the lack of | 06/07/2020 | <p>This study will investigate the duration of antidepressant treatment of patients in Wales, and whether these patients are reviewed regularly. This is important as not reviewing patients may lead to prolonged medicine use.</p> <p>Antidepressant prescribing has been increasing in Wales over the past two decades, which may in part be due to an increase in long term prescribing, lack of alternative support services or increased recognition and treatment of this illness. To date there is limited research on appropriate long- term antidepressant prescribing and whether these patients receive regular medication reviews.</p> |
| Exploring the prevalence and risk factors of cellulitis in NHS Wales | 06/07/2020 | <p>This study will use anonymised patient data from a databank to analyse primary care antidepressant prescribing in Wales. The study will</p> <p>Cellulitis is a skin infection and can affect any part of the body. Cellulitis is usually caused by a break in the skin (e.g. cut, ulcer, insect bite or dry cracked skin) which allows bacteria to enter and cause an infection. Cellulitis is not contagious and rarely affects more than one area of your body at the same time. If a person has cellulitis then they require urgent antibiotic treatment to prevent spread of the infection as well as developing sepsis. In Wales we know that over 32,000 hospital bed days in are occupied by people with cellulitis each year. Although the numbers of people who have cellulitis in a hospital are recorded there is very little understanding as to those who have cellulitis in primary care and if there are risk factors associated to gender, age, geography and comorbidities. Comorbidities could include, falls, fungal infections, heart, cancer, diabetes, venous and orthopaedics. Having greater knowledge of these factors may help us provide better care to people who have cellulitis and may be at risk of developing it. Having one episode of cellulitis is strongly linked to have recurrences and developing</p> |
| Decision Support for Severe Asthma Treatment | 06/07/2020 | <p>What is the problem? Asthma affects about 300,000 people in Wales. People who suffer from severe asthma but are not taking the right type of treatment are at high risk of death. There are several types of treatments. For example, steroids in high doses can help prevent asthma attacks, but at the same time they can cause serious side effects. Biologic medicines can be very effective and have fewer side effects. But they are expensive and don't work for everyone, and it's difficult to predict who will benefit. What do we want to do? We want to help doctors decide on which patients are likely to benefit from which treatment. We will do so by making use of patient data already collected across the NHS. We will also consider how patients feel about their disease. How will we do it? We will develop two algorithms that tell whether a patient will benefit from which treatment. We will develop the first algorithm using data of people who have attended the Severe Asthma Clinic in Swansea Bay University Health Board. This data will come from clinic letters which contain detailed information about severe</p> |
| The Role of Area-level deprivation for private and public family law cases concerning children in England and Wales. | 05/07/2020 | <p>The Family Justice Observatory has generated important knowledge about infants and older children undergoing care proceedings and about children in private law proceedings, but our knowledge about the effects of residential areas on children and their families is still limited. Especially effects of area deprivation on children undergoing public and private law proceedings and on their subsequent health are largely unexplored and need attention.</p> <p>This project seeks to explore and map associations between area-level deprivation and the prevalence of public and private law cases involving children in England and Wales. Furthermore, this project aims to examine relationships between area-level deprivation and the subsequent health of children undergoing private and public law proceedings</p> |

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| COVID-19 Symptom Tracker - Frimley Health Foundation Trust | 30/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. To compliment other work that is being undertaken locally to build leading indicators that will help executives in NHS and local government establish interventions that could help reduce the impact of a second peak. |
| Understanding limitations and bias within the ZOE symptom tracker dataset | 22/06/2020 | Many governmental and healthcare organisations are in the development or deployment stages of COVID-19 track and trace projects. Many of these efforts will be carried out via a smartphone application (hereafter “app”) that individuals download and participate through. It is currently unclear which groups of people such app sampling inadvertently over- or under-represents as a result of differential uptake. If data are collected from track and trace efforts with the aim of establishing common patterns of transmission, differential uptake and patterning of participation may hamper efforts to understand COVID-19. Findings arising from app sampling may not be generalisable to the broader population, and associations between risk factors that influence selection may be biased or even spurious. The COVID Symptom Study provides a valuable case study for modelling selection processes as it was promoted and developed during a similar period and with similar public health priorities. The COVID Symptom Study is a mobile app in which registered users can report their demographic characteristics |
| COVID-19 Symptom Tracker – CORSE Inria Research Team | 22/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. There is a crucial need to understand the relationship between severity of symptoms (as measured in a survey) and COVID so as to be able to use data (mostly from surveys) that mostly track symptoms. Such data should allow to better understand typical interval distributions between infection, contagiousity, and hospitalisation. This understanding is critical to calibrate epidemiological models that are used to specialize (age, region, context...) social distancing campaigns |
| COVID-19 Symptom Tracker – Sheffield Community Contact Tracing Project | 19/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Sheffield Community Contact Tracers project was set up to determine if it was possible to recruit volunteers and train them to be contact tracers for cases of Covid-19 in order to provide a local workforce to find, tests, trace contacts and support cases and contacts while they were self isolating. It was set up at a time when there was no contact tracing being undertaken. Although it was unique in this country it follows a model recommended by the WHO and used in many other countries. The data will be used in the report of the pilot scheme of the Sheffield |

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| COVID-19 Symptom Tracker - Brighton and Sussex Medical School | 16/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project will investigate prolonged Covid-19, which is when Covid-19 symptoms last much longer than the 2 weeks described in government guidance. Lots of stories are being published about people with prolonged Covid-19 where patients had a fairly mild case of Covid-19 (for example, they were not hospitalised) but who are still having symptoms 6, 10, or even 15 weeks later. Sometimes the symptoms of severe fatigue, high temperature, and chest |
| COVID-19 Symptom Tracker - South Warwickshire CCG | 15/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. The project aims to understand the spread of Covid-19 across the 500+ LSOAs within Coventry and Warwickshire. There are two broad project aims: 1. To understand how the virus may have spread across Coventry and Warwickshire (C&W) to better inform our understanding should a subsequent wave of infections materialises. This will include investigating any local variances in spread any relationship between factors such as demographics and deprivation. 2. To inform our understanding of the impact of Covid on the Coventry and |
| Sub-project for 0911 Multi-morbidity | 12/06/2020 | |
| Predictive ability of segmentation in relation to health care use in Cwm Taf Morgannwg University Health | 08/06/2020 | The Welsh Government have agreed to fund a project to use population segmentation. Population segmentation means to split people into groups of similar types of patients. For this we count how often patients have been to their GP, A&E and hospital (inpatient or outpatient) and had different medicines in a year. We then run a data analysis that creates groups of patients with similar use of each health care service. This has been used before in England and elsewhere to estimate groups of people with similar future health care needs. We will also be looking at the number of chronic conditions each person has or the level of deprivation to find the best method of segmentation. We want to find out whether people in these segments in the Cwm Taf Morgannwg Health Board (CTMUHB) population have similar health care needs in the future. To do this we will use older data from 2015 to group people and then check if they had the expected health care use in the following four years. This will help with service planning and also with finding new programmes to improve each group's health. Once we know how |

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| COVID-19 Symptom Tracker – Ulster University | 04/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work: 1. Analysing transmission dynamics of Covid-19 2. Analysing progression of the Covid-19 infection 2. Investigating relationship between underlying health conditions and severity of symptoms 3. Identifying group of individuals at significant risk of increased morbidity from COVID-19 |
| COVID-19 Symptom Tracker – Camden and Islington Public Health | 03/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work: • To track symptoms at a geographical level across North Central London to allow for better planning at a local level. • To understand the pattern of symptoms specific to our local level and how that might differ from the national picture. • To understand the spread of COVID-19 across North Central London by demographics and co-morbidity • To estimate public engagement and awareness of COVID-19 through use of the app and uptake of testing |
| COVID-19 Symptom Tracker – London School of Hygiene and Tropical Medicine | 02/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. As COVID-19 caseloads in England appear to have reached the first peak, to ensure continued response to the epidemic is most effective, it is imperative that we better understand (retrospectively and prospectively) the geographical evolution of COVID-19 and localised areas in space-time at higher risk of severe disease burden and mortality. Integrated daily small-area spatial analysis of COVID-19 syndromic profiling and duration of symptoms (using self-reported data from >2million users of the COVID Symptom Tracker) versus |
| Randomised Evaluation of COVID-19 Therapy (RECOVERY) | 01/06/2020 | In early 2020, as this protocol was being developed, there were no approved treatments for COVID-19, a disease induced by the novel coronavirus SARS-CoV-2 that emerged in China in late 2019. The UK New and Emerging Respiratory Virus Threats Advisory Group (NERVTAG) advised that several possible treatments should be evaluated, including LopinavirRitonavir, Interferon β , corticosteroids, and Remdesivir. These groups also advised that other treatments will soon emerge that require evaluation. A World Health Organization (WHO) expert group issued broadly similar advice. Patients admitted to hospital with proven or suspected COVID-19 will be invited to participate. If they are willing and eligible they will be randomised between the study treatments (which may change during the course of this adaptive trial). Treatments will be given as part of their routine hospital care and information collected at the earliest of death, discharge or 28 days after randomisation on the study outcomes. We wish to supplement the data we collect from hospital staff with routinely collected data such as that held by SAIL |

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| COVID-19 Symptom Tracker – Oxford University | 01/06/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. We will use the data to evaluate different nonpharmacological interventions to reduce the spread of COVID-19. In particular, we will analyse the effect of manual and app-based contact tracing. |
| First 1000 days | 28/05/2020 | Where you live and if you work and what you do for work influences your health and well-being from before you were born to when you are very old. Public Health Wales is committed to making sure that where your parents live and if they work and what they do for work helps Welsh babies get the best start in life. To help do this, this project will use data to understand the relationship between babies health and where their parents live and parent's jobs or lack of jobs. We will look at which areas in Wales do better and which do worse and why that may be. |
| Mental disorders, self-harming behaviours and mortality amongst children and young people involve in family justice court proceedings: a | 28/05/2020 | This work will focus on mental health and self-harming behaviours of children and young people (and their family members) involved in family justice court proceedings, and also whether those involved die younger than the general population. We will also study educational outcomes (such as absenteeism and attainments) for children and young people with mental disorders. The Children and Family Court Advisory and Support Service (Cafcass) Cymru dataset in SAIL houses all family court proceeding since 2011, this dataset provides information on both public and private law family court proceedings. The family court makes decisions on contact rights of parents/carers and the living arrangements of the children involved in these proceedings. Private law cases are brought to court by private individuals, generally in connection with divorce or the parents' separation, whilst Public law cases are brought to court by local authorities and relate to the safety of children. Some of the children involved in these proceedings may have been subject to a range of |
| COVID-19 Symptom Tracker – Public Health Wales | 27/05/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Public health analysts will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Provide estimates of the incidence of COVID symptoms. The work will also seek to validate other sources of COVID surveillance. |

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| COVID-19 Symptom Tracker – Manchester University | 27/05/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. We are working to ensure that the C-19 Symptom Tracker App Data is appropriately integrated with other signals aimed at monitoring the epidemic in real time, particularly the ONS COVID study. |
| COVID-19 Symptom Tracker – Somerset and Dorset NHS | 22/05/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Yeovil District Hospital serves a population of 220,000 across South Somerset and North Dorset, with a high proportion of elderly and COVID vulnerable individuals. The area is markedly behind the rest of the country in terms of stage of epidemic, and at risk of a surge in COVID-19 as lockdown restrictions are lifted. The hospital has built COVID Analytics alongside the wider Somerset and Dorset Health Systems, but currently has no intelligence on the extent of community transmission or where it may be occurring locally. By accessing up to date daily reports from 700 self |
| Mental health and self-harming behaviours in University students in Wales: risk factors and trajectories | 20/05/2020 | There are growing concerns about university students mental health such as depression, anxiety, eating disorders and self-harming behaviours. As far as we know, this is a unique study exploring mental health conditions and self-harm among university students in Wales. It is estimated that over 26% of students living in Wales attend Welsh universities. Students nowadays are faced with many issues that may lead to mental health issues including financial difficulties from student loans, increased tuition fees introduced in 2012, more people go to university from different backgrounds and wealth, losing support from families and friends, having to manage an independent living, and coping with exams and assignment pressures. Struggling to access a GP and/or mental health specialist services for treatment may also lead to these issues. Many do not register with GPs so even if they needed to would not see a psychiatrist for getting medications in their new |
| COVID-19 Symptom Tracker – Office for National Statistics | 20/05/2020 | To map COVID-19 across the UK and its 4 nations to inform UK, national and local decision making, with direction and priorities provided by government and those in charge of evaluating and dealing with the UK COVID-19 responses and planning. Specifically this project aims to provide insight to models for early detection of COVID-19 hotspots. Anticipated outcomes of the project are to provide the best available insight into the risks for COVID-19 and locations of potential hotspots. |

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| COVID-19 Symptom Tracker – University of Exeter | 20/05/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Identifying how the COVID 19 data may be used to calculate regional estimates of viral replication rate. |
| COVID-19 Symptom Tracker – University of Strathclyde | 11/05/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Build a computer simulation model which uses the information about COVID activity across Scotland to understand what healthcare resources will be needed to support care and maintain healthcare for patients without COVID to ensure services run as effectively as possible for all patients. |
| COVID-19 Symptom Tracker - National Centre for Geospatial Intelligence | 07/05/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work: It is imperative to identify in advance the areas of the UK which may be the hardest hit by a significant second outbreak of COVID-19. The research data is intended to be used with other warnings and indicators to identify where local authorities may need additional support and prioritise resources. |
| COVID-19 Symptom Tracker – King’s College London | 06/05/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work: A substantial number of individuals take immunosuppressants to manage chronic diseases. There is great anxiety amongst this community regarding whether immunosuppressants increase risk of COVID-19 infection or the severity of its symptoms – this is currently unknown. We will analyse data from the C-19 Symptom Tracker app to address these questions. We will use statistical models to disentangle the risks due to immunosuppressants from the risks due to other medications, health problems and sociodemographic factors. |

COVID-19 Symptom Tracker – Northumberland County Council 01/05/2020 There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. The overall aim of this project is to understand the spread of coronavirus within our county. The situation has been rapidly evolving from its beginnings in Wuhan to its now worldwide

COVID-19 Symptom Tracker – MoD 01/05/2020 There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from Independent Peer Review Not required the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. The symptom tracker data will be used in the predictive modelling of Covid-19 for the Armed Forces, with a particular focus on understanding the health care requirements generated.

COVID-19 Symptom Tracker – Grampian Data Safe Haven 29/04/2020 There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Investigating the data that is available and how this can be linked to data being currently collected in Grampian to investigate vulnerable groups affected by Covid19 and Covid19 patients themselves.

Covid Test 29/04/2020 blah

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| COVID-19 Symptom Tracker - Liverpool Women's Hospital | 28/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Liverpool Women's Hospital NHS Foundation Trust is a tertiary maternity centre in the city with 8000 births annually. In addition, the gynaecology department provides early pregnancy care with over 20,000 attendances per year as well as tertiary level gynae-oncology, reproductive medicine and general gynaecology. The patient population is spread throughout the city and understanding incidence and prevalence of symptoms in realtime will inform the clinical response including provision of services which are important but not immediately life saving |
| COVID-19 Symptom Tracker – King's College Hospital | 28/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Using techniques in machine learning and statistical analysis, we are going to identify at-risk groups of COVID-19 in terms of demographics and location. Patterns in the development of symptoms across the UK can be identified, which can then be communicated to decision makers to decide where interventions need to be focused. |
| COVID-19 Symptom Tracker – Public Health Wales | 27/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project aims to understand the extend of citizen-led community mobilisation and support, and gaps between population need and support availability throughout COVID-19 pandemic in Wales. The understanding is vital for Welsh Government and public agencies to best direct their resources and efforts. We will utilise open source, survey, Symptom Tracker app and routine electronic health records to achieve our goal. |
| COVID-19 Symptom Tracker – Cardiff University | 27/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. We would like to use the COVID symptom tracking data to model geographic cluster formation and therefore the demand on local hospital resources |

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| COVID-19 Symptom Tracker – Department of Education | 27/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Specifically, we will use anonymised data from the app to estimate the rate of infection for covid 19 for every county (local authority) in the UK. The Covid Radar site already shows estimated numbers of *current cases* by local authority, but it doesn't show the estimated infection rate (the 'effective reproduction number') based on these estimates. Many epidemiological experts have argued that monitoring the effective reproduction number will be essential if we are to respond quickly enough to developments in the spread of the virus. If you can see how fast |
| COVID-19 Symptom Tracker – Welsh Government | 24/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking to map the demographics predicted to have symptomatic covid 19 by local authority for the Welsh Government data monitor. This provides updated evidence base to support decision making across divisions of Welsh Government. |
| COVID-19 Symptom Tracker – Food Standards Agency | 22/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. The Food Standards Agency is undertaking analysis to identify ways in which individuals, families and communities may be experiencing food insecurity as a result of COVID-19. We are already looking at data that identifies pre-existing vulnerabilities to food insecurity (such as deprivation, or proximity to a food desert) as well as emergent vulnerabilities (such as proportion of the workforce that works in sectors that may be experiencing a high level of lay-offs or furloughing). In combination with the symptom tracker data, we want to understand how illness may |
| COVID-19 Symptom Tracker – Newcastle | 22/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. - understand the relationship between people mobility and the number of reported symptoms. - understand the impact of weather on people mobility and reported symptoms. Use other open data sources to develop more insights |

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| COVID-19 Symptom Tracker - DHSC/SPI-M | 21/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. |
| COVID-19 Symptom Tracker - Dorset Council | 20/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. To produce a COVID19 infection map at LSOA across Dorset, Bournemouth Christchurch and Poole, which over the last 7-14 days to show the spread of infections as reported by the App. To better understand the spread of COVID-19 Pan-Dorset and present this data to key decision makers in the Dorset ICS. This will help us identify potential spread hotspots and identify the effectiveness of social distancing interventions. |
| UK Biobank: Welsh healthcare data linkage | 20/04/2020 | UK Biobank was established to improve the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses and promote health throughout society. UK Biobank is a charity and is funded by, amongst others, the Wellcome Trust and the MRC. Recruitment of 500,000 participants to take part in the project aged, at the time of their recruitment, between 40 and 69 years, began in 2006. Participants were recruited from across England, Scotland and Wales. As part of the recruitment process participants visited clinics set up by UK Biobank where they underwent physical measures, provided blood, urine and saliva samples for future analysis and shared detailed information about themselves. All participants consented on the basis set out in the attached consent form and this explicitly provided permission for UK Biobank to follow their future health through their health records (primary and secondary). |
| COVID-19 Symptom Tracker – GSST - NHS | 20/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. Demographics and frailty score of people affected with Covid-19 and the correlation of the clinical course of the disease and symptom duration and severity in relation to one's biological and chronological age. As a research group working in the field of ageing, we hypothesise that it is not just the chronological age that determines one's prognosis with this disease. We suggest that cardiometabolic and biological age often dependant on the number of co-morbidities but even more importantly by physical health markers such as the numbers of steps, mean gait speed and |

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| COVID-19 Symptoms Tracker – Kirklees | 14/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. By identifying which areas and population groups in Kirklees have highest and lowest rates of infection, the council and partner organisations will be able to provide the most appropriate response for reducing the spread of the virus and delivering the right level of support needed. This may included targeted communications, utilisation of local voluntary groups and community engagement |
| COVID-19 Symptoms Tracker – Calderdale | 09/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work. We will combine this data with our own data sets and national ones to predict the future outbreak across Calderdale areas and target support, information and interventions as appropriate. We will look to use GIS mapping tools and share information with our Public Health colleagues. We will also be using the App to promote continual awareness of COVID-19 for the public as part of our communications and engagement work. |
| UK Public Health Emergency Response: COVID-19 Symptoms Tracker | 08/04/2020 | There is an urgent need to map the spread and impact of COVID-19 across the UK. This project will enable NHS, government and academic staff, or members of other organisations working on their behalf to gain rapid access to the COVID-19 Symptoms Tracker dataset to support the UK national response to the COVID-19 emergency. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. |
| PROUD-UC: Patient Reported Outcomes Using Digital in Ulcerative Colitis | 06/04/2020 | The long-term plan for Health and Social Care in Wales ("A Healthier Wales") states that NHS Wales must implement the principles of Value-Based Healthcare in the design of services and the allocation of resources. "Value" has been defined as the outcomes (that matter to patients) of health interventions, treatments and therapies divided by the cost |

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| <p>ZOE COVID-19 Symptoms Tracker – UK Public Health Emergency Response</p> | <p>05/04/2020</p> | <p>There is an urgent need to map COVID-19 across the UK. We will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. This project is being undertaken in the national interest during a national emergency, with information being provided across governments and health authorities.</p> |
| <p>An exploration of disparities in cancer care for people with physical disabilities in Wales and how these are experienced</p> | <p>31/01/2020</p> | <p>Research evidence suggests that people with physical disabilities are likely to be diagnosed with cancer at a later stage, are less likely to access screening services and have poorer outcomes when it comes to cancer survival. This study aims to look at whether people with and without physical disabilities have the same access to cancer care in Wales. We will be using responses from the National Survey for Wales to identify respondents who self report having a physical disability and compare their data on cancer care with those who didn't identify as having a physical disability. We will get our data on cancer care from registry and hospital data, on screening services, cancer treatment given, the stage at diagnosis and outcomes of cancer treatment. We are hoping to combine results from this part of the study with interviews with people with physical disabilities and cancer to get an idea of what the experience of cancer care is like for this group. We are aiming to get a deeper understanding of the differences in cancer care there might be between people with and without physical disabilities and, through the</p> |
| <p>Has the introduction of a new patient pathway for Intermittent claudication with the integration of the National Exercise Referral</p> | <p>27/01/2020</p> | <p>Optimal medical therapy for the prevention of cardiovascular disease (including intermittent claudication) is well established, NICE have published guidance for practitioners to address risk factors through both pharmacological interventions and exercise therapy. There is a well supported consensus that exercise, specifically walking, is a cornerstone of intermittent claudicants' optimal medical therapy. Supervised exercise programmes are established as having superior results to unsupervised exercise, but are more costly to the patient. In 2018, service improvement interventions at ABUHB were implemented to improve the risk factor management of patients with intermittent claudication within the healthboard. The interventions included - Training and advice for General Practitioners who encounter these patients prior to their referral to secondary care, patient information leaflets and a new patient referral pathway to the National Exercise Referral Scheme (NERS)</p> |
| <p>Prevalence and definition of dysphagia in older people in the community.</p> | <p>15/01/2020</p> | <p>Eating and drinking is a central part of living both out of necessity and for social interaction. When we are unable to swallow, life can be difficult and result in isolation. As one gets older there is an increased possibility that swallowing problems may occur either due to an underlying medical condition (stroke Parkinson's disease, dementia) or general weakness.</p> <p>The number of old and very old people in society is increasing and therefore so is the number of people with swallowing difficulties. Research investigating the occurrence of swallowing problems in older people have often been small and used different age groups to define "old", consequently the occurrence in old >75 years or very old >85 years people is unknown.</p> |

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| Discharge of Care Orders - A National Study | 15/01/2020 | Research has examined the process, recurrence of, and orders made in, care proceedings (including regional variation), but little is known about how/when care orders are ended, or whether children become subject to subsequent care proceedings. This study would provide evidence on the length of care orders and legal histories prior to and following formal procedures. There are contradictory views of care orders both as short-term measures aimed at re-unifying children with families and as means of securing permanency for children who cannot be cared for by their families. Whether a care order remains in place has significant implications for children and their families, and for local authorities in terms of their responsibilities to monitor and provide services. Better understanding of the practical effects of care orders by the professionals involved will support improved decision-making, reduce unwarranted variation and provide the basis for high quality advice to parents and children. |
| Private family law cases in England and Wales: profiles, pathways and outcomes. | 13/01/2020 | <p>A new data platform and analytics service is being established to provide better information about how the family justice system is working; better understanding of the pathways of children and families through services in England and Wales; their outcomes beyond involvement with the family court.</p> <p>We don't know much about family court cases where parents (and sometimes other family members) do not agree about arrangements for children, most often who the children live with and seeing the other parent. This research project will take a detailed look at the characteristics of the families involved in these type of legal disputes, how they compare over time and to the broader population and other court users. The research will go on to look at how cases</p> |
| Long-term health effects of E.coli O157 infection: a populationbased matched cohort study, Wales (UK) | 06/01/2020 | <p>Rationale: Escherichia coli O157 (E.coli O157) is a bacteria that causes gastrointestinal (stomach and intestines) disease in humans, leading to symptoms like diarrhoea, bloody diarrhoea and vomiting. It is of particular public health concern as it can also cause severe symptoms such as haemolytic uraemic syndrome (HUS), a leading cause of sudden kidney failure in children. Other gastrointestinal infections are known to cause long term health issues such as reactive arthritis, irritable bowel syndrome, inflammatory bowel syndrome and Guillain Barre syndrome (a condition causing muscle weakness, which can be life threatening if it affects the lungs or heart). However, although there is a large body of literature on E.coli O157, there is little information available on long term health effects following infection, and that available, is primarily limited to studies of cases of HUS, often very shortly after their infection. Only a few studies have looked at the long-term effects on health after a E.coli O157 infection. These studies identified serious long term conditions such as proteinuria (excess protein in the urine, suggesting</p> |
| Clinical outcomes of bloodstream infections | 02/01/2020 | <p>Bloodstream infections (also known as 'septicaemia' or 'blood-poisoning') are common life-threatening infections affecting over 4,000 people in Wales (and over 50,000 in the UK) every year. They often cause sepsis, which is a life threatening condition with a 30-day mortality of 15% which is far greater than most cancers. In those who survive, the morbidity is significant with short-term cognitive impairment, such as problems with memory or attention (known as delirium), frequently observed by doctors, patients and their families. Subsequent problems with memory and thinking are a frequent complaint of survivors of sepsis who often suffer from 'mental fogging'. However, the longer-term consequences and the risk of dementia are poorly understood. Greater understanding of the long-term consequences following bloodstream infections and sepsis have been identified as a research priority and as an unmet need by patient</p> |

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| How active travel can improve our health and well-being: a study using linked administrative data | 09/12/2019 | <p>Active travel has great potential to integrate physical activity into our day to day lives leading to significant improvements in health and well-being, whilst reducing economic costs for businesses and society. Welsh Government (WG) is aiming to increase levels of walking and cycling to realise the many benefits of active travel for individuals and for society. The Active Travel (Wales) Act, which came into force in 2014, makes it a legal requirement for Local Authorities (LAs) in Wales to map and plan for suitable routes for active travel, and to build and improve their set-up for walking and cycling. Currently, the WG monitors progress on active travel through the active travel route map and annual reports based on the National Survey for Wales.</p> <p>Administrative and survey data are now available to be linked, providing an opportunity to explore the characteristics of those who travel</p> |
| An e-cohort study of trends in the incidence of recorded Depression and anxiety diagnoses and symptoms and antidepressant/anxi | 29/11/2019 | <p>'The Welsh Assembly Government's (WAG) 'National Strategy for School-based Counselling Services', originated as a result of a recommendation arising from the Children's Commissioner for Wales's Clywch Inquiry Report. The Clywch Report suggested that all young people in schools should have a trusted adult to talk to about their concerns. In response, WAG published the 'National Strategy for School-based Counselling Services' in April 2008, setting out it's commitment that all school pupils in Wales should be able to access counselling services. The strategy was then rolled out across all schools in Wales, with full implementation achieved Wales-wide by 2011. Counselling, delivered by a professionally trained workforce, is increasingly seen as an effective early intervention for young people who have emotional, behavioural or social problems. Primary care often represents the first point of contact with healthcare services and is an important source of care for young people with common mental disorders, such as depression and anxiety. In 2010 the Welsh Government commissioned a</p> |
| What is the effect of including the Electronic Frailty Index (eFI) score in models predicting adverse health outcomes in older people prescribed | 29/11/2019 | <p>The clinical condition of frailty is deemed to be the most problematic expression of population ageing. Frailty occurs when there is a cumulative decline in various physiological systems in the body, which has progressed over a lifespan. Due to this decline, stressors such as an infection, or side effects due to a new medication for example, can have a negative impact on homeostasis. Patients living with frailty are more vulnerable, and their ability to return to homeostasis after a stressor is impaired. Relatively minor stressor events can therefore trigger disproportionate changes in health status.</p> <p>The identification of frailty typically requires a robust geriatric assessment with clinicians, however there are now new approaches to screening for frailty using routinely collected health care data. An example of this is the Electronic Frailty Index (eFI), which generates a score</p> |
| Geo-spatial disease incidence weighted by location of residence prior to diagnosis. | 29/11/2019 | <p>When people are diagnosed with a disease, public health agencies attribute that incident to the location where the person was living at the time. This data is used to explore patterns of disease within different areas across Wales (geo spatial analysis). These analyses are used to identify areas where people experience poorer health outcomes, on average, compared to other parts of the country. Geo-spatial statistics can also be used to identify potentially harmful characteristics in the environment, by analysing the location of disease incidences to see if there are any clusters - that is, groups of individuals diagnosed with the same disease in the same area around the same time.</p> |

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| Synthetic Dataset Creation | 29/11/2019 | <p>There are a number of activities that benefit from access to data in the same format as actual health data, but don't require real data. - Development: creating new software and methods for use with SAIL. - Training: familiarizing potential future SAIL users with what SAIL data looks like, how it works, and how to use it. - Education: teaching students in our health data science programmes about how to work with health data. Our plan is to create fake data that looks like SAIL data to support these activities. This is more convenient, since we don't need to deal with governance restrictions, secure environments, or approval processes. It is also safer, because not using the real data where it is not needed reduces risk. In order to create this data, we will use advanced artificial intelligence algorithms that analyse contents of and relationships within the actual SAIL datasets and then randomly generate data that looks similar.</p> |
| The Long term Outcome of STEC-HUS | 13/11/2019 | <p>A very common cause of acute kidney failure requiring dialysis in children is due to E.Coli, a bacteria which typically causes diarrhoea and vomiting. Dialysis is where a machine is needed to replace the kidneys main functions. 10-15% of patients will develop a condition called HUS (Haemolytic Uremic Syndrome) which can vary from mild symptoms to long-term kidney damage and dialysis. The long-term outcome of patients making a good recovery after HUS is unclear and previous efforts to establish the effects have been difficult. Using linked healthcare records, we will look at the effect an episode of HUS in childhood will have on patients in the future, particularly chronic kidney disease. We will estimate the risk of chronic kidney disease into adulthood.</p> |
| Large scale linkage of genetic and health informatics data in schizophrenia to investigate the impact of copy number variants on | 12/11/2019 | <p>CLOZUK Wales is part of a broader project that seeks to link the world's largest genetic sample of those with schizophrenia (CLOZUK) with the health informatics strengths across three UK countries. We will link genetic data from individuals with schizophrenia with health informatics resources across Wales (SAIL), Scotland (SAFEHAVEN) and South London (CRIS). This will lead to a unique resource in which will enable the posing of many research questions of clinical relevance to those with schizophrenia and psychosis.</p> <p>The addition of linked phenotypic data would further increase the utility of these samples and offer distinct advantages for scientific discovery. Specifically it will enable us to investigate crucial research questions relating to physical health outcomes in schizophrenia, as well as adverse effects and treatment response in our clozapine sample.</p> |
| Machine Learning and NLP in Cancer Informatics Research. | 12/11/2019 | <p>Machine Learning (ML) is a statistical technique used to create new knowledge from data. ML techniques are data hungry, the more data, the more robust the methods and results may be. In the cancer setting, there is an increasing amount of data being generated and stored. Such data is stored in a variety of locations; locally, regionally, nationally and even internationally. It is also held in a range of formats which can be generalised to structured or routinely collected data which is "coded", e.g. disease datasets, registries or unstructured, e.g. discharge letters, progress reports within an electronic health record (EHR). Whilst routinely collected data is well defined, unstructured data is less so.</p> <p>Early diagnosis and assessment of prognosis is important in cancer. By classifying an individual to a particular risk group</p> |

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| Assessment of the long-term outcomes of bariatric surgery in relation to metabolic disease in the Welsh Institute of Metabolic and Obesity Surgery | 08/11/2019 | Weight loss surgery is often reported to have a good effect on other diseases such as diabetes and cancer. However, little is known about whether the positive results we see straight after the surgery have a lasting effect. The use of SAIL data (such as clinical data from primary care General Practices and secondary care accident and emergency, hospital admissions, outpatient events, as well as other key outcome data such as lab data for blood tests, drugs prescribed and dispensed and deaths) will build up our picture of what is happening to people in their general health records, especially in the period prior to and follow up period post-surgery together with the WIMOS data (which contains details on patients in their pre and post-surgery clinical data) will allow an assessment of the long-term outcomes and effects of weight loss surgery on both the person's health status and quality of life. Weight loss surgery has been shown to benefit people with type 2 diabetes with either a reduction in the medications used to manage type 2 diabetes or through remission. However, it is not known how long these effects |
| Investigating the impact of interventions on social care: a quantitative approach using data linkage and joint modelling | 05/11/2019 | We aim to address a gap in the methods used in social-care and health research. We will achieve this by developing a data-intensive technique that will be applied to important questions in social care and health research. Our technique will enable us to analyse the dependency between changes made or which happen to people or services, healthcare and subsequent social-care needs over time. By investigating the impact over time, our technique will provide better targeted, efficient and more effective changes that are designed to reduce social-care needs and improve health outcomes. We will facilitate our technique using data held in the SAIL Databank, and we will create new and crucial statistical evidence to influence policy and inform decision-making. |
| Understanding the Role of Careers Guidance in supporting Participation in Higher Education | 15/10/2019 | <p>We aim to answer a wide range of research questions including: By how much do health events recorded in a General Practice (GP) relate to</p> <p>This project examines national datasets on education outcomes to identify the impact of careers guidance and advice on university participation. Specifically, it seeks to compare the transitions made by students into Higher Education according to whether or not these students have been in receipt of careers information, advice and guidance services provided by Careers Wales. Participation in HE is examined in terms of patterns of application for university places through the UCAS system, subsequent attendance at a HE institution and the successful progression of students through university.</p> <p>The study aims to address the following research questions. Firstly, are students in Welsh schools and colleges who receive careers guidance more or less likely to apply to university than students who do not receive careers guidance? Secondly, having applied for university, are those</p> |
| Developing a predictive tool to promote earlier diagnosis of Type 1 diabetes in childhood for use in primary care - TED study | 10/10/2019 | Early diagnosis of Type 1 Diabetes (T1D) is critical to avoid children developing diabetic ketoacidosis (DKA). DKA is a life threatening condition that develops when the body cannot produce insulin, without treatment children will become progressively more poorly, leading to diabetic coma and death. In the UK, 25% of children who develop T1D are in DKA at diagnosis. These children have far worse outcomes, with increased NHS costs. This research aims to develop and assess the usefulness of a predictive tool to identify children who may have undiagnosed T1D. Using the number and details of GP consultations, the tool will assess the risk a child has of being diagnosed with T1D. We will develop the tool using a modern technique called machine learning. Machine learning allows computers to uncover patterns in data in a very flexible way. It has proved to be more successful than traditional methods of data analysis in showing that a particular event is likely to happen. We will build on the work of our previous SAIL study, IGRP approved study 0444 - Pathway to diagnosis. The machine learning |

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| Advanced Age Parenthood and Developmental Disorders in the Offspring: an analysis of characteristics of advanced age | 09/10/2019 | <p>This study aims to explore if mothers over the age of 35, who feel stressed while pregnant, are at greater risk of having a child with autism (ASD) or attention deficit hyperactivity disorder (ADHD). This is in comparison to those who are younger or those who experience less stress.</p> <p>Research shows that pregnant mothers who are over 34 years old have a higher risk of their child being born with a developmental disorder. There has been a worldwide trend over the last 30 years for delayed pregnancy but the descriptions of older mothers are very diverse. This study will look separately at descriptions of older first-time mothers and older mothers who already have children. There appear to be many, often conflicting, traits that apply. Studies show possible connections with ASD/ADHD and health, family make up, mother's birth country and stress from the environment, such as lack of resources. This study seeks to understand if these also play a role in delayed pregnancy.</p> |
| Epidemiology of diabetic retinopathy in Wales. | 09/10/2019 | <p>Diabetic Retinopathy (DR) (damage to the back of the eye) is a major complication of diabetes, and a leading cause of blindness in the working age population. Screening for DR ensures early detection when treatment is most effective. Understanding the epidemiology of diseases is important and can elucidate possible mechanisms for treatments and allow monitoring of how interventions affect the course of diseases overtime to see if they have had the intended effects.</p> <p>Screening for diabetic retinopathy in the UK was commissioned in 2003 and in Wales the Diabetic Eye Screening Wales has been a National programme since 2007. Whilst the epidemiology of diabetic retinopathy has been explored in observational studies and clinical trials, screening programmes in the UK provide a unique opportunity to better understand the epidemiology of diabetes retinopathy. Linkage</p> |
| Administrative Data Research Wales Housing Strategic Impact Project – Homelessness Theme | 08/10/2019 | <p>The purpose of this project is to explore homelessness in Wales in order to inform policy making and practice, and forms part of a larger ESRC grant intended to generate impactful research to Welsh Government. The project will capitalise on newly available administrative data about people accessing homelessness services in Wales in order to engage in data linkage to other routinely collected administrative data. The project is split into three main areas, with two thematic and one methodological. The thematic areas cover: (1) the health of people who are homeless, and (2) the schooling of children and young people living in homeless households. These areas reflect topics of interest to Welsh Government, as outlined in their strategy Prosperity for All, as well as current campaigning areas by the third sector in Wales; findings from the thematic areas of analysis therefore have the potential to feed into current policy concerns in Wales. The project will also explore the extent to which people who are homeless are being 'captured' in other forms of administrative data, such as healthcare data, and attempt to</p> |
| Association of Breast Cancer and Lipofilling. | 07/10/2019 | <p>Breast cancer is the most common cancer diagnosis in women worldwide, the advancement in technology and medicine has meant that we are finding more cancer at an earlier stage which means there are a greater number of treatment options. Breast conserving surgery (BCS) involves cutting away only a small part of the breast with the tumour resulting in a smaller operation and shorter hospital stay. While the surgery to remove these early cancers is less impactful, the scarring left behind often needs to be corrected to restore the appearance of the breast.</p> <p>We know this is important for women and reconstruction (surgery to restore the original breast) plays a significant role in their wellbeing and mental health. These small scars are difficult to reconstruct and breast implants are not suitable as they are too big. An alternative solution is</p> |

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| Acute eye conditions in primary and secondary care | 02/10/2019 | The high demand for urgent eye care in the UK means that sometimes eye care services can be over-burdened. People with acute eye problems may seek help from optometrists, pharmacists or GPs, or they may go to A&E. Some of the eye conditions managed by doctors in A & E and GP practices could have been managed in the community by an optometrist or pharmacist at lower cost. This project aims to determine the number of urgent eye conditions presenting to A & E, GPs, optometrists and pharmacists in Wales. Of the attendances at A & E and GP practices, we seek to determine which of these cases could have been potentially resolved by optometrists or pharmacists. A & E and GP data will be examined from the SAIL databank as well as data from primary care optometry and pharmacy in Wales. In addition, individuals with an urgent eye condition attending the Royal Glamorgan Hospital Emergency Department and a GP, optometry and pharmacy practice in the local area will be asked complete questionnaires about patient satisfaction and health-related quality of life. The findings will |
| Health checks for adults with learning disability improve survival rate – a linked electronic record cohort study. Health checks for adults with learning | 02/10/2019 | People with learning disability are at risk of poorer health outcomes and early mortality. In order to address inequalities in health, annual health checks in primary care were introduced in Wales during 2006 and for England in 2007, for adults on the social services register with learning disability. The health check includes screening for conditions like diabetes, general health measures and medication review. This study examines evidence for long term effects of health check by examining if mortality rates are lower in those who have a health check compared to those who have no record of having a health check in their medical records. General practice records of people with a learning disability in Wales are split by those who (a) had a confirmed health check and (b) had no evidence of receiving a health check in their medical record. The SAIL databank was used to link GP data and ONS mortality data between the years 2005-2017. |
| The evaluation of risk factors and long-term outcomes in patients with community- or hospital- acquired sepsis: a retrospective cohort | 01/10/2019 | Sepsis is caused by an overreaction of a patient's body to an infection. It can result in widespread damage to organs in the body and in some cases can be fatal. Around 250,000 people develop sepsis every year in the UK, resulting in over 50,000 deaths. Patients who survive sepsis often experience long-term health problems as a result of the condition and require increased levels of care. There are a number of different factors that make people more or less likely to develop sepsis, including age, gender and whether they already have other conditions such as type 2 diabetes or heart disease. Most people develop sepsis in the community, however, there are a number of patients who contract it when they are already in hospital being treated for another condition or following a surgical procedure. Treatment of sepsis usually involves antibiotics, however resistance of bacteria to antibiotics is increasing, making treating conditions like sepsis more difficult. |
| REAL-Child Health; REsearch Actionable Learning Health Systems | 01/10/2019 | We want to use research to give children the best start in life. In Wales one in eight children starts primary school very overweight, while one in seven is affected with a rare disease. At present, we know very little about what the future holds for the health, well-being and education of these children. In east London, we are currently joining up the school and newborn screening records to the health and school records of children to understand this better. By using information for whole populations in Wales and north east London we will be able to understand how being very overweight in primary school, or being diagnosed with a rare condition at birth, affects future health and education. Our research findings will improve the health services children and families receive, improve their health and reduce health inequalities. |

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| International Cohort Study on Antiviral Medication and the Prevention of Alzheimer Disease (Acronym: VIRADE) – SAIL Subproject | 01/10/2019 | <p>The causes of Alzheimer disease (AD) are not known. There have been increasing suggestions that infectious agents might play a role given the presence of microbes in AD brain and that the signature protein of AD, Abeta peptide, is now known to be an antimicrobial protein induced by infection.</p> <p>A 2018 population study in Taiwan provided the first evidence for a causal link, and reported that individuals receiving antiherpetic medications had a significantly reduced risk of developing AD.</p> <p>The aim of the present project is to assess whether this holds true in other populations, including that of Wales.</p> |
| Participation in and Progression Through Education in Wales | 12/09/2019 | <p>The purpose of this project is to explore patterns and trends in education in Wales and to inform policy making within Welsh Government. The project will bring together national datasets on education from primary school to university. The aim is to explore issues around school-level attainment, school improvement, progression to higher education, high achievement, the role of the family and cross border flows for the purpose of learning.</p> |
| What is the cost-effectiveness of home adaptations for older people? | 01/09/2019 | <p>As people get older it can become more difficult to manage in the home and maintain independence. This can be a particular problem for older people living with frailty, who are at higher risk of losing independence, falling or having to move to a nursing home. This can reduce quality of life in older age and is costly for the National Health Service (NHS) and social care services.</p> <p>Adapting the home can mean that older people can continue to enjoy the comfort and security of their home, stay close to family and friends, and do what matters most to them. Previous research shows that home adaptations can maintain independence in later life and reduce falls. However, this research had not looked at whether home adaptations are cost-effective, which is very important information for the NHS and social care. We also know that preventing falls at home may be linked to having the appropriate adaptations in place, but again, have not had</p> |
| Development and evaluation of the electronic frailty index+ (eFI+) tool: integrated prognostic-decision modelling to target interventions for | 01/09/2019 | <p>Frailty is common in older age. It develops because as we get older our bodies change, and can lose their inbuilt reserves, for example we lose muscle strength. These changes mean that older people with frailty can experience sudden, dramatic changes in their health as a result of seemingly small problems, such as an infection or new medication.</p> <p>People with frailty are at risk of losing their independence, which can mean that help from home care services is needed. They are also at higher risk of falling, admission to nursing homes and death. These problems can reduce quality of life and are costly for the NHS and social care.</p> |

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| <p>InFORM: Improving care for people who Frequently call 999: co-production of guidance through an Observational study using Routine linked data and Mixed</p> | <p>29/08/2019</p> | <p>People who repeatedly call the 999 ambulance service present an operational challenge to the emergency ambulance services, and their needs are inadequately met by current service provision. Data from the Welsh Ambulance Service NHS Trust in 2017, showed that the service responded to 5,532 calls made by approximately 200 people between July and September, costing approximately £70,000 per month. In recognition that high users of the 999 ambulance service have substantial and often complex health and/or social-care needs - and are likely to require multiple, expert intervention from different parts of the National Health Service and other agencies - some ambulance services have introduced a multi-disciplinary, cross-sector approach to address the needs of this patient group. This may reduce calls, improve patient safety, and quality of care and experience by avoiding patients being shifted from one part of the healthcare system to another. However, these models of care have been introduced without fully understanding the nature of the problem such as caller</p> |
| <p>Understanding health needs of homeless groups in Wales from routine data.</p> | <p>29/08/2019</p> | <p>This study is motivated by Public Health Wales long-term strategy, 'Working to Achieve a Healthier Future for Wales', covering 2018-30. One of the strategic priorities is to influence the wider determinants of health that emphasises homelessness prevention. Findings of this study will contribute to the evidence base of reducing health inequalities by identifying gaps. The relationship between homelessness and health issues is bi-directional. Definition of homelessness varies across jurisdictions. With this study aims to understand both physical and mental health needs of homeless health service users by utilising routinely collected health data in Wales. Homeless health service users refer to all patients with an indication of homelessness in their registration information and/or health records. This study will also explore the feasibility to capture the use of drugs and alcohol of this population group by using routine data. We are going to investigate the health status and health needs of this group, and compare them with general population to measure the differences. The results will give an overview of the health</p> |
| <p>Exploratory data validation study, for selected patient cohort, using Wales Cancer Bank (WCB) and Welsh Cancer Intelligence and Surveillance Unit</p> | <p>19/08/2019</p> | <p>The Wales Cancer Bank (WCB) is a biobank that collects samples of tissue and blood from patients in Wales where cancer is a possible diagnosis. The samples are stored to form a biorepository to which researchers worldwide can apply for biosamples and/or matching data. The sample data is stored in a link-anonymised database and a subset dataset will be shared with SAIL.</p> <p>The value of the samples for research increases with the availability of validated data. This is particularly important for research based on small patient groups' sets of samples. The validity and accuracy of the data provided with each sample is crucial for producing reliable research results.</p> |
| <p>UK MS Register</p> | <p>14/08/2019</p> | <p>The United Kingdom Multiple Sclerosis Register (UKMSR) is a patient database operated and run by Swansea University Medical School. It has collected data directly from people with MS (PwMS) via a dedicated website for 8 years, making it amongst the largest collections of Participant Reported Outcome Measure (PROM) data in MS in the world. This alone represents a remarkable resource for researchers, but the second element of the project, where multiple NHS hospitals across the United Kingdom (currently ~45) link their data to the internet participants, creates a powerful asset for MS research.</p> <p>The MS Register can connect to other datasets for research to make a real-world impact to people with MS. A significant element of the MS Register's population are Welsh, and therefore also within the SAIL Databank, so connecting the two collections to make more comprehensive</p> |

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| Wales Electronic Cohort for Children (WECC): Phase 4 | 13/08/2019 | The Wales Electronic Cohort for Children (WECC) has been in operation since 2007. WECC involves creating a cohort by linking anonymised data from multiple datasets on all children living in Wales born since 1990. The datasets include births, deaths, hospital admissions, outpatient attendances, emergency department attendances, congenital anomalies (malformations at birth), cancer, national community dataset (e.g, immunisations and height and weight), school attainment (Key Stage 1-5 results from school entry to A levels), and with links to data on children participating in a number of child cohorts, such as the Welsh Study of Mothers and Babies (WOMBS), Growing Up in Wales, the Brecon Cohort (children with Type 1 Diabetes) and the Millennium Cohort Study (MCS). Analyses carried out in the first two phases of WECC demonstrated the impact of being born small or prematurely on a range of health indicators and the impact of some medical conditions, such as brain injuries or epilepsy, on assessments of educational attainment at age seven. The third stage focused on the impact |
| Welsh virtual population vaccination and outcome registry | 11/08/2019 | <p>The World Health Organisation (WHO) recently listed vaccine preventable diseases (like measles, rubella, meningococcal meningitis, whooping cough, etc.), vaccine hesitancy (which means people choosing to delay getting their routine vaccinations, or not get them at all) and global influenza pandemics (when a new strain of flu arises that people do have immunity to and there is no available vaccine) among 10 threats to global health, demanding attention from health services in 2019.</p> <p>We aim to build on previous successful projects with SAIL using data linkage to evaluate vaccination programmes to develop high-quality service-based research and evaluation, working with internationally recognised experts, which will directly benefit patients and providers in NHS Wales</p> |
| Non-interventional study on the effectiveness and safety of SGLT2-inhibitors compared with DPP-4 inhibitors in patients with type 2 diabetes | 31/07/2019 | New drugs for lowering blood sugar in those with type 2 diabetes have been developed over the past 10 years. There are currently differences in clinical opinion over the safety of these new blood sugar lowering drugs, particularly a group called SGLT-2 inhibitors (Sodium-Glucose Transport protein 2). Previous evidence from drug trials and real-world evidence suggests that these new drugs are effective in terms of blood sugar, blood pressure, and weight loss. There is also evidence that they are protective against heart and kidney disease, and death in people who are at greatest risk. However, much of the real-world evidence is based on small samples and short follow up periods. Given that these drugs are relatively new, we want to test their safety and effectiveness in a large combined real world setting in England and Wales. |
| Assessment of natural history, treatment, clinical outcomes and costs in patients with Critical Limb Ischaemia in Wales and update of | 31/07/2019 | Welsh Blood Service in collaboration with Rexgenero are partners on a funded project which is part of The Midlands & Wales Advanced Therapy Treatment Centre (MW-ATTC) project. Part of this project is conducting a phase 3 clinical trial program with Rexgenero's lead product REX-001, a new therapy for patients with critical limb ischaemia (CLI) and diabetes. This clinical trial is needed as part of the approval for the new drug to approved to be used in Europe for the benefit of patients with CLI. While running the clinical trial, there is also a health economic assessment to demonstrate the benefit of the new therapy not only for its treatment of patients with CLI, but also its cost effectiveness to the NHS, and would form part of the justification for reimbursement from healthcare payers. Although CLI is a common condition and is associated with poor patient outcomes (high risk of amputation and death, chronic pain, very restricted mobility and poor sleep) and |

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| Longitudinal trends in critical care utilisation and outcome among older patients in Wales | 25/07/2019 | <p>As national populations age, it could be anticipated that there would be observed greater utilisation of critical care facilities by older patients, given that they may experience a wider range of chronic illness and may be more vulnerable to the effects of acute illness. This has been observed in some developed countries, but not all, and given the relatively low numbers of critical care beds in Wales compared with other European countries, Wales may be particularly susceptible to the challenges of delivering equitable care to older individuals who become critically ill. Furthermore, the long-term outcomes following critical illness of older patients, and particularly those that have underlying frailty, are poorly understood.</p> <p>To better understand utilisation and need, this study intends to examine the trends in adult critical care use over an 8-year period in Wales</p> |
| Analysis of GP data: older people, falls, dementia and cause of death | 23/07/2019 | <p>This project aims to describe the health of patients registered with SAIL GP practices. Western Vale GP cluster want to examine data for the population for whom they are responsible, and in particular focusing on issues relevant to older people.</p> <p>They want to better understand the features of their practice population and so will be given a description of the people on their practice lists by age, gender and deprivation quintile. Two key areas for older people are admissions to hospital for falls and dementia, so number and rates of admission for these conditions will be described. They want to better understand the causes of death in their patients, so they will receive data describing the number and rate of death in their practice, the broad causes of death (whether the death was natural or from external causes, and for natural deaths whether due to cancer or other condition). They want to compare results for their practice with their</p> |
| Comparative safety profile of antidiabetic drug regimens containing SGLT-2 inhibitors and/or GLP-1 receptor agonists among type 2 | 17/07/2019 | <p>The management of type 2 diabetes usually involves medication, initially with metformin, but as the condition progresses additional medications may be required. After metformin, treatment decisions about other medications are generally based on the physician's choice. However, considerations may be based on the potential risk of side effects from medication use. Several newer medications have become available in recent years but their long-term effects, particularly in combination with each other, have not been extensively explored but could offer greater benefits in terms of diabetes management (blood glucose, blood pressure, weight) and lower risk of serious diabetes-related complications including heart disease.</p> <p>In recent clinical trials, the use of newer medications in combination have been shown to have greater lowering effects on blood glucose</p> |
| Paediatrics 2040 | 01/07/2019 | <p>Economic, political, and social changes mean that the role of children's doctors (paediatricians) - and the shape of paediatrics (child health specialist services provided) - is very different today to what it was two decades ago. It is likely that two decades from now, in 2040, the delivery of specialist health services for children in the UK will be very different.</p> <p>Paediatrics 2040 is the name of this project and report. The report will contain predictions of future child health conditions, needs and outcomes. It will be used to help understand what future requirements for paediatric services may look like and identify innovations that will change the way paediatric services are delivered. Using these predictions, the project will develop proposals for future models of care and a vision of how future workforces that will best serve the needs of children and young people's (CYP) populations in 20 years' time. The project</p> |

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| Data request for the health economics analysis of the Standard And New Antiepileptic Drug (SANADII) trial | 27/06/2019 | <p>Hospital Episode Statistics (HES) data are required for the purpose of the Standard And New Antiepileptic Drug (SANADII) trial.</p> <p>Epilepsy is a common neurological (brain) disorder. Approximately 2-3% of the population will be given a diagnosis of epilepsy by time they reach 60.</p> <p>A number of new drugs have been approved to treat epilepsy in the UK in the past few years. These drugs have been shown in research studies to prevent seizures and to be safe. There is as yet, however, no good evidence as to whether they are better at treating epileptic seizures or safer than the standard drugs that have been used for many years.</p> |
| Utilising routine data and machine learning techniques to discover new multi-morbidity and polypharmacy phenotype's associated with | 26/06/2019 | <p>This project will create new analytical methods, such as machine learning which uses statistical models that computer systems use to more effectively perform a specific task than a person would doing it manually and relies on patterns and learning instead. Machine learning algorithms build a mathematical model of sample data, known as "training data", in order to make predictions or decisions without being explicitly programmed to perform the task, which will help to identify people suffering from a wide range of multiple health conditions that we may not have seen or known about before. It will then investigate the short and long-term health & wellbeing outcomes of mixtures of conditions, for example, in people who suffer from high blood pressure and also have asthma. We will study how having multiple conditions effects individuals' quality of life, how long they live and patterns of treatment from general practice and hospitals. We will then investigate whether there are patterns of treatments that appear to have better or worse outcomes for people with different combinations of illnesses.</p> |
| Nuffield Family Justice Observatory (NFJO) data partnership. | 24/06/2019 | <p>The Nuffield Family Justice Observatory (NFJO), established by the Nuffield Foundation, has awarded funding for a new data partnership including the creation of a data platform and analytics service. The partnership aims to provide a) Increased capacity and capability of researchers and data scientists to use family justice and other relevant administrative datasets; b) Improved intelligence about the family justice system through routine and specific issue analyses using data from the Children and Family Court Advisory and Support Service (Cafcass) in England and Wales; c) Demonstration of the value of data harmonisation and linkage; d) Increased capacity of policy and practice stakeholders to understand, interpret and apply data for policy and practise development.</p> <p>The NFJO and the project team (based at Lancaster and Swansea Universities) will work in partnership with the SAIL Databank and Welsh</p> |
| Born into care: Newborns in care proceedings in Wales | 23/06/2019 | <p>A new data platform and analytics service is being established to provide better information about how the family justice system is working; better understanding of the pathways of children and families through services in England and Wales; their outcomes beyond involvement with the family court.</p> <p>The project team, based at Swansea and Lancaster Universities, will begin by exploring care proceedings for infants in Wales. We therefore aim to provide the first estimate, and profile, of cases of newborns subject to care proceedings. By linking this family justice data to population-level health data in the SAIL Databank, we will also examine characteristics of babies, older children, mothers and fathers involved in care proceedings, as well as health service use during pregnancy and the post-natal period.</p> |

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| <p>Understanding the harms of antihypertensives, statins and antiplatelets for prevention of cardiovascular disease: validation</p> | <p>16/06/2019</p> | <p>People are living for longer, with more long-term physical and mental conditions which worsen their health. One example is high blood pressure, where people can take 3-4 drugs to prevent stroke. However, dozens of people have to be treated for at least a year to prevent a stroke in one person. This is because these drugs only reduce the possibility of stroke, they do not remove it altogether. Some of these patients may be prone to side effects such as falls and kidney problems which may be more common than any benefits.</p> <p>We have developed a series of calculators to predict how likely it is that a person taking drugs to prevent heart attacks and strokes will experience side effects. We have focused on drugs that lower blood pressure (known as antihypertensives), lower cholesterol (known as statins) or prevent blood clots (known as antiplatelets). Side effects for these drugs include falls, muscle pain and internal bleeding. The</p> |
| <p>Prevalence and incidence of AF in care homes and treatment variations compared to the general population in Wales.</p> | <p>02/06/2019</p> | <p>The aim of this project is to understand better if people live in a care or nursing home affects Atrial Fibrillation (AF) treatment compared to the treatment received by people in the general population in Wales. People in care homes have been found to experience different healthcare access for multiple conditions. We will assess whether where people live and whether a combination of their relative education, income and occupation status effects and impacts on their health & wellbeing and outcomes if people from poorer backgrounds have different opportunities to access to health care, and if being a care or nursing home residence in comparison with these factors have a greater effect.</p> |
| <p>Determining the frequency of abnormal hepatic fibrosis measures and liver cirrhosis/decompensation in Welsh primary care</p> | <p>31/05/2019</p> | <p>Liver problems in people in the UK and internationally are becoming increasingly common, but are difficult to identify early in the course of the disease. As the liver becomes more diseased scarring forms within it (fibrosis) and this is termed advanced liver disease. We intend to look at the potential of using blood test indicators of advanced liver disease as screening in primary care in Wales.</p> <p>Firstly, we plan to use general practice data (Audit+) to determine how using different blood test indicators of advanced liver disease (fibrosis) as a screening tool would affect NHS health services. We will work out how many people would need to be referred to see a hospital consultant as a result of the screening test.</p> <p>Secondly, we plan to look and see how many people who we know end up in hospital with advanced liver disease and its complications (such as liver cancer) would have been identified earlier if we used the possible blood test indicators of advanced liver disease (fibrosis) as a</p> |
| <p>Clinical epidemiology of adult brain and central nervous system tumour in Wales.</p> | <p>29/05/2019</p> | <p>This project sets out to determine the trends in brain and spinal cord tumours in Wales, and to identify factors that are associated with survival in the most common type of fast-growing cancerous brain tumour - glioblastoma (GBM).</p> <p>Although tumours in the brain and spinal cord are considered rare, some studies have reported an increase in the occurrence of these tumours. People with these tumours require different treatment and their outcomes vary. It is therefore important to understand the trends in each tumour type to gain insights into contributions to the increase in occurrence observed. We will use the Welsh population data in the past 20 years to achieve this. By using both the cancer registry and hospital records, we will be able to obtain an accurate measure of the occurrence of brain and spinal cord tumours through time.</p> <p>Among all brain and spinal cord tumours, the most common cancerous tumour is gliomas. Gliomas are a mixed group of tumours with slow-</p> |

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| Pharmaco-epidemiology in cardiovascular disease. | 23/05/2019 | Cardiovascular disease (disease of the heart and circulation) causes more than a quarter of all deaths in Wales. There are an estimated 375,000 people living with cardiovascular disease in Wales. The risk of stroke and heart attack can be reduced through the use of medication and risk factor management in patients at risk of cardiovascular disease. In patients who have already experienced a heart attack their risk of a secondary event can be significantly reduced through the use of medication, typically known as an “antithrombotic”, and medication to reduce cholesterol. However, previous studies including those undertaken with the SAIL Databank have highlighted that these medicines are often underused and this is associated with worse patient outcomes. |
| Exploring prescribing patterns of medicines used to manage neuropathic pain in primary care settings in Wales between 2013 – 2018: a drug | 20/05/2019 | Neuropathic pain, NP, is defined as ‘pain caused by a lesion or disease of the nervous system’ (International Association for the Study of Pain (IASP), 2017). There are different types of NP depending on which part of the nervous system is affected. There is no cure for NP; people who get it will likely have it for the rest of their lives. Medicines can be used to manage the symptoms of NP and reduce the pain they feel. Although many different classes of medicines that have been shown to be effective in the management of NP, 20-40% of patients either experience less than 30% reduction in their pain or have unbearable side effects. (Finnerup et al., 2015). In the UK, the National Institute for Health and Care Excellence (NICE), provide guidelines on the specific medicines that can be prescribed in primary care settings and those which can only be initiated by specialists in the UK (National Institute for Health and Care Excellence, 2013). |
| Investigating the effect of anti-thrombotic and anti-inflammatory medications on the progression and outcomes of cardiovascular | 17/05/2019 | Cardiovascular (heart/blood vessel) disease is the biggest killer in the United Kingdom and can affect people differently. One form of cardiovascular disease is the formation of abdominal aortic aneurysms (AAA) which is best described as damage to the main blood vessel (the aorta) which leads to its enlargement, formation of clots where they should not, and eventually tearing (or rupture) of the artery wall which is fatal. This condition typically affects men over the age of 65, though it can also affect women and can happen at an earlier age. It is responsible for about 11,000 deaths per year in the UK and US combined, due to sudden rupture. Few options exist to modify its natural history, and we remain in need of understanding its underlying mechanisms beyond the traditional risk factors of blood pressure, cholesterol, diabetes and smoking. |
| Assessment of stroke and coronary heart disease (CHD) risk in people with type 2 diabetes using Automatic Retinal Image Analysis (ARIA) - Are | 16/05/2019 | Heart disease and stroke, is a leading cause of morbidity and mortality especially in people with type 2 diabetes worldwide. Many tools have been developed to predict someone’s risk of heart disease and stroke. However, they vary in their effectiveness especially in people with an already increased risk due to other conditions such as type 2 diabetes. The high costs and access to diagnostic equipment all present difficulties when conducting population screening for heart disease and stroke. Therefore, a more convenient and inexpensive risk prediction model for people with diabetes would be of considerable advantage. Identifying those at high risk of heart disease and stroke within 5 years would allow preventative treatments to be employed to reduce the risk and even delay or possibly prevent the event occurring. Previous studies have demonstrated that blood vessels in the back of the eye have predictive significance for heart disease and stroke. A risk |

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| Educational attainment of children with epilepsy in Wales | 16/05/2019 | Epilepsy is a condition associated with a range of other problems. Around 40% of children with epilepsy also have an additional neurological problem and 1 in 4 people with epilepsy have a learning disability. Behavioural issues, at home and in school, are common in children with epilepsy. Children with epilepsy are a stigmatized group, and are more likely to be bullied. A study of children with severe epilepsy saw their seizures as a barrier to a normal life. Drugs used to treat epilepsy may also have side effects. Given this, it is possible that children with epilepsy may not do so well at school when compared to children without epilepsy. In this study we aim to compare the school performance of children with epilepsy to that of children without epilepsy. We will also look at drugs used to treat epilepsy to see if they influence school performance. |
| Epidemiology of the Swansea Neurology Biobank | 16/05/2019 | The Swansea Neurology Biobank is a genetic biobank based in the South West Wales region. It contains DNA (also known as Deoxyribonucleic acid) from persons affected by epilepsy and other neurological disorders such as Multiple Sclerosis, Parkinson's Disease and Cluster Headache. The PhD aims to analyse biobank recruitment data from epilepsy patients to help design biobank collections in the future. Part of this project will compare and contrast the actual regional epilepsy population with the study cohort. Epilepsy population data will be derived from General Practice (GP) primary care data held within the Secure Anonymised Information Linkage (SAIL) Databank. This will illustrate, the level of biobank participation within the known epilepsy population, as well as the demographic and geographic factors that impact research recruitment at large around Wales. |
| Socio-economic variations in care home admission and health care utilisation in people with dementia living in Wales | 01/05/2019 | <p>Dementia is a significant underlying cause of age-related disability. With an ageing population, recent estimates project a 40% increase in dementia-related disability in older adults. As the current costs of dementia to the UK are £26.3 billion, an increasing prevalence of dementia represents a significant financial challenge to future health and social care spending.</p> <p>Accessing and using formal dementia care throughout the dementia may be difficult for some people from lower income and more disadvantaged backgrounds. Individuals may have poor health literacy and difficulties in gaining access to and understanding health service information, including how to access formal dementia care. Their location may also contribute to experiencing health inequalities, as coverage and availability of formal dementia care may differ between urban and rural settings.</p> |
| Stroke risk after Traumatic Brain Injury (TBI) | 03/04/2019 | <p>Traumatic brain injury (TBI) is a global health problem; worldwide, more than 60 million people have a TBI each year. Improvements in healthcare have meant that survival rates from TBI have increased. However, this means that more people live with the long-term effects of TBI. These long-term effects are wide-ranging and can include physical, cognitive (problems with brain functioning), social and communication difficulties. Furthermore, there is evidence to suggest that TBI patients may have increased risk of stroke, epilepsy and neurodegenerative disease. The 2017 Lancet Neurology Commission, which highlighted priorities and provided expert recommendations on clinical and research strategies to reduce the growing public health problem and improve the lives of TBI patients, recommended: "Studies are needed, in children and adults, to better understand links between TBI of all severities and an increased risk of later neurological diseases". There are a number of studies that have investigated the relationship between TBI and dementia, Parkinson's Disease and Alzheimer's</p> |

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| Which factors determine treatment choices in patients with advanced kidney failure: Co-productive study with patients and | 03/04/2019 | Patients with advanced kidney failure must choose between a number of different treatments. In Wales, the majority of patients continue to choose having haemodialysis in hospital (unit-based haemodialysis) when for many, dialysis at home may be more appropriate. Based on 2008 information, unit-based haemodialysis (UHD) is costly and has a higher death rate. The number of patients developing kidney failure is likely to increase over the next decade. More hospital haemodialysis (UHD) is not a sustainable nor sensible option for the National Health Service (NHS). The National Institute for Health and Care Excellence (NICE) have suggested that in England, encouraging patients to have treatment at home may lead to annual savings of £20 million. |
| Comparative Effectiveness Research using OBServational Data: Methodological Developments and a Roadmap. | 01/04/2019 | <p>Our pilot data suggests that there is significant variation in the number of patients choosing to have dialysis in hospital across Wales for</p> <p>Patient data collected in the course of NHS care is increasingly used for research to improve patient outcomes and safety. A randomised trial is a way of testing new treatments without bias: these are thought to be the best way of testing whether a treatment works. However people taking part in randomised trials to test treatments may not be the same as those who end up using these treatments in the “real-world,” who may have long term illnesses or take lots of different medicines. It may also be difficult to keep track of longer term outcomes and in particular safety of treatments of people who take part in a trial.</p> <p>Some of these problems might be overcome by using patient data taken from routine health records and to analyse this in a way that mimics the trial (referred to as the "emulate the target trial" or ETT approach). However, these patient data are not collected specifically for research, so we need to understand how the quality, completeness, and frequency with which they are collected affect our confidence in research using</p> |
| Repurposing statins for the treatment of epilepsy. | 31/03/2019 | Epilepsy is a common disease which affects around 1% of the UK population. Most people with epilepsy will take at least one anti-epileptic drug (AED). However, AEDs are unable to control seizures in around 30% of people with epilepsy, they also cause side effects in 88% of patients. There is a need for new effective AEDs with a low side-effect profile. Developing new AEDs is expensive and time consuming and so there is increasing interest in the “repurposing” of drugs that are already prescribed for other reasons. Statins are the most commonly prescribed medicines in the UK and are used to lower cholesterol levels in the blood. There is some evidence that statins may help people with epilepsy and reduce the risk of people developing epilepsy. In this study we will look for further evidence that statins help people with epilepsy. We will do this by studying people with epilepsy who are also prescribed statins and seeing if they need fewer AEDs, have fewer admissions to hospital because of their epilepsy and have fewer episodes of a severe prolonged form of epileptic seizure called status |
| The epidemiology of surgery to predict high risk patients | 22/03/2019 | <p>Background</p> <p>More than 5 million surgical procedures are performed in the UK NHS each year, with 49,000 deaths within 30 days. We spend £9.5 billion a year on surgical treatments (8% of NHS budget), yet we know surprisingly little about the patients who undergo surgery. We therefore lack the most basic statistical information describing numbers of patients who undergo different types of surgery, their age, and how many die. Importantly, a sub-group of around 250,000 high-risk surgical patients is concealed within the larger surgical population. These patients are typically older with complex long-term illnesses such as diabetes, heart failure or lung disease. They often experience poor outcomes after surgery and account for four out of five deaths. To plan safe and effective surgical care for this important patient group, we need up to date information describing the number of patients at risk, the short-term harms of surgery, and the long-term success in terms of quality of life</p> |

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| A realist evaluation of effectiveness, safety, patient experience and system implications of different models of using GPs in or alongside | 20/03/2019 | We wish to compare episodes of patient emergency attendance and admission at a number of Emergency Departments (ED), each using specific models of 'GPs-in-EDs' provision, including control (that is, no 'GPs-in-EDs'). The terminology is constantly evolving, but we currently identify three different categories of GP provision within an ED. These are (a) co-located, where GPs work in buildings geographically adjacent to EDs; (b) embedded, where GPs serve in a triage and screening capacity; and (c) integrated, with GPs fully integrated into ED service provision. In addition, there are EDs which do not use GPs in or close to the service. The proposed research will help to assess if EDs with these models of 'GPs-in-EDs' are better - in terms of patient emergency attendance and admission rates - than EDs with no GP provision, and (if so) whether any one model is the best. These findings are of interest to Health Service providers, with the potential to inform and influence policies on GP provision in EDs throughout the UK |
| The Wales Liver Registry | 15/03/2019 | <p>Liver disease is increasing in the UK and is now a major cause of loss of work and early death. Many liver diseases are linked to alcohol excess, drug use and previous exposure to blood borne viruses and are the result of damage over many years. Current attempts to tackle liver disease in its early phases are limited by a lack of epidemiological data and poor understanding of the natural history of these diseases in the general population. We aim to assess the number of cases of liver disease, liver failure, liver cancers and death in Wales using routinely collated GP, hospital and mortality data.</p> <p>Machine learning approaches are advanced statistical models that enable computer programmes to progressively improve their performance to make predictions and optimise the analysis of datasets. We shall apply cutting edge machine learning techniques to identify high risk</p> |
| Incidence and Prevalence of Inflammatory Bowel Disease across All Welsh Health Boards as recorded in Welsh Primary Care data | 05/03/2019 | <p>Currently there is no accurate record of the number of people in the UK with Inflammatory Bowel Disease (IBD) although there are estimated to be in excess of 15,000 such individuals thought to be resident in Wales. Current estimates are largely based on data from Secondary Care situations with the associated limitations i.e. not all people with IBD are necessarily seen and recorded within secondary care in any given year. It is likely, however, that the majority of people with IBD will have had contact with their Primary Care team during that same time period and hence this data will provide a more accurate indication of the overall numbers.</p> <p>Crohn's and Colitis UK are working within IBD Wales, a sub group of the Welsh Association of Gastroenterology, and alongside representatives of the Welsh Government and Welsh Health Boards in seeking to improve IBD services across Wales. This data will represent the most accurate estimate available in relation to the incidence and prevalence of these conditions and hence will underpin and influence</p> |
| Exploring SAIL administrative data as a potential source to improve the Welsh Index of Multiple Deprivation (focus on the health domain) | 14/02/2019 | At present, Welsh Government use an area-based deprivation measure called the Welsh Index of Multiple Deprivation (WIMD). The WIMD explores different forms of deprivation, for example poor health and economic outcomes, and every few years the WIMD undergoes a review so that it remains relevant and reflects the current economic and social situation in Wales. The WIMD is currently undergoing such a review, and the aim of this project is to contribute to the review of how deprivation in health is measured. By drawing on health data sources held by SAIL, the project will attempt to develop new indicators for health deprivation, such as the experience of long-term conditions and mental health issues. By feeding into the review of the WIMD, the results from this study have the potential to impact the measurement of deprivation in Wales. Any improvements in the WIMD's ability to identify deprivation has the potential to lead to improvements in how services and funding are targeted, and therefore improve the lives of people living in deprived areas |

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| Understanding experience, completion and outcomes of colorectal cancer screening among participants with multi-morbidity | 08/02/2019 | <p>Background: Currently in Wales, people aged 60-74 are invited to take part in bowel screening every two years. Bowel cancer screening has many stages, and involves completing a stool test, follow-up of abnormal results, diagnostic and surgical procedures, and then rescreening. Estimates suggest that 40%-60% of people of bowel screening age have two or more long-term conditions; this is known as multi-morbidity. The impact that multi-morbidity has on bowel cancer screening experience, completion and outcomes is not currently known.</p> <p>Aims: Identify interventions and ways to address the influence that multi-morbidity has on colorectal cancer screening participants, the health professional who consult with them and the screening service.</p> <p>Methods: A triangulation protocol will be developed and carried out to bring together the projects mixed-method findings. This study is mixed-methods as it has quantitative (statistics) and qualitative (interviews) phases. The triangulation protocol will explain the steps that need to be</p> |
| Stroke related health impacts and outcomes in Wales | 08/02/2019 | <p>Atrial Fibrillation (AF) is the most common type of abnormal heart beat affecting about 2 percent of the population. In patients with AF, blood clots can form in the heart and later travel to the brain resulting in stroke. Clots may also travel from the heart to the blood supply to the gut or limbs (known as systemic embolism SE) blocking blood flow to these areas resulting in amputation, bowel surgery or death. Patients with AF have a five-fold increase in the rate of stroke compared to patients without AF.</p> <p>However, the risk of these clots forming and resulting in a stroke or clots elsewhere in the body can effectively be reduced by about 66% with the appropriate use of anticoagulation (drugs that reduce the risk of clots developing). However, as with any medication there is also risks, and with anticoagulation there is an increased risk of bleeding. In patients with AF the risk of stroke needs to be balanced with the increased</p> |
| Cluster randomised trial of PSA testing for prostate cancer (CAP) | 01/02/2019 | <p>Whilst the NHS has a limited amount of money the cost of treatments is an important comparison to make; termed the cost effectiveness. Would introducing PSA testing be cost effective compared to current NHS practice? In other words, if PSA testing is effective, allowing men to be cured (saves more lives), do treatment costs compare favourably to current NHS practice.</p> <p>When comparing the cost effectiveness of treatments it is important that information is collected on all people to ensure researchers arrive at the right answer. This involves finding out about their health and any other treatments they may have had. The NHS collects a wealth of routine information for administrative purposes when people access healthcare (such as the type of operation they have and the amount of time spent in hospital). Using these routine data will allow us to include all individuals in the trial in the cost effectiveness comparison.</p> |
| Campath, Calcineurin inhibitor reduction and Chronic allograft nephropathy: the 3C Study | 07/01/2019 | <p>Kidney transplantation is the best treatment for most patients with kidney failure. Although short-term outcomes have improved over the past few decades, long-term outcomes (eg, transplant survival) have not. One important cause of transplant failure may actually be one type of drug (called calcineurin inhibitors) given to transplant recipients to prevent rejection, which may in the long-term damage the transplant and contribute to its failure. The 3C Study is a randomized, controlled trial investigating two strategies to see whether minimising exposure to these drugs can improve long-term outcomes.</p> <p>Most previous trials in kidney transplantation have focussed on short-term outcomes, whereas long-term outcomes have largely been ignored partly because of the costs of following patients for extended periods of time. The 3C Study has therefore explicitly sought to follow participants for the long-term using linkage with registries of routinely-collected data such as the UK Renal Registry, UK Transplant Registry</p> |

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| Legal aid in Wales: An assessment of availability and accessibility. | 18/12/2018 | <p>In September 2017, the First Minister announced that he was setting up a Commission on Justice in Wales to review the operation of the justice system and to set a long-term vision for its future. An important part of this work is to establish the current provision of legal services in Wales and to identify areas where legal need is not being met. This project will look to improve the understanding of legal need in Wales and to highlight regional differences in how people can access legal services. Using a combination of various survey and administrative data, we aim to answer the following questions:</p> <ol style="list-style-type: none"> 1) What are the legal needs in Wales and can these needs be quantified? 2) To what extent are legal needs being met by current provision? 3) How do legal needs, and the extent to which they are being met, compare regionally in Wales? |
| VVA Wales: A study to investigate the incidence and management of vulvo-vaginal atrophy in the Welsh post-menopausal | 03/12/2018 | <p>The aim of our study is to use the SAIL Databank to determine the number of people with VVA and how their treatment is managed compared to people who have breast cancer within the Welsh population. VVA is a debilitating condition which results as a consequence of the menopause in up to 62% of women, though it is believed to be under-reported by patients and under recognised by doctors. It is progressive in nature, worsening with declining oestrogen levels and leads to problems such as vaginal discomfort and painful sex. The changes to the vagina can also result in an increased risk of infection of both the vagina and urinary tract. VVA will only improve with hormone replacement and the first line treatment is the use of vaginal oestrogen. VVA is likely to be worse in women with breast cancer and occur at a younger age, as they frequently undergo an abrupt menopause following chemotherapy. Furthermore, the use of hormonal ‘blockers’ (used in 80% of women with breast cancer) lowers oestrogen to virtually undetectable levels, so the vagina deteriorates more rapidly. Unfortunately the</p> |
| Burdett Best Start Study - Weight Management During Pregnancy | 01/12/2018 | <p>We know that being overweight during pregnancy increases the health risks to both mum and baby. There is good evidence that diet or exercise, or both, during pregnancy can reduce excessive weight gain. The Best Start study aims to test the theory that obese pregnant women with a Body Mass Index (BMI) of 30 or over who participate in a structured programme of nutrition and lifestyle advice (Foodwise in Pregnancy™) will achieve the recommended weight gain during their pregnancy of no less than 5kg and no more than 9.1kg.</p> <p>We would like to find out if pregnant women with a BMI of 30 or over who receive the Best Start intervention are more likely to effectively manage their weight gain during pregnancy. To achieve this, we will undertake a trial that randomly puts participants into an experimental group, or a control group, which will compare those who receive the intervention to those who continue with routine antenatal care. We are</p> |
| Adolescent Data Platform (ADP): Adverse Childhood Events, part of Mythical | 30/11/2018 | <p>Things like abuse or neglect in childhood are often known as Adverse Childhood Events (ACES). People who experience ACES often have problems with health and work in adulthood. This might include things like self-harm, mental health issues or problems finding a job. We want to use the SAIL databank to learn more about how ACES affect people over a longer period of time. To do this we will need to look how ACES affect other parts of peoples’ lives and how we can see this within different sets of data. We will use the SAIL databank and data from a local health-board. This data has information about children who went to hospital after abuse or neglect. This will help us to see what these children might look like in routinely collected data and to check that we are looking for the right kinds of diagnoses.</p> <p>The first aim of this project is to link this additional dataset and to compare this with the routinely collected data available in SAIL. We will utilise these two sets of information to come up with a way of looking for ACES in data that is routinely collected. We can share this with other</p> |

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| Do systemic antibiotics prior to cancer diagnosis affect the effectiveness of chemotherapy for malignant cancers? | 30/11/2018 | <p>Bacteria that live inside the human intestines (gut microbiota) is made up of more than 1,000 different bacterial species. These bacteria are important for our digestion and health. Antibiotic treatment kills bacteria in the gut, which change the number of bacterial species in the gut and how they work. Scientific evidence shows disturbance of the gut bacteria can change how some cancer treatments work (i.e., medicines like chemotherapy, that kill dividing cancer cells in the body no longer works). Currently this work is done in mice or tissue samples. Little work in humans has been done to see if antibiotics affect how cancer treatments work.</p> <p>This study will use the secure anonymised information linkage (SAIL) to test any link between recent use of antibiotics and the effect on patient death in patients that have recently been diagnosed with cancer. Patients who have been exposed to antibiotics in the past, with no cancer history, who developed cancer during the study will be our cases. We will test the number of cases who die after their diagnosis of</p> |
| MRC Pathfinder - MytHICAL - Mental Health Informatics in Children, Adolescents and young adults - Education | 22/11/2018 | <p>Over half of all mental ill health starts before the age of 14 years, 75% by the age of 18 . About 1 in 10 adolescents in the UK at any given time, approximately 850,000, have a mental health disorder. This rises as high as 1.3 million if all children are included. The diagnosis, management and services for mental health problems in children and young people are of growing concern and a source of huge controversy in the UK. Mental disorders in children and young people are often present when they have other illnesses and have been found to lead to life outcomes (such as educational underachievement) and serious disruptions to their lives and those of their families.</p> <p>5.2 Workstream 1: Routine data We will use the routinely collected health and educational data available in the SAIL Databank to study the characteristics and outcomes of children with a diagnosed mental health illness, building on previous work.</p> <p>5.3 Workstream 2: NCMH cohort We will continue to work with the National Centre for Mental Health, to examine the temporal association</p> |
| Rates of Major Psychiatric Disorders in ASD | 21/11/2018 | <p>People with Autistic Spectrum Disorder (ASD) usually develop differently when they are children. They often have particular characteristics such as having trouble interacting with others, finding communication difficult, having a very narrow set of interests, showing certain types of repetitive behaviours and finding change very difficult.</p> <p>Estimates based on information collected by health and care staff who come into contact with people with ASD tell us that around 1 in 100 people in the UK have some sort of ASD. This information also tells us that more males than females have ASD with 3 men/boys having ASD for every 1 woman/girl with ASD.</p> <p>Most research until now has looked at the most severe cases of ASD and has been focused on ASD in children. Very few studies look at how adults with ASD live and what other mental health difficulties they may experience. This study will use data from SAIL Databank to find out</p> |
| SAIL Data Quality Subproject: Analysis of factors associated with failure to match | 13/11/2018 | <p>Using machine learning methods to identify differences among individuals who do not receive an ALF.</p> <p>As an internal project that investigates data quality, this falls under approved SAIL core activities. However, we plan to submit an IGRP application to gain approval to publish results (in line with the SAIL Access Policy)</p> |

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| The Impact of 'Non-Clinical Patient Factors' (NCpF) on Clinical Decision-Making: Uncovering the Impact on Mental Health | 01/11/2018 | <p>Good quality healthcare is required to understand how a variety of factors (e.g. educational level, gender, demographics) impact peoples' interactions with healthcare and healthcare professionals. This is an important missing piece in the implementation of healthcare systems as unintentional influences may impact the specific needs of different societal groups 4-7.</p> <p>Using a combination of the Administrative Data Research Centre in Wales (ADRC-Wales) and the Secure Anonymised Information Linkage (SAIL) databanks, the databases within each shall be linked and used to examine the influence of these different factors on mental health diagnoses, treatment, and referral.</p> |
| Incidence of skin cancers in patients on immunosuppression : an e-cohort study. | 10/10/2018 | <p>This project will use data from the SAIL Databank to identify the number of people with skin cancer that have received an organ transplant. In order to prevent these organs being rejected, patients that have had a transplant are required to take drugs that reduce the body's immune system. This however also reduces the response to infection and the ability to deal with certain types of cancer. It is known that patients taking these drugs are at higher risk of developing skin cancer however, the true numbers and risk is not known.</p> <p>We need to know the true risk of developing skin cancer in order to provide better education to people. We also need to know this risk so that we can provide better more effective services for our patients.</p> |
| Clinical management and outcomes in non-metastatic castrate-resistant prostate cancer (nmCRPC) | 09/10/2018 | <p>Janssen-Cilag Ltd UK, a major pharmaceutical company, is compiling evidence around the current management of non-metastatic, castration-resistant prostate cancer (which is a type of prostate cancer that is not responding to hormonal therapy, and has not spread to other parts of the body). They are interested in current management of this type of prostate cancer and also want to get a better understanding of clinical outcomes following treatment. To do this, the project proposes:</p> <ul style="list-style-type: none"> • To investigate whether it is possible to identify a group of people with this type of prostate cancer in SAIL. Identifying individuals with this specific type of disease is complex. Determining castration resistance will depend on developing a set of rules based on the sequential appearance of treatment codes and test results; measuring whether the cancer has spread (become metastatic) is not possible for all patients because the absence of any recorded evidence in the data that the cancer has spread is not always proof that it has not happened. |
| EMRTS (Emergency Medical Retrieval and Transport Service) evaluation | 09/10/2018 | <p>Building on the currently active SAIL project (0448), the evaluation of the Emergency Medical Retrieval and Transport Service (EMRTS) Cymru, is a service for seriously injured and ill people across Wales whereby rapid help is provided by specialist doctors transported by helicopters and ambulances. The intention is to improve the survival of seriously injured or very ill people, including those suffering cardiac arrest (heart stopped). The service started in April 2015 and will reach an estimated 300 people every year. In some parts of the world, but not everywhere, similar services have led to improved survival. This proposed evaluation would bring together complex data on patients treated by the service over 5 years of service and will compare outcomes with a group of similar people before the service was introduced or when it is not operational, such as at night time or during bad weather when the helicopters cannot fly.</p> |

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| Association between medications and risk of dementia. | 09/10/2018 | <p>Around 670,000 people in the UK are currently living with dementia, and this number is expected to double over the next twenty years. There is an urgent need to better understand the causes of dementia so we might learn how to prevent its onset. Some of the risk factors for dementia are well understood, but they only explain part of an individual's risk - this suggests that there are other, unknown risk factors for dementia.</p> <p>We have previously used primary care, hospital admissions, mortality and demographics data from the SAIL Databank to build an e-cohort for use in dementia research. We plan to use this e-cohort to find out whether some prescription medications are linked to developing dementia.</p> <p><i>We will do this in two ways:</i></p> |
| MQ Adolescent Data Platform – Wales. | 08/10/2018 | <p>The mental health of children and young people and how we support them are of growing concern in the UK. The teenage years, as people grow from children to adults with lots of life changes, can be an intense emotional period. We want to understand why some young people become mentally unwell while others do not. Can we pick up those at risk early and give them the right support at the right time or even prevent it from happening?</p> <p>Maybe we can. Every day as part of the running of hospitals, general practices, schools and elsewhere we are collecting data, however this data is not collected for research purposes and is often a bit messy. But properly sorted, made so people cannot be identified, and safely stored: we can use this data to better understand, treat and support young people. We can also link different data together and try to see</p> |
| Exploring the use of routine data to inform and improve patient management in common musculoskeletal problems | 03/10/2018 | <p>This research examines the events logged within primary and secondary care information systems regarding patients with common musculoskeletal conditions. A musculoskeletal condition effects the muscles, bones and joints and may include such conditions as osteoarthritis, back pain, knee pain and rheumatoid arthritis. The research will apply process mining techniques to the data from these health information systems to identify actual clinical pathways. Process mining techniques are relatively new and allow for patterns to be generated and clearly visualised from real data stored in information systems. The research will be looking at patterns of service utilisation including diagnostic tests, referrals and patterns of drug prescribing, combined with diagnosis codes to determine if early indicators exist for patients who accumulate musculoskeletal problems and therefore have an increased risk of worse outcomes. Pathways will be compared based on factors such as a patients age, gender, IMD (index of multiple deprivation), ethnicity and geographical region. The study period will be</p> |
| Optimising Blood Pressure in Older People with Frailty | 03/10/2018 | <p>This PhD plans to find out how we might improve blood pressure treatment for older people who have frailty.</p> <p>Frailty</p> <p>Frailty is common in older age. It develops because as we get older our bodies change, and can lose their inbuilt reserves, for example we lose muscle strength. These changes mean that older people with frailty can experience sudden, dramatic changes in their health as a result of seemingly small problems, such as a new medication, or an infection. One in ten people over the age of 65 years has frailty and this rises to up to around half of all people aged over 85 years.</p> |

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| Evaluation of the effect of using nursery school vaccination sessions to improve uptake of live attenuated influenza vaccine. | 02/10/2018 | All children aged two and three years old in Wales are eligible for influenza vaccination using the Live Attenuated Influenza Vaccine (LAIV). Cwm Taf University Health Board conducted a pilot intervention to enhance delivery of this service, by offering LAIV to three year olds in nursery school vaccination sessions. We would like to assess whether offering LAIV through nursery schools in this health board led to improved and more equitable uptake. Provisional data indicate that this pilot may have led to improved uptake, however establishing accurate uptake is difficult due to the mixed model of delivery. Individual routine data sources used by Public Health Wales to monitor vaccination uptake may underestimate uptake in this age group in Cwm Taf UHB, due to under-reporting/ under-recording of vaccinations given different providers. By linking General Practice data to Child Health System data we hope to obtain a more complete dataset for evaluation |
| Prevalence and patterns of comorbidity (defined chiefly using medication usage) as well as the risk of subsequent events among real- | 02/10/2018 | People with co-existing diseases (comorbidity) are less likely to receive guideline-recommended treatments than people without comorbidity. This is true even where the comorbid conditions are not specific "contra-indications" for the treatment (eg blood-thinning drugs in someone with a disease which causes bleeding). Whether this difference in clinical practice benefits or harms people with comorbidity is uncertain. One reason for this uncertainty is that people with comorbidities are underrepresented in clinical trials. However, the extent of under representation, and its implications for clinical practice are uncertain. Therefore, we are undertaking a wide-ranging project using clinical trial and routine healthcare data to produce more valid and representative treatment effect estimates for people with multiple diseases |
| Evaluating the impacts of Welsh Government funded schemes designed to improve the energy efficiency of the homes of low income households | 02/10/2018 | The World Health Organisation recommend a minimum indoor temperature of 18 degrees and recognise that living in cold and/or damp house may be harmful to health. Inadequate indoor temperatures increase the risks of mortality and excess winter deaths. There is also evidence to support that living in cold homes has an effect upon cardiovascular, respiratory and mental health. Rising fuel costs in the past decade have led to an increase the number of people living in fuel poverty and inadequately heated houses. Fuel poverty is particularly acute in Wales; in 2011 UK estimates indicate that 29% of households in Wales were in fuel poverty compared to the UK figure of 17%. The Welsh Government's fuel poverty strategy sets out to reduce the number of people in Wales living in fuel poverty or at risk of fuel poverty. A key action in the strategy is to develop programmes to improve the energy efficiency of homes and to target these improvements |
| Enriched Patient Health Records using Machine Learning and Natural Language Processing in Clinical Letters to identify Heart Failure | 02/10/2018 | Rich information in doctor's notes & reports has great potential for research, with the use of free text information being able to possibly improve detection of difficult to diagnose diseases. Standard tools are not currently good enough when applied to doctor's notes which are often written in unique and personal ways which are suitable for their own use but not when running via a large computer based approach to pull out information. Our project consists of two phases: Phase 1: develop new methods to process medical free text and extract relevant information into structural data; Phase 2: utilize this data into the SAIL Databank, combining it with available routine data to improve identification of conditions of interest, specifically congestive heart failure. |

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| Mood and Wellbeing Study | 02/09/2018 | Children of depressed mothers are at increased risk of mental health problems and lower educational development. However, there is substantial variation in the mental health outcomes for this group consistent with the idea that high-risk cases vary considerably in risk. For instance, in our work to date, around 30% of the adolescent offspring of depressed parents had experienced clinically significant mood or anxiety problems, 25% were doing better than expected mental health compared to population norms. It is not yet known which individuals will go on to develop chronic long-term depressive symptoms. The proposed work seeks to investigate this. We will investigate whether factors such as the level of severity and chronicity of the mother's depression and the extent to which other family members are affected by mental health problems play a role in explaining mental health outcomes for children. This study aims to investigate health and education of children with living with a depressed parent. This is a mixed methods study and so has a number of approaches: |
| Improving the experience of dementia and enhancing active life: living well with dementia - the IDEAL study | 01/09/2018 | Living well with dementia, whether as a person with dementia or primary (usually family) carer, can be understood as maximising life satisfaction, reaching one's potential for well-being, and experiencing the best possible quality of life. This project aims to understand what 'living well' means from the perspective of people with dementia and their carers. It will identify what helps people to live well or makes it difficult to live well in the context of having dementia or caring for a person with dementia. To understand what 'living well' means to people with dementia and primary carers, we will explore how people adapt to the challenges that the condition presents over time. We will explore factors important to adapting to dementia, such as the assets, resources and support networks people have available. Over a two-year period we will recruit 1500 people with early-stage dementia from England, Wales and Scotland. We will also include at least 1000 primary carers. We will make contact with potential participants through the local research networks that link with NHS memory |
| SAIL AF Bleeding and Thromboembolic Complication Evaluation | 01/09/2018 | Atrial fibrillation (AF) is the most common abnormal heart rhythm in clinical practice, and hospitalisations because of AF are increasing. Patients with AF have a 5- to 7-fold greater risk of stroke than the general population. Medicines called oral anticoagulants can decrease the stroke rate by more than two-thirds; however, these medicines can also put patients at increased risk of bleeding. Warfarin is currently the most prescribed oral anticoagulant used in patients with AF to reduce the risk of stroke, but it requires careful management of the dose in order to be effective. In a previous study (project 0646), we have found considerable variation in the effectiveness of Warfarin management, with a high proportion of patients having one of several indicators of poor control. |
| WOMB-C | 20/08/2018 | Pregnant women have an ultrasound scan when they are about 20 weeks pregnant. The purpose of this is to look for problems with the baby, such as abnormal development of the heart. We're not sure if the some of the things we see on this scan mean that the baby has a health problem. For example, we sometimes see bright spots in the baby's heart. These are called "cardiac echogenic foci". We don't know if seeing these means that the baby will have heart problems when they are born. In this study, we will follow children who had these bright spots on their scans, and a group of children who did not, until they are five years old. We will look to see whether children with these spots have more heart problems than the children who did not. We will also examine if children with more spots, or spots in certain areas of the heart, have more heart problems. The data from the study will help doctors to know how to treat mothers and babies when we see these spots on the pregnancy scan. The information will also help families to understand and not feel so worried after the scan. |

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| Outcomes following discontinuation of dosulepin in patients in Wales | 17/08/2018 | <p>The tricyclic antidepressant dosulepin is associated with an increased risk of toxicity compared to other antidepressants, particularly when taken in overdose. In order to reduce the risk of patients experiencing adverse effects associated with dosulepin, the All Wales Medicines Strategy Group (AWMSG) introduced a National Prescribing Indicator (NPI) to monitor its usage in primary care in Wales in 2011. A previous study conducted by the All Wales Therapeutics and Toxicology Centre (AWTTC) showed a reduction in prescribing of dosulepin following the introduction of the NPI.</p> <p>The aim of the present study is to investigate the outcomes of patients who discontinued dosulepin treatment and those who remained on treatment, in order to assess whether the reduced prescribing of dosulepin has in fact led to improved patient outcomes.</p> <p>The study will use data provided by the Secure Anonymised Information Linkage (SAIL) database. This database includes information from GP</p> |
| Anti-epileptic drug combination therapy in Wales. | 15/08/2018 | <p>Epilepsy is a common disease which affects around 1% (30,000) of people in Wales. Most people with epilepsy will take at least one anti-epileptic drug (AED). Around 30-40% of people with epilepsy will need to take two or more AEDs. There is evidence and guidelines to help patients and healthcare professionals choose the first AED but there is very limited evidence or data available to help patients and healthcare professionals choose their second and third AED.</p> <p>In this project we will look at the prescribing patterns of AEDs for people with epilepsy in Wales using the SAIL Databank. We will find people with epilepsy and then look at the different combinations of AEDs that they are prescribed. We will identify the most common combinations. We will also look at how long different combinations are prescribed for. Combinations of AEDs which are prescribed for longer are more likely</p> |
| Determination of current standard care for management of patients with Venous Leg Ulcers | 14/08/2018 | <p>The study aims to describe the management of diabetic patients with Venous Leg Ulcers (VLUs). We hope to be able to quantify the potential clinical and economic impact of the burden of VLUs on the Welsh NHS and also investigate the potential for introducing an alternative approach to reducing the pain associated with LVU wound cleaning.</p> |
| Paediatric Validating Injury Burden Estimates Study (VIBES-Junior). | 02/08/2018 | <p>Injuries are a leading cause of death in children and adolescents in many countries, including in Wales. Measuring the burden of injuries is an important part in getting and maintaining support for injury prevention initiatives and for post injury rehabilitation. The Paediatric Validating Injury Burden Estimates Study (VIBES-Junior) study is an international collaboration aiming to provide more accurate figures on the impact of injuries on children's health and educational development to help press the case for prevention. The VIBES-Junior project will use data collected from five longitudinal studies of injured children across the world together with analyses of routine health and educational records in Wales and South Australia. The analyses are very similar to a previous study approved by IGRP in which we showed that certain types of brain injuries had a substantial impact on how well children did at school at age 7. A copy of that paper is provided with this application. This study aims to extend this work by including a larger number of children for whom educational records are available and looking at the impact</p> |

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| Association of severe hypoglycaemia and mortality in people with type 1 diabetes | 02/08/2018 | Hypoglycaemia (low blood sugar level) is an adverse side effect of insulin therapy in patients with type 1 diabetes. However, good glycaemic control (avoidance of high blood sugars) is associated with an increased risk of severe hypoglycaemia that can lead to coma. Self-reported severe hypoglycaemia was found to be associated an increased risk of death in both people with type 1 and type 2 diabetes. However, these data were only assessed via questionnaire; there is a lack of information if there is a direct relationship between severe hypoglycaemia (hospitalisation) and death in individuals with type 1 diabetes. Therefore, the aim of this present investigation is to assess whether people with type 1 diabetes that have a severe hypoglycaemic event are at greater risk of death than a diabetic control population. |
| Social exclusion and use of care services in Wales: experiences of people with cognitive impairment and dementia | 04/07/2018 | People are living longer and need more help from health and social care workers than before. It is important that groups who arrange help for people can plan for these changes. To do this they need as much information as possible about what help people need, how they are currently getting help, and how they might need help in the future. Knowing how people currently use health services such as their General Practitioner (GP) or hospital is important. We can ask people how often they visit their doctor or hospital, or we can get this information from National Health Service (NHS) records. However, we currently do not know how similar information from these two sources are and if we can use them in the same way. This project will look at how similar information from GP and hospital records are to the information that people tell us during interview. |
| The Welsh Government Flying Start Data Linking Project | 25/06/2018 | <p>The Welsh Government's Flying Start programme aims to improve outcomes for children in some of the most disadvantaged areas across Wales. This is done through providing four key Flying Start entitlements to children under four years old and their families: enhanced health visiting, parenting support, support for early language development (primarily in the form of Language and Play programmes) and free, high quality, part-time childcare for two to three year olds.</p> <p>The project aims to examine the impact the Flying Start Programme has on families receiving Flying Start support. Flying Start eligibility is based on geographical area (specifically post codes) and the programme was rolled-out to certain deprived areas in Wales at different time points. The proposed project will define the Flying Start population using Residential Anonymised Linking Fields (RALFs) in the SAIL databank</p> |
| An investigation into the impact of congenital anomalies on infant and child death rates | 15/06/2018 | <p>Background and rationale:</p> <p>The UK has one of the highest child death rates in Europe. How particular causes of deaths have contributed to the high infant death rate in the UK remains unclear. Congenital anomalies are structural or functional problems that occur while a baby is developing during pregnancy. They are sometimes called birth defects. Infant death refers to babies who die in the first year after birth.</p> <p>Congenital anomalies are the second leading cause of infant deaths in the UK, accounting for over one-third of all infant deaths; and the first</p> |

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| Investigating the clinical and social characteristics of dystonia | 15/06/2018 | <p>Dystonia is the third most common movement disorder worldwide, and is caused when opposite muscle groups are over active, causing pain, spasms and abnormal body positions and postures. The most common part of the body to be affected is the neck or arms, but the legs and body can also be affected, particularly in children. As well as problems with movement, research studies have also shown that people with dystonia often have psychiatric symptoms, particularly depression and anxiety. The combination of difficulties with movement and mood often result in problems with work and education, having a big impact on day-to-day living. Although dystonia is common, it is often difficult to diagnose, with individuals waiting months or years before receiving a diagnosis and treatment. The treatment itself can also be complex, with physiotherapy, medication and surgery available.</p> <p><i>Our aim with this project is to better understand: a) the number of people with a diagnosis of dystonia in Wales. b) the number and types of</i></p> |
| Hidradenitis Suppurativa (HS): validation of prevalence by linking between the Secure Anonymised Information Linkage databank and | 01/06/2018 | <p>Hidradenitis suppurativa (HS) is a long term condition in which multiple painful skin boils affect creases such as the arm pits and groins. The boils leak pus and leave scarring and HS has a large impact on quality of life. Working out how many people are affected by HS is difficult because quite a lot of GPs do not recognise the condition and just provide antibiotics for individual boils.</p> <p>GPs routinely collect information about their patients in electronic databases and these can be used to check how many people have been diagnosed with HS. Undiagnosed patients can also be found by looking for patients who have seen their GP lots of times for skin boils in the creases, or who have been prescribed multiple short courses of antibiotics used to treat skin boils. However, it is important to double check that these undiagnosed patients really do have HS.</p> |
| Prescribing Trends and Compliance in Parkinson's Disease (PD): a comparison of community and Residential Care home patients | 01/06/2018 | <p>Parkinson's disease (PD) is an incurable progressive condition causing a characteristic movement disorder and host of other medical issues. Medications available to treat the condition target the motor disorder but as the disease progresses greater comorbidities are evident and there is increased use of medications to manage psychotic events, dementia and mental health issues. There were continuous changes in the PD treatment literature and guidelines between 2000 and 2017. Recently, the National Institute for Health and Care Excellence (NICE) published updated treatment guidelines for PD, which included recommendations regarding those changes in the literature and how to implement them in clinical practice. In addition, NICE 2017 guidelines have provided the clinician with recommendation regarding the most updated and evident way to treat other conditions associated with PD such as depression, psychosis, and dementia.</p> |
| Evaluation of the clinical impact of Myocardial Perfusion Scintigraphy in Wales: a retrospective linked population cohort | 01/06/2018 | <p>Stress Myocardial Perfusion Scintigraphy (MPS) studies involve injection of a radioactive tracer and evaluation of its uptake by the heart to determine blood flow. This provides important information regarding the presence and extent of coronary artery disease, and is a well-established method for investigation of people with chest pain and other cardiac symptoms. The clinical and cost-effectiveness in a modern UK healthcare setting remains an important question. It may also be possible to establish new ways in which the information from MPS is collected and interpreted, in order to improve the accuracy and predictive power of this technique.</p> <p>In this study, we propose to derive three parallel MPS databases from our records of over 3000 patients who have been investigated over the past 10 years at Singleton Hospital. Each of these databases will include the same source data from our clinical testing database (Cardibase:</p> |

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| Epilepsy, anti-epileptic drugs and the risk of cardiovascular events | 01/06/2018 | <p>Epilepsy is a common disease which affects around 1% (30,000) of people in Wales. It is known that people with epilepsy die at a younger age than people without epilepsy. There is some evidence that this may be because people with epilepsy have more cardiovascular problems. Cardiovascular problems affect the heart and/or blood vessels, for example: heart attacks, strokes and other heart or blood vessel problems. Some of the medications that people with epilepsy take may also increase the risk of having cardiovascular problems.</p> <p>In this project we aim to see if people with epilepsy have more cardiovascular problems. To do this we will look at anonymised routinely collected data held within the SAIL Databank. We will find people who've had a new diagnosis of epilepsy and then look to see if they develop cardiovascular problems by searching their anonymised general practitioner (GP), hospital discharge and death (if applicable) records. We will</p> |
| Survival Improvement with Colecalciferol in Patients on Dialysis – The SIMPLIFIED Registry Trial | 30/05/2018 | <p>This study will test whether patients on dialysis stay healthier for longer if they take the “natural” form of vitamin D, called colecalciferol. This is currently rarely used. Instead, most patients receive “artificial”, active forms of vitamin D such as alfacalcidol and paricalcitol. People need vitamin D to stay healthy. Getting calcium from the diet into bones depends on vitamin D. Low vitamin D levels (vitamin D deficiency) leads to soft bones, fractures, weak muscles, heart and blood pressure problems, and may increase the risks of infections and cancer. People with kidney failure on dialysis often have low vitamin D levels for at least 3 reasons.</p> <ol style="list-style-type: none"> 1. When kidneys fail, the body is less efficient at making its own vitamin D. 2. Foods rich in vitamin D are mostly restricted because of high phosphate or potassium. 3. Patients are usually asked to avoid excessive sunlight or wear sunscreen to avoid skin problems such as cancer. |
| The health cost of mould and damp in Welsh homes. | 30/05/2018 | <p>One in six Europeans live in unhealthy buildings. Damp and poor airing particularly affect the lungs. The cost of lung diseases in the United Kingdom in 2014 was £11.1 billion according to the British Lung Foundation.</p> <p>Cystic fibrosis (CF) is a genetic disease that affects mostly the lungs and lasts throughout a patient’s life. Most patients become unable to breathe because of repeated lung infections. On average, patients with CF in the UK live until the age of 41. Every CF patient costed about £40,000 in 2012 according to the London School of Economics. 57% of the cost was not related to health care. This project is comprised of and has expertise from building scientists, clinicians, and health economists.</p> |
| Green-Blue space exposure changes and impact on individual-level wellbeing and mental health: a population-wide record-linked | 29/05/2018 | <p>Existing scientific evidence suggests that Green-Blue Space (GBS), such as parks, woodlands, beaches may be beneficial for population health and wellbeing. However, robust evidence is relatively limited, and cannot fully inform national and local policies that shape our living environments. In this project we will take a large-scale population approach, considering the majority of Wales’s environment and population, and changes over time. The study findings will inform decisions about urban and rural environments in Wales, and the rest of the UK, that might benefit our health and wellbeing.</p> <p>In two linked pieces of work, we will study both the characteristics of GBS around people’s homes (e.g. how close a park is), and how often people visit GBS. We will find out whether people with greater GBS exposure are happier and are diagnosed with fewer mental health</p> |

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| Which birthweight growth percentile charts and thresholds best predict stillbirth, neonatal and infant mortality | 23/05/2018 | <p>Birth weight and fetal growth charts are used to identify babies at an increased risk of adverse outcomes. Babies that are born substantially larger or smaller in weight than average for their gestational age (length of pregnancy) are known to be at increased risk for outcomes such as stillbirth (not alive when born) and infant mortality (death within a year of birth). However, there is still uncertainty on at what weights a baby is too small or too large. Therefore the analysis of births and their outcomes in large-scale data is necessary to find out at which birth weight thresholds the rare outcomes start becoming more frequent. In medical care practice, the birth weight charts are usually standardised for the baby's sex and gestational age, but they are sometimes also customised further to account for mother's ethnicity, height, weight and number of previous births. However, it is still unclear whether the customisation improves the ability to correctly identifying babies at risk. This study</p> |
| A real time pharmacoepidemiological surveillance system for children with asthma. | 01/05/2018 | <p>Children are often prescribed drugs off label as there are few drugs that have been tested in children. However, children may have different adverse events from adults given they are growing, their metabolism is different and starting a medication in childhood means they are exposed to it for much longer than adults. Therefore, there is a need to develop a surveillance system to pick up signals or patterns of events (e.g. diagnosis, admission to hospital, other medications prescribed) that are associated with a prescription of a drug in a child. This study develops the methods for a surveillance system in one dataset (SAIL in Wales) and tests the methods in a dataset (pharmacology and GP data) in France. It is the first steps in developing a surveillance system for drugs in children. This work focuses on asthma drugs as a case study.</p> |
| PhRASE - Prehospital Recognition and Antibiotics for 999 patients with Sepsis: Protocol for a Feasibility Study | 01/05/2018 | <p>Sepsis is a common condition killing between 36,000 and 64,000 people every year in the UK. Early recognition and management of sepsis has been shown to reduce death and to improve the health and well-being of people with sepsis. Paramedics frequently come into contact with patients with sepsis, and are well placed to provide early diagnosis and treatment.</p> <p>This study aims to find out if it would be feasible to carry out a larger trial of whether paramedics can accurately and safely identify severe sepsis and give the correct antibiotics to patients. Sixty paramedics will be recruited to the study and will receive an enhanced level of training to assist them to recognise severe sepsis. If severe sepsis is suspected, paramedics will select a scratch card, which will inform them whether to provide enhanced care (intervention) or usual care (control). All patients managed by study paramedics will benefit from an enhanced</p> |
| Prevention of major amputations secondary to diabetic foot disease. | 26/04/2018 | <p>Diabetic Foot disease is a major complication of diabetes, and the leading cause of amputation of lower limbs in the working age population. Annual diabetic review includes a foot check which aim to ensure early detection of foot diseases such as foot deformity and ulceration when treatment is most effective. Current recommendations are that screening for diabetic foot disease should be carried out on an annual basis in all patients with diabetes.</p> <p>Data on all patients with diabetes in Wales including those patients who develop diabetic foot disease and require amputation are available via the databases already available with SAIL and include information on these patients and any amputations that occur (e.g. blood pressure, glycaemic control, treatment, etc). From this data we aim to identify risk factors, with a specific focus on social and psychological factors</p> |

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| Reducing inequalities in child health: understanding pathways, interventions and policies | 11/04/2018 | <p>Reducing health Inequalities and improving child health are UK and International policy goals, with poverty and social inequality harming children's health. The poor health associated with poverty limits children's potential and development, leading to poor health and life chances in adulthood. The costs to society as a whole of the resulting inequalities, which have their origins in childhood, amount to around £60 billion per year in the UK.</p> <p>Tackling the poorer health of poorer children is a major challenge for public health in the UK. For this to happen, however, we need to identify how to break the link between adverse socio-economic conditions (SECs) with worse child health. One major challenge is that, while the association of poverty and children's health is clear, we lack understanding of the complex pathways linking adverse social conditions to</p> |
| Pattern of IL-6 inhibitor versus TNF inhibitors use in patients with Rheumatoid Arthritis in South Wales: a Real-Life Study | 03/04/2018 | <p>There are many expensive biologic treatments currently available for the treatment of Rheumatoid Arthritis (RA). These biologic therapies are expensive but effective treatments for rheumatoid arthritis. The most commonly used biologic treatments are Tumour Necrosis Factor inhibitors and Intereukin-6 inhibitors. Clinical trials have shown these treatments to work well, however participants in clinical trials tend to be younger and healthier. Therefore it is important to assess the effectiveness and safety of these treatments used in real-life practice. The purpose of this study is to assess and compare how these treatments are currently being used in daily practice; 1. Identifying the clinical characteristics of patients being treated; 2. How frequent patients stopped treatments because of side effects or them no longer working well to help their symptoms.</p> |
| Pattern of NSAID, csDMARDs and bDMARD use in patients with Psoriatic Arthritis and Axial Spondyloarthropath v in South Wales | 03/04/2018 | <p>Psoriatic arthritis (PsA) and ankylosing spondylitis (AS) are common chronic inflammatory diseases of the spine and joints. The National Institute of Health and Clinical Excellence (NICE) has produced guidelines on managing these conditions to improve health and quality of life. Recent studies have suggested there is a significant delay in diagnosis of PsA and AS, however, the effect of starting treatments later in the disease process is not known. It is also not clear what happens to patients from onset of symptoms to diagnosis and treatment in the UK. The purpose of this study is to examine how patients with PsA and AS journey from onset of symptom to diagnosis, assessing if they receive appropriate treatment in line with NICE guidelines. We aim to examine factors that may influence hospital referral, treatment choice and outcome. Identifying and removing barriers to diagnosis and treatment of PsA and AS will prevent disability and improve quality of life.</p> |
| Risk of alcohol-related death in people with epilepsy | 29/03/2018 | <p>Epilepsy is the one most common serious neurological condition in the world. It affects around 600,000 people in the UK (almost 1 in 100 people). Around 87 people are diagnosed with epilepsy in the UK every day.</p> <p>In a previous analysis, we found that people with epilepsy are approximately three times more likely to die from unnatural death than those without the condition. In particular, we noted a higher prevalence of alcohol misuse in the epilepsy cohorts than the comparison cohorts. However, to date, there is no research on the specific risk of alcohol-related mortality in people with epilepsy.</p> <p>We therefore aim to estimate the risk of alcohol-related mortality in people aged 18 or over with epilepsy, and the contribution of alcohol-</p> |

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| All Wales Injury Surveillance System (AWISS) | 09/03/2018 | The All Wales Injury Surveillance System (AWISS) is a population-based, multi-data sourced injury surveillance system which uses the data in SAIL to routinely conduct analyses on injury occurrence, identify risk factors, measure and monitor changes in the severity, outcomes and costs of injury to the National Health Service (NHS) and society as well as supporting the feasibility assessments of injury-related research projects. Its purpose is to inform and support injury prevention practitioners, clinicians and policy makers across Wales to make the best evidence based informed decisions on prevention, treatment and rehabilitation of injuries. AWISS analyses can be used to identify groups at high risk of injury and to support the planning and evaluation of injury related interventions and policies. |
| EUROlinkCAT: Establishing a linked European Cohort of Children with Congenital Anomalies | 26/02/2018 | Over 130,000 children born in Europe every year will have a congenital anomaly (CA). These CAs, which are often rare, are a major cause of infant mortality, childhood illness and long-term disability. EUROCAT is an established European network of population-based registries for the monitoring of CAs across member states. CARIS (Congenital Anomaly Register & Information Service) [http://www.caris.wales.nhs.uk/home], the all-Wales CA registry, is a contributor to EUROCAT and links data into SAIL. EUROlinkCAT will use the EUROCAT infrastructure to support 21 EUROCAT registries in 13 European countries to link their CA data to mortality, hospital discharge, prescription and educational databases. Each registry, including CARIS/SAIL, will send standard summary tables and analyses' results to a Central Results Repository (CRR) thus respecting data security issues surrounding sensitive data. The CRR will provide standardised summary data and analyses on an estimated 200,000 children with a CA born from 1995 to 2014 up to age 10, enabling research questions on their |
| Investigating the early adult outcomes of childhood ADHD: Establishing a Wales-wide sample | 16/02/2018 | Children with Attention Deficit Hyperactivity Disorder (ADHD) are at increased risk of developing additional mental health problems in early adulthood and using A&E Departments. The reasons for this are unknown with little research on this topic. One major barrier to researching this topic is that tracking children with ADHD into early adulthood is very difficult as they are poor outpatient attenders. GP data-linkage studies offer an attractive solution. The Wales-based Secure Anonymous Information Linkage (SAIL) databank anonymously collates routinely collected data (from the NHS, Government and schools) for almost everyone in Wales. Using this resource, we plan to identify all children diagnosed with ADHD in Wales, then electronically track their outcomes using routine data from this population dataset to identify predictors of poor outcomes. |
| An e-cohort study of trends in the incidence of recorded anxiety and depression symptoms and diagnoses and antidepressant | 07/02/2018 | A previous study by this research team found an increase in prescribing of antidepressants and anxiolytic medication in children and young people with no concurrent increase in the diagnosis of anxiety/depression. It was also found that while fluoxetine is the only antidepressant licenced for children and young people GP's were frequently prescribing citalopram instead. This is despite the known toxicity of citalopram in overdose. This was followed by a Welsh Health Circular (WHC) to GPs, CAMHS clinicians and pharmacists highlighting the requirements of NICE guidance and the BNF for children in relation to prescribing practice, as well as, a Welsh Medicines Resource Bulletin and case study on Depression in young people in 2016. |

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| Exploring relationships between gastrointestinal and mental health | 06/02/2018 | <p>he brain and the gut communicate to each other in a complex communication system known as the gut-brain axis (GBA). The purpose of the GBA is to monitor and link gut functions with the emotional and information processing areas of the brain. Communication between the gut and the brain is made possible by hormones and messengers from the immune system and the brain. In fact, the gut is now seen as an independent nervous system in its own right and has been described as the 'second brain,'</p> <p>Recently, a study reported that the risk of dementia, a mental health condition, is increased in individuals who take a particular family of drug known as proton pump inhibitors (PPIs) used to manage excess acid in the gut. These drugs are taken by many people and are vital in the management of their gastrointestinal issues and these findings were of great concern for many. However, the study had limitations which mean that further study is needed using more appropriate methods to investigate any relationship between PPIs and dementia</p> |
| Opioid overdose death in Wales from 2012 to 2015: A linked data autopsy study | 31/01/2018 | <p>We seek to use routine linked data to improve our understanding of fatal opioid overdose in Wales. We will use this data to understand the demographic characteristics of victims of fatal opioid overdose such as index of deprivation at area of residence, decedent age, gender, employment status and educational attainment. We will look at what opioid drugs are involved in fatal overdose, what proportion of deaths are deemed intentional, accidental or unknown. We will also look at what kind of health conditions overdose victims are diagnosed with and receive health service contact for in the years before death, and what NHS services they make use of.</p> |
| Mortality and sudden unexpected death in epilepsy | 30/01/2018 | <p>The aim of this project is to see whether we can identify when people have died of epilepsy related causes, including sudden death in epilepsy (SUDEP), by looking at routinely collected health data. For example, if we know that a patient's death was linked with SUDEP, is this recorded as cause of death in GP records? If not, is there another cause of death commonly reported instead? This is important because it tells us whether we can accurately do research into SUDEP using this type of data. If we want to research, for example, risk factors linked with SUDEP, which is much more difficult if you cannot reliably identify cases.</p> <p>The project would also aim to learn more about things which may be linked with SUDEP and epilepsy related mortality in Welsh patients. Understanding the factors linked with SUDEP is important because this supports further research into possible prevention strategies to reduce risk and helps people with epilepsy better understand the risk of SUDEP as part of their own lives. Looking at this issue in the Welsh</p> |
| International comparison in neighbourhood walkability and hospital burden in type 2 diabetes patients | 18/01/2018 | <p>Placing the worldwide increase in type 2 diabetes (T2D) within the international context of our urban and physical surroundings is crucial. How walking-friendly our neighbourhoods are (otherwise known as “neighbourhood walkability”) could affect our body weight over time by promoting physical activity. While some comparative work among different countries has provided evidence for a universally positive impact of the built environment on physical activity, little work has been done to compare the impacts of walkability on health and in turn, hospitalization, among different people, places and health care systems. Considering more and more of the world’s population live in cities, data linkage presents the opportunity to study the impacts of the built environment on populations.</p> <p>Having developed linked data strategies to assess the relationship between neighbourhood walkability and subsequent hospital burden, we</p> |

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| Care and Repair - Safe in my own home. Investigating the impact of community home modification services on hospital utilisation for fall | 03/01/2018 | <p>As people become older, they may find it harder to live independently in their own home. Reduced mobility, perhaps associated with a fall, can make moving around the home more difficult and potentially risky. Changes may be made so homes are more suitable for the person to remain there and stay healthy, by agencies such as Care & Repair (C&R) Cymru. This project aims to explore what impact the changes made to homes have on the health of older people in terms of emergency admissions to hospital. We will also see if they are able to return home to live independently in the community, or if the care and repair service delays when they need to move to residential or nursing home care.</p> <p>We hope to discover who benefits most from the home modification service; do those in the frailest group benefit most with a reduction in falls? Do those living alone show the greatest reduction in emergency admissions? Do advice visits and modifications allow them to stay</p> |
| Linking epilepsy next-generation sequencing datasets with routinely-collected healthcare records | 04/12/2017 | <p>Whole Exome Sequencing (WES) is a method of looking at an individual's genetic DNA 'code' found within their cells. WES targets the most important part of an individual's genetic code (approximately 1–2% of the total) comprising of genetic 'instructions' that code for proteins. It is possible to use WES to obtain a list of genetic variants for an individual across all known 25,000 genes. This gene-variant list typically contains around 30,000 – 40,000 genetic variants for each person. The vast majority of these variants will be harmless population-wide changes, but some may cause a genetic predisposition to certain diseases or conditions.</p> <p>Epilepsy is a common, chronic condition affecting approximately 1% of the UK population (approximately 30,000 people in Wales). It is well established that most epilepsies have a genetic basis, but apart from a small minority of cases, this link is not fully understood. It is likely that</p> |
| Idiopathic intracranial hypertension (IIH) in Wales. | 04/12/2017 | <p>Idiopathic Intracranial Hypertension (IIH) is a neurological condition which causes an increase in the pressure inside the head. Symptoms include headache, ringing in the ears, visual changes and sometimes visual loss and blindness. It is not known exactly what causes IIH but it is thought that there might be a problem with spinal fluid flow. There is a strong link with obesity and IIH, almost all people with IIH are overweight. It is thought (although not known) that the number of people with IIH is increasing in line with the rising rates of obesity. IIH can be a very disabling condition for some people causing days off work due to severe headache. Some people with IIH also need regular lumbar punctures and may need brain surgery in severe cases.</p> <p>This project aims to find out more about the number of people with IIH in Wales and whether this is changing with time. We also wish to study the risk factors associated with developing IIH, healthcare use and outcomes of people with IIH. This is of particular importance in Wales</p> |
| Characterising patients in Wales diagnosed with atrial fibrillation (AF), and managed with warfarin, by their level of warfarin control | 21/11/2017 | <p>Atrial fibrillation (AF) is the most common abnormal heart rhythm in clinical practice, and hospitalisations because of AF are increasing. Patients with AF have a 5- to 7-fold greater risk of stroke than the general population. Medicines called oral anticoagulants can decrease the stroke rate by more than two-thirds; however, these medicines can also puts patients at increased risk of bleeding. Warfarin is currently the most prescribed oral anticoagulant used in patients with AF to reduce the risk of stroke, and it works by thinning (anti-coagulating) a patient's blood. Using warfarin requires monitoring of anticoagulation effect by the International Normalized Ratio (INR) test. An INR level of 2 means that blood take twice as long to clot, a level of 3 means that blood takes three times as long to clot, compared to blood in patients not treated with anticoagulant medication</p> |

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| The Airwave Health Monitoring Study | 09/11/2017 | <p>The Airwave Health Monitoring Study was established to evaluate possible health risks associated with the use of TETRA (terrestrial trunked radio; formerly known as Trans-European Trunked RAdio), a digital communication system used by the police forces and other emergency services in Great Britain since 2001. This project is a long-term observational study following up the health of consenting police force employees (officers and staff) with respect to TETRA exposure, specifically looking into both cancer and non-cancer related health outcomes. Participants have consented to the use of their data to support medical research into the causes of many diseases.</p> |
| Using Big data Research to tackle antibiotic resistance (BRIT) | 06/11/2017 | <p>Antibiotics are used to kill bacteria when we get an infection or to protect us when our immune systems are vulnerable. At the moment we are facing a crisis in public health. The bacteria are becoming more resistant to the antibiotics and as a result they are becoming less effective, in the future there's a chance they might stop working completely. One of the reasons for this is over-prescription. Antibiotics are being given out too often and the bacteria are becoming immune to them. This project, delivered by the Greater Manchester Connected Health Cities (CHC), is developing a tech savvy solution to help understand and tackle the problem. By making better use of health data and presenting this in a more powerful way the researchers working on this project believe they can start to reduce the UK's reliance on antibiotics.</p> |
| Cost of not treating Multiple Sclerosis with a Disease Modifying Therapy | 31/10/2017 | <p>At the moment there is some information available that tells us about the health care costs related to people living with Multiple Sclerosis (MS) who are able to receive treatment with Disease Modifying Therapies (DMTs), which are not a cure for MS, but they can reduce how many relapses someone has and how serious they are. They can also slow down the damage caused by relapsing MS that builds up over time. This project investigates the societal and personal costs of treating MS with DMTs or not, such as the financial impact of having to reduce or give up work. In order to do this we wish to access and review information provided by people with MS that has already been collected via the MS Register, and their available records in the SAIL Databank; we believe that this information can be used to help us understand what the societal and personal costs are as well as health care costs. Having information about the cost of MS at a personal and societal level will improve awareness and understanding of MS, as well as the financial impact it has on people with MS, the family members who provide their</p> |
| Building a virtual dementia e-cohort using routinely-collected health dataset | 06/10/2017 | <p>We aim to use a combination of GP, hospital records and death data to build a 'virtual' cohort that will help facilitate dementia research.</p> <p>Around 670,000 people in the UK are currently living with dementia, and this number is expected to double over the next twenty years. There is an urgent need to better understand the causes of dementia so we might learn how to prevent its onset.</p> <p>Currently, many epidemiological cohort studies involve a group of people who consent to be recruited. They are then followed up and tested over many years. These cohorts have been crucial for gaining insights into dementia, however they suffer from 'selection bias', in that the people that sign up for such studies are not necessarily representative of everyone in a population.</p> |

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| Analysing the relationships between health and homelessness services in a Welsh local authority | 04/10/2017 | <p>This project proposes to explore homeless people’s use of healthcare services (GPs and Emergency Services) and their health conditions. Given that homelessness services in Wales are going through significant change as a result of the Housing (Wales) Act 2014, this study will provide timely insight into the health of homeless people. The evidence base relating to the health of homeless people has been limited by a reliance on small surveys, and dependent on homeless people’s recollection of their use of healthcare services. By contrast, this project will use linked administrative data to provide a far more robust picture of homeless people's health in Wales. This study will form the basis for a larger data linkage project as part of an ADRC-Wales funded PhD, involving negotiating access to local authority homelessness administrative data across Wales. Though this study is exploratory in nature and focuses on a single Welsh authority, its findings and future work leading from it have the potential to improve the lives of the most vulnerable people in Wales.</p> |
| Anti-epileptic drug prescribing for children in Wales, a data validation project | 03/10/2017 | <p>Epilepsy is a common disease affecting around 1% of the general population. The majority of patients with epilepsy will have to take lifelong medication. It is very important therefore for doctors to prescribe the most appropriate medication for the patient. Swansea University Neuroscience Group have been previously studied anti-epileptic drug (AED) prescribing trends in Wales (Seizure 2014;23:77–80) and have updated this information in a recent project (SAIL project 0387) to look at the numbers of different AEDs prescribed to children in Wales with and without epilepsy. UCB pharmaceuticals have commissioned us to produce a report on this data – the prescription of anti-epileptic drugs (AEDs) in children with epilepsy in Wales. UCB would like to use this report as part of a proposal to the All Wales Medicines Strategy Group (AWMSG) for a health economic evaluation for one of their anti-epileptic drugs possibly soon to be given European Marketing Approval.</p> |
| Investigation of the incidence of dementia with hearing aid use in the adult population: novel data analysis using audiology and | 01/10/2017 | <p>Hearing loss is known to lead to social difficulties, and potentially social withdrawal, depression and reduction in health-related quality of life, with hearing aids having a positive effect on these. There is also clear evidence of a link between hearing loss and dementia; however, the effect of hearing aid use on the risk of dementia is less established. Evidence so far is not clear, with published studies ranging in quality and population samples considered. In addition, populations studied have been primarily those able to participate in large scale questionnaire studies, relying on self-report of hearing levels and hearing aid use, and suggestion that these may not relate directly to the general UK population in terms of cognitive ability.</p> <p>The research question considered is: For the population in Wales, do people who have hearing aids and are known to use them have a lower</p> |
| Wellbeing Chronic Conditions and Limiting Illness based on Survey and Administrative data | 27/09/2017 | <p>The aims of the project are to:</p> <ul style="list-style-type: none"> • Develop an understanding of the relationship between how health conditions are reported via sample surveys and administrative data. • Explore the value of surveys as an information source in understanding chronic conditions. • Establish the nature of the relationship between chronic conditions and self-reported subjective well-being. • Explore an under-researched subject area by utilising the opportunities for detailed analyses offered by the SAIL Databank. <p>The project is expected to:</p> <ul style="list-style-type: none"> • Provide a contribution to the understanding of subjective well-being as reported by respondents to sample surveys |

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| International Meta-Analysis of Vasovasostomy and Prostate Cancer in Vasectomised Men | 21/09/2017 | <p>There are plausible biological mechanisms for the theory that vasectomy might cause prostate cancer (see attached paper for more details). The Western Australia Record Linkage Project has investigated this relationship with their data and the results were inconclusive due to the small number of vasectomy reversals and the relative lack of observed person-time at risk in older men where prostate cancer risk becomes more frequent. As a member of the IHDLN (International Health Data Linkage Network), HIRU would like to explore this relationship with the SAIL data and pool the anonymised data to perform a large international meta-analysis of vasectomy reversals and prostate cancer in vasectomised men.</p> |
| Making visible the mental health needs of children and young people from Gypsy and Traveller communities using advanced data linkage | 08/09/2017 | <p>The aim of this project is to make visible the the mental health needs of children and young people (CYP) from Gypsy/Traveller communities in Wales. In the NHS the ethnic categories from the 2011 census (which included Gypsy/Travellers for the first time) are not used. This means that the health needs of Gypsy/Travellers cannot be matched to the health information which the NHS collects about patients, and this conceals their health needs. Gypsy/Travellers are known to have poor mental health, but little is known about mental health issues in childhood and adolescence.</p> <p>We have developed a new technique which will allow us to match people living Gypsy/Traveller sites in Wales with their health records. This technique has already been developed at Swansea University and we know that we can identify the health records of people living on</p> |
| Inclusion and the academisation of English secondary schools: trends in the placement of pupils with significant SEN and those permanently | 07/09/2017 | |
| NERS linkage to SAIL | 22/08/2017 | <p>Physical activity is related to lowered risk of heart disease and diabetes, and improved well-being. However, most adults in Wales do not meet public health recommendations for physical activity. Increasing physical activity is a Welsh public health priority, particularly for groups of adults who are most at risk of developing chronic diseases or suffering from poor mental health. In 2007, a National Exercise Referral Scheme (NERS) was introduced in Wales to increase physical activity among patients attending GP surgeries who are most at risk of health problems that might be prevented by physical activity.</p> <p>An earlier evaluation of the scheme showed positive findings for individual's taking part, with some individual's improving physical activity levels and others improving mental wellbeing. On the basis of these promising findings, NERS was rolled-out across all local authorities in</p> |

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| Utilisation of variation in hospital stays to measure the effectiveness of the management of conditions in primary care | 21/08/2017 | Cwm Taf Local Health board have worked with the Public Health Observatory and NHS Wales Information Service beginning to find which factors affect the variation in costs of patients undergoing similar procedures. Previous work has already shown that it is possible to measure differences between organisations in the ‘additional’ cost of treating patients who have diabetes when compared to patients without diabetes. The cost of treatment and the length the patient stays in hospital are also affected by the age of the patients, the number of other illnesses they have but also whether they are treated on specialist wards. This shows that the hospital data which is routinely collected by the organisation contains differences in performance depending on the patient pathway. |
| Use of blood eosinophil count to predict inhaled steroid responsiveness in patients with COPD using primary care health records | 20/08/2017 | A previous project (0449) using the SAIL Databank data succeeded in showing that the stay in hospital for diabetic patients was linked to the Chronic obstructive pulmonary disease (COPD) is a long-term respiratory condition which affects over one million people in the UK, usually as a result of smoking and causes cough and breathlessness which generally worsen with time. Steroid inhalers are commonly prescribed, but there is uncertainty over how beneficial they are to all patients living with COPD, and steroid inhalers are expensive and have been associated with a range of adverse effects including an increased risk of pneumonia. Some patients with COPD have higher levels of a type of cell called eosinophils in their blood and lungs suggesting greater inflammation in their lungs and thus greater chance of benefit from steroid inhalers. However, this hasn’t been investigated yet in general practice using results of blood levels of eosinophils that have been routinely tested for other reasons. |
| Social Deprivation and Oesophageal Cancer | 15/08/2017 | Oesophageal cancer has one of the worst outcomes of any cancer diagnosed. Wales, specifically has higher rates of this cancer compared to many other parts of the UK. Risk factors for the development of oesophageal cancer and a precursor condition that can often lead to it include “non-modifiable elements” (i.e. risk factors that cannot be treated or altered) such as increased age and male gender and “modifiable elements” (i.e. factors which can be treated or altered) such as obesity, poor diet, and smoking. These latter factors are commonly associated with social deprivation (lower socio-economic status). This link between social deprivation and oesophageal cancer has never specifically been investigated. By using a database with national coverage such as SAIL, this association can be investigated and if proven to be true, can influence healthcare providers to allocate resources appropriately. |
| The burden of facial scarring in Wales: A topographical and aetiological analysis of a decade of anonymised patient records | 14/08/2017 | Scars are extremely common, with most people having some scars on their skin from a previous injury. Scarring can vary in severity, size and locations, with these variables affecting psychological and functional wellbeing. The psychological impact has the potential to impact on social interactions, limitation of educational potential and employability and lead to a higher incidence of depression. The scars that are most likely to have a psychological impact are those that affect the face. However, the number of people affected by facial scarring is largely unknown. Furthermore, the causes of facial scarring are also largely unknown. It may be that the majority of disfiguring facial scars are related to injuries such as burns, but that the highest number of facial scars are actually caused as a result of surgical procedures. It is therefore the aim of this work to use the power of routinely collected anonymised patient data to provide a comprehensive |

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| Active Children Through Incentive Vouchers - Evaluation (The ACTIVE Project) | 01/08/2017 | ACTIVE is a mixed method randomised control trial (a study in which people are allocated at random) based in 7 secondary schools in Swansea, South Wales aiming to improve the cardiovascular fitness of teenagers by increasing physical activity levels. The ACTIVE intervention consists of the provision of activity vouchers to 4 intervention schools. The project will distribute vouchers in schools with the purpose of being used by pupils to: i) spend on existing activities, ii) fund new activities in the schools or communities, iii) purchase sporting equipment for themselves or a club. |
| Supporting People | 31/07/2017 | <p>The Supporting People (SP) programme provides support to vulnerable individuals who are at risk of losing, or who have lost their homes, or who need housing-related support to retain or regain their independence. SP aims to prevent problems in the first place, or provide support and assistance as early as possible in order to reduce the demand on other services such as health and social services.</p> <p>The previous Welsh Government Supporting People Data Linkage Feasibility study (published in March 2016) demonstrated that it is feasible to evaluate the SP project through linking routine administrative data. The proposed project will build on the conclusions and recommendations from the feasibility project in order to answer the following general, overarching questions:</p> <ol style="list-style-type: none"> 1. Does the Supporting People Programme help people? If so, how and who does it help? 2. How does the Supporting People Programme impact on other public services and help to reduce inequalities? |
| Treatment in Morning vs Evening (TIME) | 28/07/2017 | <p>The Treatment in Morning and Evening (TIME) Study is a British Heart Foundation funded study, endorsed by the British and Irish Hypertension Society. It is being undertaken to determine if morning or evening dosing of commonly used blood pressure lowering medications is more effective in the prevention of heart attacks and strokes.</p> <p>Poor night-time blood pressure control is an important risk factor for heart attacks and strokes. The reason that this study is required is that recent research has suggested that blood pressure lowering medications taken in the evening have a greater effect on night-time blood pressure than when the same medications are taken in the morning. A small study conducted in Spain found that people who took at least one of their usual blood pressure lowering medications at bedtime suffered significantly fewer heart attacks or strokes compared with those taking all their blood pressure lowering medication in the morning. Since the publication of that study there have been several calls by doctors</p> |
| (TIER) - Transient Ischaemic Attack 999 Emergency Referral: A feasibility trial for a randomised controlled trial | 01/07/2017 | <p>This is a study of a pathway of further care which is an alternative option to the Emergency Department (ED) for patients who present to the emergency ambulance service with a mini stroke, otherwise known as a Transient Ischaemic Attack (TIA). A TIA occurs when there is a temporary interruption in the flow of blood to the brain. Symptoms may be similar to that of a stroke. To be classed as a TIA, the symptoms must last less than 24 hours. Patients who have a TIA are at risk of having a stroke. How high this risk is depends on the 'severity' of the TIA, which can be assessed with a simple scoring tool which considers symptoms, duration of symptoms and risk factors. Those at high-risk should be assessed by a specialist within 24 hours. Guidelines state that, however, patients with low-risk TIA do not require immediate assessment, and can be assessed by a specialist within one week of the TIA.</p> <p>Currently, if a patient calls 999 because they have symptoms of a TIA, paramedics are likely to take them to the ED to be assessed by a doctor</p> |

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| Episodes of infection as predictors of cardiovascular risk in dialysis patients | 20/06/2017 | Dialysis is a treatment used when patients have kidney failure. Patients on dialysis have reduced life expectancy, compared to the general population and the main causes of death are heart disease and infections. Both heart disease and infections also occur more frequently in patients undergoing dialysis compared to healthy individuals. Therefore, it has been speculated that these two entities may be related, with infections increasing the risk of events such as heart attacks or stroke. Evidence from studies in the general population shows that a heart attack or stroke is more possible to occur during the first few days after an infection, than in any other time. Similarly, older patients undergoing dialysis who are admitted to hospital for a serious infection or blood poisoning (septicaemia), have a higher possibility of suffering a heart attack or stroke in the following months. |
| Longitudinal analysis of critical care outcomes in Wales | 19/06/2017 | Critical care provides specialist treatment for patients with life-threatening illnesses and injuries. Outcomes data are fundamental to identify where resources need to be focused to provide safer care. Limited data exists on outcomes for critical care patients in Wales. The purpose of this collaborative research initiative between the Farr Institute, the Critical Care Implementation Group, Aneurin Bevan University Health Board, Abertawe Bro Morgannwg University Health Board, Betsi Cadwaladr University Health Board and Public Health Wales is to conduct research utilising the SAIL Databank to identify factors that increase the risk of adverse outcomes, thus providing the opportunity to change models of care to improve outcomes for patients. The project will involve linking three new project specific datasets relating to critical services, with the critical care minimum dataset, along with the existing primary and secondary care data, mortality data, the Welsh Demographic Service data, and other data held within the SAIL Databank to complete the patient pathway. From the linked data, we will |
| Educational attainment of children born to mothers with multiple sclerosis | 15/06/2017 | It is possible that children born to mothers with a long-term illness may have poorer educational attainment when compared to children born to mothers without such a chronic disease. In this project we aim to test this hypothesis by looking at the educational attainment of children born to mothers with multiple sclerosis (MS). We will do this by anonymously linking a list of women with definite multiple sclerosis obtained from hospital records with anonymous records held within SAIL. We will then match the children born to these mothers with their key stage test results and compare with a matched control group of children born to mothers without MS. |
| Healthcare utilisation and educational outcomes among children exposed to adverse childhood experiences, children who receive | 12/06/2017 | The aim of this study is to examine and compare healthcare utilisation and educational outcomes among Children in Need/in Receipt of Care and Support (CIN/CRCS), LACYP, children exposed to Adverse Childhood Experiences (ACEs) but not receiving care, and the general population. This will enable us to explore whether there are differences in outcomes between these groups, and whether care is indeed protective. Providing the data are of sufficient quantity and quality, sub-group analysis of children in care will be performed to examine the role of placement stability, length of time in care and deprivation in outcomes. Given the lack of robust quantitative data in social care, this project will test the feasibility of using linked and anonymised administrative sources. Specifically, we propose linkage of routinely collected health data in Wales, pupil educational performance data, and data relating to LACYP. The study will identify common risk and protective factors for LACYP, with the aim of informing intervention strategies and improving the life experiences of some of the most vulnerable |

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| Lung cancer initiative campaign | 08/06/2017 | <p>A lung cancer initiative was set up in Wales because lung cancer has such a poor outcome in Wales compared to other countries in Europe. Hence the Welsh Government has declared that lung cancer should be explored in further detail. Following this, the Welsh Cancer Intelligence and Surveillance Unit (WCISU) is tasked with producing various outputs about lung cancer in Wales to determine reasons why Wales has such low survival.</p> <p>This project is following up the recent lung cancer awareness campaign which was run in July and August 2016 in Wales. The campaign was run using TV adverts and posters which encouraged the public to visit their GP if they have had cough symptoms for more than 3 weeks.</p> |
| The Effect of Mode of Delivery at Birth on the Child's Health | 24/04/2017 | <p>Some studies have found that babies born by caesarean sections have worse outcomes in childhood compared to those born vaginally. These include obesity, diabetes, asthma and allergies, as well as infectious diseases. A possible biological mechanism that might explain this effect, is through change in the microbiome flora. The microbiome is the community of bacteria, viruses and fungi that naturally inhabit the human body and are important to health. The microbiome composition has been shown to be altered in infants born by caesarean section, as these babies had not benefited from the natural seeding of the maternal flora when passing through the birth canal.</p> <p>Our study will investigate the association between mode of delivery at birth (vaginal delivery, instrumental vaginal delivery, planned caesarean and emergency caesarean) and child's health. First, hospital admissions due to respiratory infections (e.g. pneumonia and bronchiolitis) and gastrointestinal infections (e.g. diarrhoea) will be examined. Second, we plan to investigate the association between mode</p> |
| Stroke Prevention through targeted interventions for unknown Atrial fibrillation (AF) population and the unmet need for anticoagulation | 21/04/2017 | <p>Stroke is a sudden and devastating illness - however, many people are unaware of its widespread impact. Stroke is the fourth single leading cause of death in the UK. Stroke is a leading cause of disability in the UK – almost two thirds of stroke survivors leave hospital with a disability. Atrial fibrillation (AF) is a heart condition that causes an irregular and often abnormally fast heart rate. There are about 1.2 million people with AF in the UK. Stroke risk increases five-fold for people with AF. AF is a contributing factor in up to 1 in 5 strokes in the UK. AF often goes undiagnosed. It is estimated there could be another half a million people in the UK with undiagnosed AF. Anticoagulant drugs, such as warfarin, can be given to people with AF to reduce the risk of blood clots forming. But, anticoagulants continue to be under-prescribed. In the UK, around a quarter (24%) of eligible patients with AF do not receive anticoagulation. It is estimated that if AF were adequately treated, around 7,000 strokes would be prevented and over 2,000 lives saved every year in England alone. Less than half (45%) of UK patients with</p> |
| An investigation into the role of socioeconomic deprivation on pancreatic cancer survival | 21/04/2017 | <p>Pancreatic cancer is rare, accounting for only 3% of cancer diagnoses per year. The disease does, however, have a huge impact on society because, despite the sparse incidence, it is the 5th and 4th most common cause of cancer death in the males and females respectively¹. Despite great advances in both surgical care and chemotherapy options, the 5 year survival of patients with pancreatic cancer has only improved from 2.4% in 1971-72 to 3.3% in 2010-11¹.</p> <p>Socioeconomic deprivation has been shown to impact on health throughout the World². The exact reasons are multiple and vary but their effect has been measured in other cancers such as lung³, gastric⁴ and breast cancer⁵. The effect in patients with pancreatic cancer in the UK is less well reported. Public Health England estimate that if everyone with pancreatic cancer in England, between 2006 and 2010, had had the same level of SED as the least deprived members of society, then 594 deaths would have been avoided⁶.</p> |

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| Data-driven methods for predicting the risk of type 2 diabetes | 21/04/2017 | The prevalence and burden of disease associated with type 2 diabetes has rapidly increased worldwide. Doctors often utilize prediction scores which use a range of clinically measurable biomarkers (e.g. body mass index, blood pressure) to assist in clinical management of patients and predict how likely they are to develop diabetes. Although several prediction scores exist, none is widely accepted or established and most make use of single values from a limited set of hand-picked measurements despite the fact that many exist. The increasing use of electronic health records in general practice means that large amounts of potentially relevant information about a patient's medical history are available for analysis and could be of potential benefit in guiding diabetes care. For example, patient records cover a huge range of test results, symptoms, prescriptions, lifestyle factors and more which could improve the accuracy of diabetes prognostic models. This project will develop and test new statistical learning methods of using this information in disease prediction in order to take advantage of the richness of the |
| Antibiotic prescribing and deprivation | 10/04/2017 | A study undertaken in Scotland confirmed that increasing levels of deprivation are significantly correlated with prescribed antibiotic volume in Scotland and that the relationship is maintained irrespective of the patient's age or sex or the antibiotic. That study used data for 2010–12. This study aims to look at data for Wales for a later period to see whether similar relationships are present. SAIL's GP data contains Read codes and these include codes for medicines prescribed. Using those we will be able to count how many antibiotic were prescribed. By linking the patient's GP records with data from the Welsh Demographic Service we will be able to identify the patient's sex and age at the time the drug was prescribed, and in which Lower Super Output Area (LSOA) the patient was living. From that, we will be able to categorise the area in which the patient lived by degree of deprivation (as measured by the Welsh Index of Multiple Deprivation) |
| School Travel and Child Safety Survey Project | 06/04/2017 | The School Travel and Child Safety Survey (STCSS) is an online survey designed to improve our understanding of children's travel and safety related behaviours and exposures to hazards. It has been designed to be undertaken in schools by children aged between 11 and 13 years of age. The survey is currently being rolled out to all schools in Neath Port Talbot by Neath Port Talbot Council (during the 2016/17 school year). Via SAIL's split file approach, the survey results held at the local authority will be anonymised and incorporated into the SAIL databank and linked to other health and educational data in SAIL anonymously. Once in SAIL, it will be possible to explore associations between travel and safety related exposures and health/educational outcomes (e.g. the association between active travel and educational attainment). |
| An analysis of skin cancer and its management in Wales using anonymised data-linkage | 05/04/2017 | Skin cancer is a very common problem. Approximately 1 in 3 cancers diagnosed worldwide is a skin cancer and 1 in 5 Americans will develop a skin cancer in their lifetime. Skin cancer is a wide group of cancers, which consist broadly of: basal cell carcinoma (BCC), squamous cell carcinoma (SCC) and melanoma. Basal cell and squamous cell carcinomas are often grouped together into the non-melanoma skin cancers (NMSC) and greatly outweigh the number of melanomas diagnosed. In the UK there were 72,000 new NMSC diagnoses made in 2013, with 80% of these lesions located on the head and neck. Worryingly there has been an unstoppable trend for increasing incidence of skin cancer worldwide with a reported 3-8% annual rise in the number of NMSCs since the 1960s. It is predicted that the number of skin cancer diagnoses is going to continue to increase year-on-year, with a doubling in number in the next 30 years, along with a fall in the average age of first diagnosis |

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| Mind the Gap! An examination of the interface between primary and secondary healthcare for eating disorders | 03/04/2017 | <p>Eating disorders have the highest mortality of all mental disorders, and greatly affect health. Eating disorders tend to strike adolescents and young adults and derail their lives, leading to both lost potential and high healthcare costs. Evidence suggests prompt diagnosis and early intervention can help people recover; it also halves healthcare costs. However, many general practitioners (GPs) feel unequipped to identify and manage eating disorders. GPs also have to provide ongoing care and medical monitoring for these patients and refer them to secondary care. There are delays before patients seek help, are diagnosed, and obtain the treatment they need after referral to secondary care.</p> <p>The interface between primary (general practice) and secondary (specialist mental health) care for eating disorders is a critical one in the treatment of eating disorders. Prudent Healthcare is a Welsh initiative. It aims to provide timely and appropriate healthcare that both meets and addresses the needs of patients in partnership with them. It should also be cost effective and evidence based. At the primary and</p> |
| Evaluation of the impact of the national Safe At Home scheme on injury rates in children under 5 using secondary care data | 02/04/2017 | <p>Childhood injury is largely preventable but is still too common, resulting in over 60 deaths, 40,000 hospital admissions and nearly half a million emergency department attendances per year. Most of these injuries occur at home and are more common in poorer households. Providing families with advice and safety equipment improves safety behaviours, but it is not known if this results in fewer injuries or whether it is good value for money.</p> <p>Between 2009 and 2011, the Department for Education funded an £18 million scheme in England to provide safety education and equipment to the poorest families with children under 5. The scheme (Safe At Home) was overseen by the Royal Society for the Prevention of Accidents (RoSPA) and led by local authorities. Health visitors played a key role, referring families to the scheme and doing home safety assessments. Over 66,000 families took part.</p> |
| Joint Hypermobility Syndrome | 06/03/2017 | <p>Joint Hypermobility Syndrome (JHS), a.k.a. Hypermobility Ehlers-Danlos Syndrome (EDS-HT), is the most common heritable disorder of connective tissues. JHS is historically considered as a rare condition with prevalence commonly cited as 1:5000 or even 1:10000.</p> <p>However, it is now known that the condition is very poorly diagnosed and its prevalence is in fact unknown. Grahame (2008) has estimated that JHS accounts for up to 45% of routine general rheumatology referrals, but only 1 in 20 patients are fortunate enough to be correctly diagnosed by a rheumatologist in England. Its under-diagnosis, overlap with other heritable tissue disorders and multisystemic nature make it a challenging topic to study, with studies typically based on small numbers of patients or limited by the specialties involved in the study.</p> |
| Use of Administrative Data in Capturing Direct Measures of Social Capital | 06/03/2017 | <p>Social capital is a conceptual approach concerned with understanding how social networks can lead to shared norms of reciprocity that can be harnessed to solve collective action problems. Past studies have shown higher levels of social capital are generally associated with more positive societal outcomes, such as lower levels of crime, better health, and increased economic growth². The purpose of this project is to investigate the use of existing sources of administrative data in capturing small-area measures of social capital as part of a wider study concerned with using spatial analytical approaches to measure accessibility to library and other public services and investigating potential associations with levels of social capital within Welsh communities.</p> |

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| Individual deprivation in Wales: Exploring the feasibility of constructing a measure using linked data | 09/02/2017 | <p>At present Welsh Government use an area-based deprivation measure, called the Welsh Index of Multiple Deprivation (WIMD). What is not known is the extent to which WIMD reflects the conditions of people living within each area. For example, the fact that an area suffers from multiple deprivation as measured through the WIMD does not necessarily mean that all individuals living in the area will suffer multiple types of deprivation or any deprivation at all. This project will therefore explore the construction of an individual measure of deprivation for Wales using linked data. Moving the analysis of deprivation forward to explore the deprivation of individuals will make it much easier to determine the nature and distribution of deprivation. Findings will allow Welsh Government (WG) to devise more holistic and potentially effective policy responses to poverty and deprivation that target individuals rather than areas.</p> <p>The use of linked administrative data is necessary as this project forms a feasibility study for a population level individual deprivation measure</p> |
| ABMU Dashboard | 01/02/2017 | <p>Part1: To enable the engagement of our GP community via the demonstration of analytics that make use of SAIL population level data. Part2: To use the We-Predict dashboard as per section 4 showing outputs at resident and registered populations for service planning, business cases and showing population health insights for our ABMU population. This will include refreshes of the existing product to show more up to date outputs but not new analysis at this time. For full documentation of the dashboard outputs please see the technical documentation provided with this application.” Please provide a copy of the technical documentation</p> |
| Building Evidences on Polypharmacy | 31/01/2017 | <p>Polypharmacy is the usage of multiple, varied medications in the treatment of singular or multiple diseases. Polypharmacy is becoming increasingly common within Britain especially those aged 65 and over. Between 2001 to 2011, the average number of items prescribed per person per year has increased by 53.8% in England. Among the elderly, 1 in 6 of those aged 65 and over in Scotland take multiple drugs. Indeed, the use of multiple medications is necessary to treat some diseases. However, it has raised ever increasing concerns about the adverse side effects apparent in polypharmacy, especially within the elderly. The need to understand, identify and predict drug interactions is required to ensure safe practice for the continually growing population affected. An especially challenging issue is the wide variety of drugs available. But there is a great difficulty in predicting the interactions between different drug combinations unless specifically researched. In</p> |
| Support for PRIME | 17/01/2017 | <p>This project will provide a way for SAIL PRIME analysts to check if important NHS primary and emergency care service based questions can be answered using data within the SAIL databank. Questions from across different professionals working to improve the health of the public are considered and prioritised by the SAIL PRIME group. Questions are assessed using the following criteria:</p> <ul style="list-style-type: none"> •The research fits with PRIME strategic plan •The research has a unique requirement for using SAIL data •The research is likely to have a public health impact •The research is realistic and achievable |

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| Me-D-Links: Metformin for diabetes in pregnancy – an analysis of health and educational outcomes using linked | 13/01/2017 | <p>Gestational diabetes (GDM), diabetes which develops during pregnancy, and type 2 diabetes are increasingly common during pregnancy, affecting up to 18% pregnancies. This is important as diabetes during pregnancy increases the risk both the mother and the baby.</p> <p>Traditionally insulin has been considered the ‘gold standard’ for the treatment of diabetes in pregnancy. However, the recently published National Institute Health and Care Excellence Diabetes in Pregnancy Guideline (2015) recommends metformin, an oral blood glucose lowering drug, for those with GDM. In those with type 2 diabetes the guideline states that metformin may be used when the likely benefits outweigh the potential for harm.</p> |
| HERO (Hypoglycaemic episode resource outcomes) | 06/01/2017 | <p>Type 1 diabetes is a metabolic disease where insulin producing cells of the pancreas are destroyed by the individual’s own immune system. The destruction of these cells leads to a complete lack of insulin and subsequently the individual’s body loses its ability to control blood glucose levels. The person’s blood glucose levels become too high in the absence of this control. Therefore, insulin therapy is administered in an effort to control blood glucose levels. Patients with type 1 diabetes can experience high blood glucose (hyperglycaemia) or low blood glucose (hypoglycaemia), both of which can be a life-threatening emergency. Hypoglycaemia can be mild and corrected through eating/drinking, while more severe episodes may lead to confusion, convulsions, coma or death. Mild cases can be treated by patients (or lay people), but more serious cases may require an ambulance call-out or hospital admission. Fear of a hypoglycaemic episode may make a patient decide not to adhere to insulin therapy, through fear of over-shooting their therapy, and therefore affect the patient’s blood glucose</p> |
| Understanding the determinants of educational achievement and the association with health and well-being by age 14 in Wales | 04/01/2017 | <p>Understanding the determinants of educational achievement has been a public policy priority and the focus of many research studies in recent years. The insights generated from such research are now common-place in UK education policy-making, most notably (a) the importance of direct intervention to try to mitigate the impact of socio-economic disadvantage (e.g. the Pupil Premium in England and the Pupil Deprivation Grant in Wales), and (b) the need to intervene early in a child’s education (e.g. Sure Start in England and Flying Start and the Foundation Phase in Wales).</p> <p>However, most studies have recognised lack of information relating to the background and educational experiences of children. For example, recent studies for England and Wales are dependent upon the indicator that a pupil is eligible for free school meals (FSM) as a measure of</p> |
| Air Pollution | 22/12/2016 | <p>-The aim of the proposed study is to understand whether a child’s exposure to certain air pollutants and pollen at home and at school in the summer exam period have an effect on asthma and hayfever, and also whether there is an effect on exam results. The air pollutants are NO₂, O₃, PM, which are Nitrogen dioxide, Ozone, and Particulate Matter (a term describing a mixture of solid particles and liquid droplets found in the air) respectively.</p> <p>-This is a feasibility study and will test whether the study could be carried out at a larger scale. The study will make use of data routinely collected from healthcare and education organisations, and we will bring this data together with environmental data (pollution and pollen levels). The data will be joined using a technique known as data linkage and will also ensure that the identity of people in the data remain</p> |

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| Exploring associations between job characteristics and objective and subjective measures of well-being | 22/12/2016 | This project will link administrative health data to survey data (collected in the Skill and Employment survey series) to explore the associations between self-reported job well-being, job characteristics (such as long hours) and health outcomes (such as depression, anxiety and stress). |
| Trends in Opioid Prescribing and Associated Resource Utilisation in Wales (TOPAS) | 21/12/2016 | <p>Opioids are drugs, derived directly from or related to the naturally occurring alkaloids found in the opium poppy (<i>papaver somniferum</i>). Traditionally, opioids have been used to treat pain following trauma and surgery and also in the management of pain due to cancer and at the end of life.</p> <p>In the last twenty to thirty years, there has been increasing use of opioids for the long-term treatment of chronic, non-cancer pain (CNCP), arising from conditions such as osteoarthritis, low back pain and fibromyalgia. This is despite the medical evidence being limited to short-term benefits and side effects of these drugs. Much less is known about the effectiveness and safety of opioids when given over longer treatment periods and in high doses for non-cancer pain.</p> <p>Scientific literature and national media in the United Kingdom have expressed concern about whether the known increase in opioid</p> |
| Optimising health care service pathways for the diagnosis and management of cancer in Wales | 21/12/2016 | <p>Cancer will affect 1 in 3 of the population. Despite considerable improvement in survival rates for many cancers, Wales and the rest of the UK lag behind many comparable countries in the stage at diagnosis, treatment options and outcomes for many cancers.</p> <p>The purpose of this collaborative action research initiative between the Farr Institute, South West Wales Cancer Centre (ABMU and Hywel Dda health boards), and the Welsh Cancer Intelligence and Surveillance Unit (Public Health Wales NHS Trust) is to conduct research using SAIL's privacy protecting system to identify areas where changes in services provided, including treatment regimes, could improve both patient outcomes and the efficiency of the NHS in providing the best care possible. The plan is to link data on detailed cancer treatment (chemotherapy, immunotherapy, hormonal therapy and radiotherapy) with data from the Wales Cancer Registry and the general GP and</p> |
| A regional wellbeing and health needs assessment to inform the ARCH case for change. | 21/12/2016 | <p>ARCH stands for A Regional Collaboration for Health. The ARCH consortium (ABM University Health Board, Hwyl Dda University Health Board and Swansea University) has been funded by Welsh Government to develop a case for change to providing services that just don't treat the ill but also improve the health and wellbeing of the people of South West Wales.</p> <p>The case for change will identify the best ways of measuring wellbeing and its important determinants and how these can be monitored at a population level to judge progress of the changes to services. In order to do this we propose to:</p> <p>1. Hold meetings with a wide variety of staff and members of the public on how wellbeing and its determinants should be defined. I am</p> |

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| Risks following use of anticoagulants after intercranial haemorrhage | 13/12/2016 | Some people suffer from conditions that put them at a higher risk of heart attacks or strokes caused by blood clots, often caused by an irregular heart beat called atrial fibrillation. This group tend to be treated with ‘blood thinners’, such as Warfarin, but this is associated with much bother to patients by having repeated blood tests to monitor how well it is working. There is also a risk of thinning the blood too much and leading to a bleed inside the body. This is particularly dangerous if it happens in the brain and can lead to a fatal stroke and other problems. A new type of blood thinning drug called a TSOAC has appeared on the market and appears promising from the point of how well it works and not needing repeated blood test for monitoring. However, it has a serious problem in that, unlike Warfarin, its blood thinning activity is not easy to reverse in a crisis, such as the person suffering from a major bleed. It is important to study the potential benefits and risks of drugs in large populations to better understand how well they suit or not certain groups. |
| Diabetes and educational outcomes | 18/11/2016 | Diabetes is one of the most common chronic childhood illnesses, affecting 1 in every 700 children. There are two types of diabetes which affect how insulin regulates blood glucose levels. In this application, we focus on Type-1 diabetes which is the most common form in childhood, arising from immune-mediated beta-cell (which produce insulin) destruction. A child with Type-1 diabetes must self-inject insulin to keep blood glucose within acceptable limits, the amount needed varying with what they have eaten and physical activity. Type 1 diabetes is estimated to account for £1 billion in direct costs and £0.9 billion in indirect costs for the UK each year. A better understanding of the processes that affect self-management during childhood will help reduce the need for costly interventions. |
| Evaluating the impact of Solva Care | 14/11/2016 | Solva Care is a community led project set up by Solva Community Council to improve local people’s health and quality of life. They do this by offering the services of trained, approved volunteers to go to “clients” homes to help them with day to day tasks which they are not able to do due to short or long term ill health, etc. Tasks may involve walking their dog, taking them to a GP appointment or simply visiting for a chat to keep them company. |
| Examining the link between family health events and pupil performance indicators in Wales | 21/10/2016 | School outcomes are known to play a significant part in determining not only the range of opportunities available to individuals in their own lives but also the future lives of their children. As a result there has been much interest, and research undertaken, to identify the key factors determining educational attainment. This proposal will add to this body of knowledge by looking at a relatively under researched area in terms of the UK evidence base: namely untangling the nature of the complex relationship that exists between major episodes of parental and pupil ill-health (including mental health issues), the timing of these events, and their effect on subsequent levels of pupil attainment. The analysis will focus initially on outcomes within Wales and use data from the Annual School Census and Pupil Attainment records, which can be linked to administrative Welsh Health Records currently held in Swansea under the Secure Anonymised Information System (SAIL). Whether such events have temporary or persistent effects has important implications for the design of appropriate policy interventions that seek to |

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| An Evaluation of Long Term Outcomes and Healthcare Utilisation Before and After Epilepsy Surgery In Wales | 10/10/2016 | <p>Epilepsy is a common condition affecting more than 50 million people worldwide. Around 1% of people in Wales have epilepsy (around 30 000 people). Surgery for epilepsy can be life-changing for patients with epilepsy that cannot be controlled by medication. Surgery can result in seizure freedom having a dramatic effect on quality of life for people with epilepsy (for example people can return to work, return to drive and have a substantial improvement in their mental health. Nevertheless, epilepsy surgery continues to be under used.</p> <p>Given the financial strain in the national health service and the need for “prudent healthcare”, establishing the safety and effectiveness of epilepsy surgery for treatment of drug-resistant epilepsy is extremely relevant. We aim to review healthcare use over a twenty-year period following epilepsy surgery and determine outcomes and cost-effectiveness in Wales. Access to the SAIL database would enable us to measure</p> |
| The Long-Term Follow-Up of Urinary Tract Infection (UTI) in Childhood (LUCI) | 09/10/2016 | <p>The aim of this project is to determine the short and longer-term outcomes of urine infections (UTI) in childhood and to determine whether there is a difference between UTI that is identified through routine practice and UTI identified through systematic urine sampling (where all ill children have their urine sampled).</p> |
| Participation in post compulsory education training in Wales | 03/10/2016 | <p>This research project aims to look at how pupils in Wales progress from secondary school, into sixth forms and further education colleges (post-16 education). Specifically, it seeks to identify different learning pathways into post compulsory education and to look at factors which affect vocational learning over academic qualifications.</p> <p>By linking primary, secondary and further education data together, it is possible to trace individuals through the education system to entry to post-compulsory education. Within Wales, such a database will allow us to investigate the relative impacts of the social characteristics of individuals, their previous educational attainment and their progression through the education system, in order to create a classification of types of learning pathways. In doing so, it is hoped that distinct pathways into and through post-compulsory education will result. Secondly, the impact of various characteristics on entry into vocational or 'academic' learning in post-compulsory education will be analysed for</p> |
| Prudent Healthcare Intelligence Unit Feasibility Project | 15/09/2016 | <p>This project will provide a way for Farr Swansea analysts to check if important NHS service based questions can be answered using data within the SAIL databank. Questions from across different professionals working to improve the health of the public are considered and prioritised by the Public Health Wales SAIL group. Questions are assessed using the following criteria:</p> <ul style="list-style-type: none"> •The research fits with Public Health Wales strategic plan •The research has a unique requirement for using SAIL data •The research is likely to have a public health impact •The research is realistic and achievable |

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| Public Health Wales Feasibility Project | 15/09/2016 | <p>This project will provide a way for Public Health Wales analysts to check if important public health questions can be answered using data within the SAIL databank. Questions from across different professionals working to improve the health of the public are considered and prioritised by the Public Health Wales SAIL group. Questions are assessed using the following criteria:</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> The research fits with Public Health Wales strategic plan <input checked="" type="checkbox"/> The research has a unique requirement for using SAIL data <input checked="" type="checkbox"/> The research is likely to have a public health impact <input checked="" type="checkbox"/> The research is realistic and achievable <p><small>SAIL IGRP Application Form, version 4.0, valid from 16/06/2014</small></p> |
| SWP - DV and CSE in the Swansea area | 12/09/2016 | <p>The National Crime Agency identified Domestic Violence (DV) and Child Sexual Exploitation (CSE) as one of the highest priority threats facing the UK in 2014. Due to the nature of DV and CSE, victims rarely identify themselves as victims and as a result, many cases go undetected by police, which can have a devastating impact on victims' lives. Due to current difficulties in identifying victims, we wish to conduct a pilot study to explore whether administrative data can aid our understanding of risk factors for DV and CSE. The results of this project will inform future work in this area and will explore any potential impact it could have on informing policy.</p> <p>Sadly, Domestic Violence (DV) and Child Sexual Exploitation (CSE) are far from rare occurrences. A survey carried out by the NSPCC, showed that nearly a quarter of young adults experienced some form of sexual abuse during childhood however, many of these cases will go</p> |
| Pregnancy outcomes in women with T1D | 11/09/2016 | <p>Pregnancy in women with type 1 diabetes is associated with an increased risk of complications for both mother and baby. In 1989 the St Vincent's declaration outlined a series of targets for improving the care of individuals with diabetes. One of the aims outlined, was that the outcome of diabetic pregnancies should be no worse than those of nondiabetic pregnancies by 1994. Previous studies have shown that this goal was not reached. Very little has been published in the last 15 years regarding the outcomes of pregnancies in mothers with type 1 diabetes. However, within this timeframe, much progress has been made in terms of advancing the care of individuals with diabetes. The care of expectant mothers has also advanced significantly in this time. With this in mind, we believe that it would be useful to re-examine the risks associated with pregnancy amongst mothers with type 1 diabetes.</p> |
| ADHD and Relative Age | 11/08/2016 | <p>This early pilot study aims to confirm findings from a Taiwanese study, described below, as well as determine to what extent month of birth is correlated with ADHD diagnosis and treatment. If successful, further datasets will be linked to determine other factors related to ADHD diagnosis and treatment.</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> <p>Researchers in Taiwan found that age matters when it comes to ADHD. In a large study of 380,000 local children: those born in August were significantly more likely to be diagnosed with ADHD, and receive medication for the condition, than children born in other months, especially those just a month later. According to their research, published in the Journal of Pediatrics, 4.5% of boys born in August were diagnosed with ADHD compared with 2.8% born in September. For girls, it was 1.2% in August versus 0.7% in September, an even bigger gap, relatively.</p> |

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| Identifying policy relevant determinants of health inequalities in Cystic Fibrosis using data linkage | 10/08/2016 | <p>Reducing health inequalities in chronic conditions is a national and international policy goal. Cystic fibrosis (CF) offers an ideal case to study inequalities in outcomes and access to treatment in a chronic condition as socio-economic status (SES) does not affect CF disease risk but does affect the health and social outcomes of having CF. Furthermore there have been significant improvements in outcomes in cystic fibrosis, but all socio-economic groups have not benefitted equally. In order to design effective policies to reduce these inequalities, we need to know how, and at what stage of life, they are established. Furthermore, the social consequences of CF are poorly understood. Our research has demonstrated that deteriorations in lung function and time in hospital are more damaging to employment chances in more disadvantaged populations with cystic fibrosis in the UK, and this evidence has been used to develop social policy recommendations. However the influence of having cystic fibrosis on school outcomes and attainment has not been explored at a population level.</p> |
| Cardiovascular and neuropsychiatric risks of varenicline in Wales | 27/07/2016 | <p>Cigarette smoking kills more than 6 million people every year and causes many serious diseases. Fortunately, quitting smoking increases the odds of living a longer and healthier life.</p> <p>Some medicines such as nicotine replacement treatment (NRT), bupropion and varenicline help smokers quit smoking. Varenicline is the most effective one, and it's been approved and recommended by health authorities in the UK and the US since 2006.</p> <p>However, a small number of patients who used varenicline over the years complained of serious side effects to the heart (e.g. heart attacks), blood vessels (e.g. blocked leg veins), brain (e.g. stroke), and mental health (e.g. depression).</p> <p>Some studies have been done to find out whether these side effects were actually caused by varenicline.</p> <p>The majority of studies found no evidence that varenicline caused these side effects.</p> |
| An Assessment of Data from Routine Sources Applied to a Randomised Controlled Trial | 25/07/2016 | <p>All new medical treatments need to be studied to see how they compare to standard treatments. This allows us to determine which treatment is most effective, determine what the side effects might be and also tell us if the treatment is cost effective. The Study of Standard and New Antiepileptic Drugs (SANAD II) is an example of a Randomised Controlled Trial (RCT) in which people with newly diagnosed epilepsy are given different antiepileptic drugs and followed over time.</p> <p>In studies such as SANAD II the way in which we measure benefits and side effects of treatment can be time-consuming for participants and expensive for researchers. For example, participants may be asked to return to hospital for a clinic appointment, be telephoned by the study team or asked to fill in questionnaires.</p> |
| Gilles de la Tourette Syndrome | 28/06/2016 | <p>Gilles de la Tourette syndrome (GTS) is a neurological condition which starts before the age of 10 and lasts for longer than a year. It can have profound effects on the lives of sufferers. It is characterised by the presence of both motor and vocal tics. We will determine how many cases are detected in the SAIL GP and hospital data. We will see how the number of diagnosed patients compares with published figures. We will also look for evidence of treatment, both behavioural therapy and medication. Other tic disorders which do not meet the strict conditions for diagnosing GTS will also be assessed.</p> <p>In many children, the intensity of tics reduces through adolescence until they are essentially free of the conditions. In others, however, tics continue through adult life. There is a group of adults who received their diagnosis later in life, because when they first had symptoms</p> |

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| Screening for Diabetic Retinopathy | 28/06/2016 | Diabetic Retinopathy (DR) (damage to the back of the eye) is a major complication of diabetes, and a leading cause of blindness in the working age population. Screening for DR ensures early detection when treatment is most effective. Current recommendations are that screening for diabetic retinopathy should be carried out on an annual basis in all patients with diabetes. In the retinopathy screening database all patients have existing eye photographs and basic demographic data (age, sex, type and duration of diabetes). Data available via the databases already available with SAIL will include more information on these patients (e.g. blood pressure, glycaemic control, treatment, etc). From this data we aim to devise a method, using modelling and statistical techniques, to predict patients who will or will not develop diabetic retinopathy. The health economic benefits of stratified screening will also be ascertained. The objective therefore is to determine a safe and more cost effective program of screening for diabetic retinopathy and to decide at which age this should begin. In addition to the work of creating a |
| Kidney Transplantation 3C Trial | 14/06/2016 | Kidney transplantation is the best treatment for most patients with kidney failure. Although short-term outcomes have improved over the past few decades, long-term outcomes (eg, transplant survival) have not. One important cause of transplant failure may actually be one type of drug (called calcineurin inhibitors) given to transplant recipients to prevent rejection, which may in the long-term damage the transplant and contribute to its failure. The 3C Study is a randomized, controlled trial investigating two strategies to see whether minimising exposure to these drugs can improve long-term outcomes. Most previous trials in kidney transplantation have focussed on short-term outcomes, whereas long-term outcomes have largely been ignored partly because of the costs of following patients for extended periods of time. The 3C Study has therefore explicitly sought to follow participants for the long-term using linkage with registries of routinely-collected data such as the UK Renal Registry, UK Transplant Registry |
| A-SPICE | 27/05/2016 | Coronary Artery Disease (CAD) is the leading cause of death in the UK. The care of patients with CAD frequently involves the use of antithrombotic medication (such as aspirin). Atrial fibrillation (AF) is the most common type of abnormal heart rhythm. The management of AF usually requires oral anticoagulants such as warfarin to reduce the risk of stroke. The risk factors for CAD closely mirror those for Atrial Fibrillation (AF) and these diagnoses often coexist. In patients with CAD complicated by AF it is sometimes necessary to use combinations of aspirin and warfarin to reduce the risk of stroke from AF and blockage of the coronary arteries from CAD. However, this approach is associated with an increased risk of severe bleeding. The approach to managing these patients is poorly documented hence we aim to study the management of patients with CAD with particular |
| Consultation prevalence of mental health problems: a cross-national electronic health record database study | 24/05/2016 | Routinely collected electronic healthcare data provide a valuable source of information on trends and variation in the occurrence of health problems. However, comparing prevalence of health care between databases can be difficult and even more so in cross-national comparisons. We previously showed the feasibility of comparing the number of patients with a recorded consultation for musculoskeletal conditions in primary or secondary care over one year (2010) and over seven years (2004-2010) between a UK (English) and a Swedish electronic health record database despite differences in health care systems, different recording practices and different coding systems. The study showed similar prevalences for some musculoskeletal conditions, such as osteoarthritis and joint pain in the elderly, but expected differences for others such as low back pain and inflammatory conditions due to known variation in recording practice and health care systems. There is some evidence that the prevalence of major depression, anxiety and panic syndromes varies between European countries based on |

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| SWISH | <p>03/05/2016 This study delivers a brief intervention running between January-December 2015. It delivers a 4-6 week contact programme (the intervention) to patients in Carmarthenshire over 18 who have either self harmed or have suicidal ideations. It is an adaptation of a study in Australia where a brief intervention provided to patients who presented at the Emergency Department with deliberate self harm reported significant improvements in wellbeing for those who received the intervention. The intervention is designed to work with those who have low level mental health needs to help support them and try to prevent their situation becoming more serious. Because of different health systems, this study has expanded its patient base to beyond A&E presentations to include referrals from GP's to Local Primary Mental Health Support Services.</p> |
| HALF | <p>03/05/2016 This application is for Phase 1 of 3 and part of a PhD looking at peoples health and well-being in terms of the households they live in in Wales. Although we have information that is linked securely and anonymously on individuals health and well-being, we do not know how the home environment might affect an individual. For example, a person caring for a chronically-ill child in a household may well be affected by their caring duties. In Phase 1, we will be creating new ways to link health and well-being information to the individual's household, so that we can begin to look at the wider social environment and how it might affect health and well-being.</p> |
| Lung Cancer Survival and Treatment | <p>03/05/2016 The Welsh Government stated that lung cancer should be explored in further detail in 2015/2016 as lung cancer survival in Wales is among the lowest in Europe. Following this, we are planning to produce various reports about lung cancer in Wales to investigate reasons why Wales has such low survival.</p> <p>For 2015/2016, we have already published analysis at GP cluster level and are currently collaborating with Cancer Research UK on a burden of cancer in Wales project. The additional project detailed here will examine the risk factors that affect lung cancer survival, access to treatment and route to diagnosis (for example, GP referral or emergency presentation). We propose to link various data sources together to predict (i) lung cancer survival, (ii) lung cancer treatment and (iii) lung cancer route to diagnosis. A number of risk factors are to be considered but we</p> |
| Acute Kidney Injury: Alerts and Outcomes in Wales | <p>03/05/2016 Acute Kidney Injury (AKI) is a serious condition leading to or complicating around 20% of hospital admissions. It is associated with an increased risk of death and illness. The serum creatinine level is measured from a blood test which enables diagnosis and management of AKI. It is thought that by informing the clinician who is managing the patient's condition to changes in their serum creatinine levels with an alert may enable the clinician to make changes to patient management. This may in turn improve patient outcomes.</p> <p>Hospital episodes should be coded for significant diagnoses. Accurate coding is important to monitor trends, assess complication rates and though outside of the scope of this study - are used to enable comparisons of hospital performance. This is done by using measures such as the RAMI (Risk adjusted Mortality Index) score. Validation of the reliability of coding for AKI will help justify whether studies or scores can rely on coding statistics as a measure of performance</p> |

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| HAPPEN: Health and Attainment of Pupils in the Primary-school Education Network | 26/04/2016 | HAPPEN brings together education, research, and linked health data to examine whether a collaborative approach can improve the health and education of school-aged children. This multidisciplinary approach enables child-reported health information to be linked to routinely-collected data including academic achievement, such as key stage results and attendance, as well as general health and well-being. A comprehensive database such as HAPPEN, can help researchers, schools and local public health practitioners understand the current health and educational status across a diverse selection of children. This in turn can help identify population and subgroup risk factors for poor health and educational attainment, in addition to identifying potential strategies for intervention. Furthermore, this database can prospectively capture whether this collaborative approach, and early identification of potential intervention points, can lead to long-term improvements in health and education for children. |
| ARRISA - UK | 04/03/2016 | Despite the availability of excellent drugs for asthma, and clear advice on prescribing these, approximately 72,000 patients with asthma are admitted to hospital every year and approximately 1150 deaths from asthma are reported. It is known that certain asthma patients are at greater risk of being admitted or dying than others and that targeting intensive support and care to these patients improves their health. Arrisa-UK is a study that aims to identify 9170 patients at risk of severe asthma attacks from 262 GP practices in six regions within the UK, by searching their practice records for factors that predict risk of attacks. In half of the GP practices, a pop-up alert will appear on the computerised medical notes whenever any of the 'at-risk' patients make contact with anyone in the practice. This alert will, for example, remind receptionists to book urgent appointments, GPs and nurses to advise patients to take their medication and follow their written asthma action plans, and pharmacists to ensure patients take their medicines. 'Practice staff will be trained on what to do when they see the |
| Patients presenting with dental complaints | 04/03/2016 | Patients may present to their medical practitioner for dental problems, rather than visit their dentist, which may result in a wasted trip for the patient and the practitioner as appropriate treatment cannot be carried out. Little is known about the extent of this attendance pattern. The aim of this project is to examine the number of patients presenting to their medical practitioner for dental problems over a 40 year period. The SAIL database will be searched for READ codes indicating that a patient has presented to their GP with a dental problem. Information collected will include patient gender, deprivation, geographical area and age. The number of patients presenting per year will be identified and any trends in numbers over the 40 year period will be examined. The data collected will inform further research looking into care pathways of patients presenting with dental pain. |
| Trisomy 18 and 13 | 04/03/2016 | Trisomy 13* and 18*, are associated with poor outcomes with the majority resulting in fetal loss (miscarriage) or still birth. Termination of pregnancy is normally offered after diagnosis is made through the tests done during the pregnancy. Recently reports published mainly from United States, Poland and Japan, describe continuing pregnancies where the resulting live births were given intensive care and surgical treatment of varying degree. The reports did suggest the interventions prolong survival for some time but the overall outcome remained poor. There is limited population based data available and there is no International agreement on their management of these babies. In our study we aim to provide a review of a large population and obtain information on this group of congenital anomalies (defects present from birth). All cases of trisomy 18 or 13, reported to the Congenital Anomaly Register and Information Service (CARIS) for Wales, were |

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| Linking Bacterial Genome and Patient Records Pilot | 15/02/2016 | Bacterial infections impose a major global public health and economic burden on humans and animals. Bacteria can infect in many ways, through food consumption or interpersonal or environmental transmission. Hospital-acquired infections (HAIs) are among the leading causes of severe illness and death in Wales, and the rest of the world. These infections are acquired during hospital visits, and are commonly associated with assisted ventilation, intravenous catheters, indwelling devices, and other invasive surgeries. Severe infections are often fatal but many of these deaths could be prevented with a better understanding of the organisms responsible and the epidemiology of infection. Despite Government commitments to prevention and control programs to reduce HAIs, they remain common, occurring in approximately 6.4% of acute patients of hospitals in Wales. The incurred cost to the NHS is estimated to be £50m/year, but importantly there is evidence that disease is not evenly distributed among patients with some patient groups at increased risk of infection for example those visiting |
| NCMH-SAIL | 15/02/2016 | The National Centre for Mental Health (NCMH) brings together high quality mental health researchers from Cardiff, Swansea and Bangor Universities to undertake research to improve our understanding of the causes, triggers, diagnosis, treatment and support for those suffering with mental health disorders in Wales. It is funded by Health and Care Research Wales until 2019. So far five thousand volunteers have been recruited from across Wales to take part, about 150 people join the study each month. Participants have been interviewed and completed questionnaires about their mental health symptoms, physical illnesses, social circumstances and the treatments they have received. In addition, some participants have provided a small blood sample for genetic testing. We would now like to link this data to the anonymised routinely collected data held in the SAIL databank to advance mental health research. Ethical approval has already been obtained and only those individuals who have given their consent will be loaded into SAIL |
| Fuel Poverty Evaluation | 02/02/2016 | The World Health Organisation recommend a minimum indoor temperature of 18 degrees and recognise that living in cold and/or damp house may be harmful to health. Inadequate indoor temperatures increase the risks of mortality and excess winter deaths. Also there is evidence to support that living in cold homes has an effect upon cardiovascular, respiratory and mental health. Rising fuel costs in the past decade have led to an increase the number of people living in fuel poverty and inadequately heated houses. Fuel poverty is particularly acute in Wales; in 2011 UK estimates indicate that 29% of households in Wales were in fuel poverty compared to the UK figure of 17%. The Welsh Government's fuel poverty strategy sets out to reduce the number of people in Wales living in fuel poverty or at risk of fuel poverty. A key action in the strategy is to develop programmes to improve the energy efficiency of homes and to target these improvements |
| Children with Cerebral Palsy (CP) | 11/01/2016 | Cerebral Palsy (CP) is a disorder of movement and posture resulting from a non-progressive injury to an immature brain, affecting two to three per 1000 live births. Associated conditions can include epilepsy, communication and learning difficulties, hearing loss, visual impairment, behaviour issues and feeding difficulties. Children with CP frequently develop respiratory, digestive, musculoskeletal and nutritional disorders that can require hospitalisation. As CP is not a common condition, large samples of children with CP are rarely studied The availability of routinely collected data covering the entire child population of Wales, provides an excellent opportunity to describe the nature and extent of health needs and healthcare utilisation of children with CP. Cerebral palsy is wide ranging in severity and so educational experiences of these children vary wildly. Some children with mild forms of CP may flow through mainstream curriculum with minimal intervention and support whilst those with complex needs require tailored support within a mainstream setting or a special school |

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| Tagged Electronic Cohort Cymru (TECC) | 11/01/2016 | <p>In line with the aims of the National Centre for Population Health and Wellbeing Research, the Tagged Electronic Cohort Cymru (TECC) can help us to understand illness better and the effects of medications used to treat disease. The cohort will be developed from the linkage of routine data collected in Wales. Linking data from general practitioner records, hospital records and disease specific datasets (for example, for cancer and arthritis) will create a vast dataset of adults, comprising healthy individuals and those who may present with different conditions. This dataset allows researchers to report the number of people who have certain illnesses, who the illnesses are most likely to affect and when, as well as identifying illnesses that often exist together. The medications given to treat conditions can be examined, including associated adverse effects and interactions of medications.</p> <p><i>The dataset which will comprise linked SAIL data and be held in the secure SAIL Gateway environment can answer basic questions about</i></p> |
| Health Care Utilisation, Care Pathways and Educational Status in Children and Young People with Adolescent Mental Health (AMH) | 11/01/2016 | <p>Mental health issues are of growing concern and a source of controversy in children and young people (CYP) in the United Kingdom (U.K). They have been found to contribute to adverse life outcomes (such as poor educational achievement) and serious disruptions to CYP's lives and those of their families . It is estimated from Office of National Statistics population survey data that, at any one time, four in 100 of CYP, have a clinically diagnosable or relevant emotional disorder (anxiety or depression). Some disorders such as anxiety may start when children are as young as 11 years. Earlier age of onset appears to be associated with greater severity and poorer long term outcomes . Concerns are heightened by the persistence of childhood or adolescent mental health issues into adulthood where up to a fifth of the adult population may be affected by a common mental disorder at any one time. Many of these conditions are managed in primary care and there are issues about the transition of care between primary and hospital care and appropriate settings to deliver care to children. There are also issues relating to</p> |
| Follow up study of patients with LADA | 08/01/2016 | <p>The majority of cases of diabetes after the age of 35 are type 2 diabetes, but there is a significant proportion of these (approx. 4%) who have a type of diabetes more like type 1 called Latent Autoimmune Diabetes in Adults (LADA), who require insulin treatment more quickly. These can be distinguished with an antibody test (GADA). We have a group of people from South Wales already in SAIL who have had the antibody test done so we know who has type 2 diabetes and who has LADA. This was a pilot study carried out between 2004 and 2007 and GADA tests continued for a few years. GADA testing is not routine in Wales or any other part of the UK.</p> <p>We will be able to see, from GP and hospital data, how these 2 groups have been treated and what their glucose levels are. We can also see the various complications they may have developed. From this we can determine whether LADA patients received best treatment and</p> |
| Paramedic Supplied "Take Home" Naloxone | 07/12/2015 | <p>Naloxone is an extremely effective antidote which is used to reverse the symptoms of an acute opioid overdose. It is administered routinely by clinicians in emergency departments and in the prehospital setting by ambulance paramedics and emergency medical technicians Since the mid 1990s, interest has grown in providing THN to opioid users, families and carers as an intervention to reduce drug related deaths. In 2009, the Welsh Assembly Government introduced a national THN initiative, following a positive evaluation of a  demonstration  project, where a small number of drug service provider sites in Wales supplied THN training and kits to known opioid users. There is a general consensus amongst professionals who work within the substance misuse community, that those at highest risk of near-miss or fatal opioid overdose are probably not engaged with traditional treatment services. Indeed, data from the Welsh Regional Confidential Review Panels into drug related deaths (since 2006) have shown that the highest number of deaths occur amongst those that have never accessed or have dropped out of</p> |

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| Examining contributory factors in road traffic collision data involving older people in Wales | 30/10/2015 | <p>Older people, especially those aged over 75 years, are more likely than middle aged people (aged 25-65 for example) to be involved in road traffic collisions as a driver and as a pedestrian. Older people have different types of collisions than younger people including issues involving:</p> <ul style="list-style-type: none"> ◆ Junctions; ◆ Merging traffic; ◆ Right-hand turns (when driving on the right-hand side of the road) and; ◆ Busy traffic (see Clarke et al., 2009 for review) |
| Routine data extraction for CAP | 27/10/2015 | <p>This project will add to this knowledge-base by providing additional data from STATS19 (the form filled in by police at the scene of a road</p> <p>Whilst the NHS has a limited amount of money the cost of treatments is an important comparison to make? termed the cost effectiveness. Would introducing PSA testing be cost effective compared to current NHS practice? In other words, is PSA testing effective, allowing men to be cured (saves more lives), and do treatment costs compare favourably to current NHS practice, where men who request a PSA test receive standardised information about the potential benefits and harms of PSA testing.</p> <p>When comparing the cost effectiveness of treatments it is important that information is collected on all people to ensure researchers arrive at the right answer. This involves finding out about their health and any other treatments they may have had. The NHS collects a wealth of routine information for administrative purposes when people access healthcare (such as the type of operation they have and the amount of time spent in hospital). Using these routine data will allow us to include all individuals in the trial in the cost effectiveness comparison</p> |
| Cedar Evaluations for NICE | 19/10/2015 | <p>NICE provides guidelines to the NHS about which medicines, procedures, medical devices, etc. are the best to use. To contribute to an evidence base upon which recommendations are made, NICE commissions work from External Assessment Centres to evaluate existing evidence or to conduct new research. Cedar conducts these evaluations and would like to use SAIL as a source of data to provide evidence. SAIL contains a large amount of information about many procedures and devices that are used, as well as a wealth of detailed information about individual's health and care, making it an ideal resource for this purpose. Even when SAIL does not contain information about the device or technology in question, it may be possible to import data about it and then use SAIL's health and care data to measure the effectiveness.</p> |
| Treatment of depression in patients with epilepsy | 13/10/2015 | <p>It is known that people with epilepsy are more likely to suffer from psychiatric illnesses, especially depression, than the general population. There is some evidence that depression in people with epilepsy may be inadequately treated despite treatment recommendations, although there have not been any large-scale studies to our knowledge.</p> <p>Building on previous depression (led by Ann John) and epilepsy (led by Mike Kerr) research using the SAIL databank, we aim to study the treatment of depression in people with epilepsy. We will compare anti-depressant prescribing rates and secondary care referral rates in people with and without epilepsy. Identification of an inequality in such treatment in people with epilepsy could partly explain the high rate of significant depression-related problems, such as suicide attempts, in this population. The identification of any inequalities in treatment could also help to prioritise and guide service provision for people with epilepsy.</p> |

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| Dental procedures under GA in children | 13/10/2015 | <p>Admission of children to hospital for essentially preventable conditions such as dental caries constitute a public health issue of concern. The project is designed to quantify the extent of the problem in Wales. It mirrors to some extent an earlier study undertaken in England but seeks to build on it to look in more detail at the children's socio-demographic and medical background.</p> <p>The project aims:</p> <ul style="list-style-type: none"> i. To describe the characteristics of children hospitalised with a dental condition; ii. To see how they may have changed over time and how they relate with deprivation; iii. To examine the use of general anaesthetics in their treatment; and iv. To describe the previous encounters of those children with GPs compared with the encounters of children not subsequently hospitalised |
| Cardiovascular risk, alcohol-related harm and mental health | 13/10/2015 | <p>We are investigating the linkages between three of the greatest threats to the health of the adult Welsh population, namely coronary heart disease, excess alcohol and poor mental health. We have so far investigated these three health outcomes in separate projects in the SAIL databank. We have now planned a new project to link these anonymised studies together and investigate further the links between heart disease, the adverse effects of excessive alcohol consumption and poor mental health. We will assess whether people with a high risk for heart disease have a higher risk of an hospital admission caused by alcohol and the role of poor mental health in this process. This will give use preliminary data on which to prepare a full application to a major UK research funding body.</p> |
| EMRTS Evaluation | 13/10/2015 | <p>Evaluation of the Emergency Medical Retrieval and Transport Service (EMRTS) Cymru. This is a new service for seriously injured and ill people across Wales whereby rapid help will be provided by specialist doctors transported by helicopters and ambulances. The intention is to improve the survival of seriously injured or very ill people, including those suffering cardiac arrest (heart stopped). The service started in July 2015 and will reach an estimated 300 people every year. In some parts of the world, but not everywhere, similar services have led to improved survival. This proposed evaluation would bring together complex data on around 600 patients treated by the service over two years and compare outcomes with a group of similar people before the service was introduced or when it is not operational, such as at nighttime or during bad weather when the helicopters cannot fly. The data would come from datasets already in SAIL such as emergency department, inpatient and GP datasets, new data collected by the EMRTS service and the Welsh Ambulance Service Trust, and data already collected by</p> |
| Utilisation of specific factors in the Primary Care dataset to understand variation in secondary care costs for patients | 09/10/2015 | <p>Cwm Taf Local Health Boards has worked with the Public Health Observatory and NHS Wales Information Service beginning to ascertain which factors affect the variation in costs of patients undergoing similar procedures. Previous work has already indicated that it is possible to measure differences between organisations in the additional cost of treating patients who have diabetes when compared to patients without diabetes. The cost of treatment and the length the patient stays in hospital are also affected by the age of the patients, the number of co-morbidities they have but also whether they are treated on specialist wards. This shows that the PEDW dataset which is routinely collected by the organisation contains differences in performance depending on the patient pathway.</p> <p>The purpose of working with SAIL is to utilise the links between the primary care and secondary care data. The plan is to ascertain whether</p> |

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| Pathway to T1D Diagnosis | <p>01/10/2015 The aim of the research is to get a better understanding of the pathway to diagnosis of type 1 diabetes (T1D) in childhood. By exploring the number and reason for children's appointments with their GP, prior to being diagnosed with T1D, we may be able to develop ways to aid earlier diagnosis which ultimately will help to reduce the number of children who are seriously unwell with diabetic ketoacidosis (DKA) at diagnosis. DKA is a life threatening condition and the most common cause of hospitalisation and death in children with T1D. Sadly, children continue to die at presentation of T1D including in South Wales, as reported in the local news in January this year. DKA also causes significant illness with impacts on financial and medical resources. It has also been shown that children who do not present in DKA at diagnosis are less likely to have long term diabetes-related complications. Currently, the rate of DKA is unacceptably high in the UK.</p> |
| Health impact of adults participation in sports in Wales | <p>01/10/2015 The 'Programme for Government' is the Welsh Government's plan of action. One of its commitments is to widen access and participation in sports programmes and facilities in order to increase physical activity which in turn improves our health and well-being. In particular, research has found that individuals participating in sports are more likely to engage in health enhancing behaviours (e.g., non-smoking and healthy diet), and less likely to engage in antisocial and violent behaviours , . Previous studies have also highlighted the positive influence that access to sport facilities may have on sport participation.</p> <p>While a positive association between participation in sport and self-assessed health and life-satisfaction has been reported for England and Scotland, research on the health impacts of sport participation has been limited in Wales. Sport Wales, the national organisation responsible</p> |
| Antipsychotics and Learning Difficulties | <p>16/09/2015 This study examines the characteristics of people with learning difficulties (mild and severe) who are prescribed antipsychotics. This will be performed among children (under 18) and adults. The impact will be determined by comparing the people with antipsychotics and learning difficulties (severe and mild) to people on antipsychotics and to people with learning difficulties (severe and mild). This comparison will allow the impact of antipsychotics on the lives of people with learning difficulties to be determined.</p> <p>In addition, the study will use new statistical analysis methods (data mining) to examine clusters of diagnosis and symptoms that are associated with the use of antipsychotics. For example, antipsychotics may be associated with higher numbers with diabetes but the non-use of antipsychotic may be associated with higher likelihood of injury.</p> |
| Living Well Living Longer | <p>26/08/2015 The Living Well Living Longer programme in Gwent aims to find individuals in more deprived areas who are at high risk of developing cardiovascular diseases, such as heart attack and stroke, so that they can be offered the best available treatments for preventing these diseases.</p> <p>As part of this program, it is important that an assessment is made of whether as a result of this process individuals get those treatments appropriately and whether the risk of cardiovascular disease is reduced for people who have been through the programme. In order to make this assessment, we would like to use the SAIL databank to compare the levels of treatment, disease and death in those who have been</p> |

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| WECC Phase 3 | 26/08/2015 | <p>The Wales Electronic Cohort for Children (WECC) has been in operation since 2007. A cohort study is a longitudinal study (a study that follows individuals over time) of a group of people with a common characteristic. WECC involves creating a cohort by linking anonymised data from multiple datasets on all children living in Wales born since 1990. The datasets include births, deaths, hospital admissions, outpatient attendances, emergency department attendances, congenital anomalies (malformations at birth), cancer, national community dataset (e.g, immunisations and height and weight), school attainment (Key Stage 1-5 results from school entry to A levels), and with links to data on children participating in a number of child cohorts, such as the Welsh Study of Mothers and Babies (WOMBS), Growing Up in Wales, the Brecon Cohort (children with Type 1 Diabetes) and the Millenium Cohort Study (MCS). Analyses carried out in the first two phases of WECC demonstrated the impact of being born small or prematurely on a range of health indicators and the impact of some medical conditions such</p> |
| WHEAR | 28/07/2015 | <p>Musculoskeletal diseases are the most common cause of disability in the UK. Working within the National Centre for Population Health Research (NCPHR), the Welsh Arthritis Research Network (WARN) aims to use routinely collected data, such as general practitioner and hospital records to fully assess arthritic conditions, such as Rheumatoid Arthritis. The impact on patients, healthcare providers and society will be assessed. The project will also identify conditions that may affect patients alongside arthritis and factors that may increase the risk of developing arthritis (such as hereditary factors) as well as the efficacy and potential side-effects associated with treatments of the conditions. Greater understanding of these issues will improve the measurement of the burden of arthritis and will allow us to identify ways in which we can improve the outcomes for individuals living with arthritis.</p> |
| Supporting People | 28/07/2015 | <p>The proposed work here is a feasibility project aimed at exploring the possibility of linking Local Authority Supporting People (SP) administrative data to health (GP, A&E, outpatient and hospital admission) data in the SAIL databank. We will use the standard Secure Anonymised Information Linkage (SAIL) system (Swansea University) which will allow linking of the datasets in such a way that individuals remain anonymous. The feasibility stage will look at the range and the quality of the available SP data and to see how many SP service users match with health records already held in the SAIL databank. If possible we will also investigate patterns of A&E/hospital/GP attendances for SP service users before and after service use. The feasibility project will also report on the kinds of analysis likely to be possible in future, including whether a control group can be created</p> |
| Glucose Control in Impaired Renal Function (GCIRF) | 27/07/2015 | <p>Patients with chronic kidney disease and diabetes mellitus have a higher risk of heart disease. Treatment therapies for diabetes targeting glucose control are limited. The treatment choices are primarily insulin and sulphonylurea which may cause hypoglycaemia, especially in patients with kidney impairment. Metformin is an oral drug typically used for glycaemic control to manage type 2 diabetes. Current recommendations suggest that metformin and exenatide should be avoided in patients with elevated creatinine levels or a poor estimated glomerular filtration rate, which indicate impaired kidney function. A recent study conducted for Hywel Dda and Abertawe Bro Morgannwg Diabetes-Renal Group examined the treatment choices for glycaemic control in a sample of secondary care hospital patients with moderate or severe kidney disease. Estimated glomerular filtration rate was found to be significantly higher in the metformin group, indicating better kidney function. No significant differences were observed for</p> |

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| Childhood Obesity and Neighbourhood Environments: Integrating MEDMI and SAIL | 22/07/2015 | This pilot project will investigate the opportunity to combine the strengths of the Medical & Environmental Data Mash-up Infrastructure project (MEDMI) and SAIL (The Secure Anonymised Information Linkage Databank, at Swansea University) to link environmental, health and socio-economic data. Specifically, the project will study the association between neighbourhood characteristics by measuring distances in a Geographic Information System (GIS) to greenspace such as public parks, woodlands and the coast and beaches. These distances will then be linked in SAIL to childhood Body Mass Index (BMI) to see if there is a link between proximity to opportunities to exercise and BMI. |
| Alcohol Misuse in the Military | 22/07/2015 | The aims of this project are to examine the associations between alcohol misuse, mental health and physical morbidity (and accidents and injuries) in approximately 10,000 UK serving and ex-serving military personnel. Physical morbidity will be assessed using ICD-10 diagnosis codes recorded in secondary healthcare records for England, Scotland and Wales (this application for Welsh data from SAIL will run in parallel with applications for English and Scottish secondary care data), which will be linked to the King's Centre for Military Health Research cohort study that includes assessments of mental health and alcohol use. This study will also include economic analyses that will identify predictors of the costs for the number of inpatient days, outpatient visits and A&E attendances examining alcohol misuse and mental health as exposures. |
| FeMUR Triangulation Study | 09/07/2015 | Trials need to assess the health economics of new treatments being tested, as well as whether or not the treatment is successful. This includes an assessment of change (increase or decrease) in the use of health services by the participant. Traditionally such information is obtained through interview, even though much of the data has already been provided by the participant and is available electronically. This project tests a proposed methodology to reduce patient interview by obtaining relevant data from SAIL and is intended to reduce the patient burden. As part of the FeMUR trial, routinely collected primary care data related to patient health service use after a hip fracture will be captured from SAIL and the accuracy and completeness of this data will be compared to that gained by the traditional method of patient questionnaire. |
| Parkinson's disease epidemiology | 09/07/2015 | The intention of this project is to create a visual representation of Parkinson's disease occurrence in Wales. Using a mapping tool such as leafletJS http://leafletjs.com/ (accessed 27th November 2014) we will 'layer' data pertaining to the residence of individuals diagnosed with Parkinson's disease in Wales and demographic information about those with the disease, such as age, age at diagnosis and where possible occupational background. This information will enable us to visually demonstrate where in terms of geographical areas, there appear to be more people living with Parkinson's and whether more people of certain social groups (as derived from the Welsh Demographic Service). Visualising Parkinson's incidence on a map of Wales will also us to identify whether specialist services for people with Parkinson's are best located for purposes of accessibility and whether any denser areas of disease occurrence do or do not exist. |

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| WECC and Adverse Childhood Experiences | 04/07/2015 | <p>This study will examine the relationship between exposure to adverse childhood experiences (ACEs; including parental mental health issues; parental alcohol use; one-parent household; childhood victimization; being born to a teenage mother) and healthcare utilization and educational outcomes. We propose to use the Wales Electronic Cohort for Children (WECC) for this analysis. Previous research has demonstrated a link between exposure to adverse experiences in childhood and negative health, social and educational outcomes in adulthood. Although this link is well established, what is less well known is the impact of exposure to adverse experiences on childhood outcomes. In addition, the impact of ACEs has traditionally been examined using retrospective self-reported surveys. The present study aims to outline the epidemiology of ACEs using routinely collected data. We will also examine the influence of age of ACE exposure on outcomes, as this has not been previously reported. For a detailed description of background and methodology, please see the attached project outline.</p> |
| Validating Epilepsy and Neurological Case Definitions within SAIL | 29/06/2015 | <p>Our epilepsy research in SAIL to date relies on using diagnosis codes from general practitioners (GPs) to identify people with epilepsy. This method has not been extensively validated and there are concerns that this method of identifying people with epilepsy is not sufficiently accurate.</p> <p>We will make sure that our method for identifying people with epilepsy in SAIL is accurate by carefully comparing GP diagnosis codes with definite diagnosis from hospital specialists. We will do this by importing and anonymously linking within SAIL lists of around 100 people definitely with and without diagnosis of epilepsy. The lists will be obtained from hospital registries with the appropriate consultants permission and will remain within the NHS until appropriately anonymised using the usual SAIL methods.</p> <p>If successful, we would like to extend this method for other neurological disorders such as Parkinson's disease.</p> |
| Recurrent admissions in diabetic children | 26/06/2015 | <p>The aim of the project is to identify children with diabetes who require recurrent hospitalisation. Our goal is to identify possible risk factors for recurrent hospital admissions, such as the impact of living with a single parent, having a parent with diabetes and coming from low income level family. Moreover, we are going to look into the length of stay in the hospital required in order to predict if there are any risk factors for long hospital stay.</p> |
| MCS- childhood obesity, asthma, infections and injury | 27/05/2015 | <p>K birth cohort studies have made important contributions to understanding of disease and health through early childhood and into adult life. The UK Millennium Cohort Study was set up to understand the health and social and economic circumstances of British children born in the new century. It includes children from disadvantaged social circumstances, ethnic minorities and those living in all four UK countries. We plan to add to the information already collected on these children at ages 8 months, 3, 5, 7 and 11 years by obtaining information recorded electronically about their use of hospital services as either inpatients or outpatients. This will help us answer important questions about children's health, particularly concerning children who become obese or overweight in the preschool years, who have developed asthma or other allergic disorders, infections or serious injuries, by 11 years of age. We will also compare survey data with health records to understand more about the quality, completeness and consistency of recording of a child's ethnic group in hospital health records (not possible for Wales).</p> |

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| Endometrial cancer in patients taking Tamoxifen | 21/05/2015 | <p>The purpose of the GP Engagement team is to expand the number of practices who are signed up to SAIL and to retain the current GP practices who are signed up to SAIL. The GP Engagement strategy determines priorities and activities to realise these key objectives. One of the main requirements of the strategy is to provide an incentive for GPs to sign up to SAIL and as part of this work we need to identify research projects with relevance to Primary Care. The pressure of secondary care and reducing unscheduled admissions leave GPs with big challenges that they find difficult to achieve. Providing a tool that could enable GPs to monitor and investigate the number of admissions in secondary care using data linkage from SAIL has been identified as useful by a number of practices. Improving cluster/locality work between practices is now part of the QOF QP area of the revised GP contract. There is an opportunity for SAIL to facilitate this cluster work by providing linked data around these areas back to GP practices. This information will help them make informed decisions about work to be addressed.</p> |
| ELASStiC | 21/05/2015 | <p>Alcohol-related harm continues to attract media attention and is of interest to the general public. We will engage with the BBC, which has a strong reputation for producing quality scientific programming, in the second year of the study. The intention is to develop interest and plan for coverage as findings emerge.</p> <p>In addition, the following Third Sector organisations have agreed to sit on the project Steering Group:</p> <ul style="list-style-type: none"> ◆ Alcohol Health Alliance ◆ ARUK ◆ Alcohol Concern |
| Thyroid dysfunction and Obstetric outcomes | 21/05/2015 | <p>This project will examine thyroid function in pregnancy and neonatal outcomes, using data collected for the CATS study. This study took blood samples of about 15,000 pregnant women in the Cardiff area and randomized some of those with subclinical hypothyroidism to treatment, about 10 years ago. The dataset of all women who were tested will be imported into SAIL for linkage to the mother's and baby's medical records.</p> <p>The primary research question is the effect of subclinical hypothyroidism on pregnancy outcomes, with the effect of treatment also being considered secondarily.</p> <p>The primary outcome of the study will be stillbirth, with other available neonatal outcomes considered secondarily: birth by C-section, Infant NICU admission, APGAR score, small for gestational age, pre-term births, and congenital anomalies.</p> |
| Creating and utilising a Wales Asthma Observatory | 30/04/2015 | <p>Studies on asthma frequency and associated impact and costs have tended to provide high-level national snap-shot pictures. Whilst these have been useful, we need to understand how these considerations are changing, both at a national and a small-area level (e.g. Health Board), to inform national/local health policy and planning.</p> <p>Traditionally, health data has been managed by computer experts. However we now need doctors trained in informatics to supply useful asthma data. Our clinically-trained doctoral student will have access to a large amount of recent anonymised asthma data (e.g. GP visits, admissions, medications). A large dataset of asthma patients will form an observatory which can be regularly updated. This will initially be</p> |

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| Health Iris | 23/04/2015 | <p>The SAIL Linkage Databank is a world-class population health database and therefore a valuable resource for medical & health research. When potential projects are being formulated, it is necessary to determine if SAIL contains enough relevant data to support the project. Currently these questions are handled by SAIL data analysts manually programming often complex queries within SAIL.</p> <p>Digital Health Labs (DHL) developed the prototype Health IRIS software tool as part of the recent ABMU-SBRI competition. SAIL have commissioned DHL to develop this prototype into a tool that allows exploration of the SAIL data for the purpose of assessing the feasibility of potential SAIL projects. This will consist of a visual interface allowing a population to be defined using a set of rules (such as age, health conditions, treatment received, etc.). The tool will provide a count of individuals with those characteristics, as well as an overview of information about the population, such as demographics, where the people live, and so on.</p> |
| Density of fast food outlets near to schools & childhood obesity? | 07/04/2015 | <p>The easy availability of “fast food” from unhealthy food outlets is thought to be linked to obesity rates. This study will investigate whether the high number of unhealthy food outlets on home-to-school routes has an impact on childhood obesity. Data on the location of food outlets will be collected and grouped around schools. This dataset will be brought into the SAIL databank using standard procedures and linked to demographic and health data. Using children’s Body Mass Index data, this project will investigate the link between an unhealthy food environment and children who are overweight and obese.</p> |
| Osteoporosis and fracture risk: are we achieving secondary prevention? | 07/04/2015 | <p>Fractures in older people are generally caused by loss of bone strength - a process called osteoporosis. These fractures are very common and lead to much pain and suffering, disability, loss of independence, and death (especially hip fractures). Caring for such people also utilises a lot of NHS resources. On an average day patients with hip fractures occupy about 400 hospital beds in Wales, with surges in cases contributing to cancelled elective procedures. The proposed study aims to create an anonymised dataset of people in Wales with a presumed osteoporotic fracture (based on age). Then, to use this to quantify the incidence and distribution of cases in Wales, measure trends in the uptake of interventions designed to prevent second fractures and assess the potential to do more to reduce the scale of this problem and its impact on individuals, the NHS and wider society.</p> |
| Practice Population Profiling | 10/03/2015 | <p>The purpose of the GP Engagement team is to expand the number of practices who are signed up to SAIL and to retain the current GP practices who are signed up to SAIL. The GP Engagement strategy determines priorities and activities to realise these key objectives. One of the main requirements of the strategy is to provide an incentive for GPs to sign up to SAIL and as part of this work we need to identify research projects with relevance to Primary Care. The pressure of secondary care and reducing unscheduled admissions leave GPs with big challenges that they find difficult to achieve. Providing a tool that could enable GPs to monitor and investigate the number of admissions in secondary care using data linkage from SAIL has been identified as useful by a number of practices. Improving cluster/locality work between practices is now part of the QOF QP area of the revised GP contract. There is an opportunity for SAIL to facilitate this cluster work by providing linked data around these areas back to GP practices. This information will help them make informed decisions about work to be addressed.</p> |

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| School Health Research Network Boost Schools (Data Linkage) Study | 04/03/2015 | <p>This study examines if declining in education (e.g. achieving key stage 1 but not achieving key stage 2) is associated with poor health behaviours in the teenage years when compared to those who achieve key stage 1 and achieve key stage 2. We will compare this with children who do not achieve key stage 1 or 2 and those who do not achieve key stage 1 but do achieve key stage 2. The measure of poor health in the teenage years will be self reported smoking, self reported drinking, self reported general health. All these health measures will be collected from the Health Behaviour in School Aged Children Survey. The findings from the work will complement the findings from a larger study examining hospital admissions for teenagers compared with their primary school education.</p> |
| Feasibility Assessment data for CIPHER | 16/02/2015 | <p>Farr Institute CIPHER is studying various aspects of infection in order to improve the health of people (e.g. looking at whether efforts to reduce the use of antibiotics has had any effect on the how resistant various diseases are to these drugs).</p> <p>Researchers from Farr Institute CIPHER would like to use certain SAIL data to work out whether SAIL contains enough microbiology and other data to carry out this work. This IGRP application is to ask for permission to access specific datasets so that they can do this.</p> |
| HealthWise Wales | 12/02/2015 | <p>HealthWise Wales is a national initiative to engage large numbers of people in Wales with health and social care research. The aim is to improve the health and wellbeing of the Welsh population, by putting people at the heart of knowledge creation and translating new knowledge into policy and practice.</p> <p>HealthWise Wales will develop a dedicated research programme focusing on population health and wellbeing. This large cohort study based on the Welsh population will enable the investigation of the widest possible range of social and environmental determinants of health and social outcomes during the life-course. These data can then be used to inform the development of interventions to reduce health inequalities and improve health and wellbeing of future generations. Healthwise Wales will engage the population of Wales to become actively involved in</p> |
| Understanding Suicide Clusters through Exploring Self Harm Behaviours (CHERISH) | 11/02/2015 | <p>This study will set out to explore the factors and mechanisms that may trigger and maintain a suicide cluster and cause it to subside. To do this an anonymised e-cohort of individuals who presented to the Princess of Wales Emergency Department with self-harm from December 2006 to February 2009 will be created. A descriptive and time trend analysis will be conducted in which the basic demographic and clinical characteristics of this cohort will be collected.</p> <p>Additionally an electronic anonymised case-control study will be conducted. A case will be defined as any individual who presented to Princess of Wales Emergency Department with any mention of self-harm during the cluster (December 2007 to February 2008). Controls will be non-cluster related Emergency Department attendees for self-harm (i.e. separated from the cluster by either distance or time). This will allow for an exploration of the characteristics of the population that presented to Emergency Departments for self-harm during the cluster</p> |

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| Whitehall II Study | 02/02/2015 | <p>The Whitehall II Clinical Events project is at the core of the Whitehall II Study. It will involve linking with electronic hospital records from England, Scotland and Wales, in order to obtain objective health outcomes that will validate and supplement the self-reported information provided by the study participants. These clinical data will be suitably anonymised and will be used in the UCL premises by the Whitehall II researchers for statistical analysis to study how midlife factors contribute to adverse ageing outcomes such as chronic disease, depression, cognitive impairment and functional health in later life. They will also assess how the adoption of healthy lifestyle at older ages modifies functional health.</p> |
| Real-World Data Collection for Type 2 Diabetes Mellitus | 02/02/2015 | <p>Type 2 diabetes mellitus (T2DM) is becoming a very common lifelong condition, occurring in parallel with a rise in obesity. Managing blood sugar and cardiovascular disease (CVD) risk factors in patients with T2DM is critical for slowing the progression of the disease as well as preventing long-term vascular complications. Diabetes can be managed through diet, exercise, and medication. The SAIL Databank will be used to get an overall picture of the care of patients with T2DM, as well as the effects the disease has on their health.</p> <p>Specific areas of investigation will include: what NHS services and treatment are being used? What health outcomes do these patients use? And, what are the costs to the NHS? In order to answer these questions, patients with diabetes will be matched to similar patients who don't have the disease. This design allows identifying what effects are attributable specifically to diabetes. Patients will be followed over many</p> |
| Improving outcomes for older people with UTIs | 08/01/2015 | <p>Urinary tract infection (UTI) is the commonest bacterial infection in older people. Major gaps in the evidence base need to be addressed to facilitate better quality of care for this important condition that affects morbidity, mortality and dignity in older people. We will use anonymised data from general practice to (1) estimate the burden of UTI, (2) investigate the effect of different commonly used antibiotic regimens on patient outcomes, and (3) derive a prognostic score to predict the risk of hospitalisation from severe or complicated UTI. Our findings will inform clinical guidelines and improve patient care.</p> |
| Clinical Object Library - Demonstrator Phase | 05/01/2015 | <p>Currently to get information from SAIL, analysts have to write queries in a computer language called SQL. Often research or work is repeated for example in every research project about diabetes, the analyst has to define what combination of clinical codes are to be used to recognise patients with diabetes, and code these into a complex string of computer programming language called a SQL query. The clinical object library (COL) will be a tool available for use within SAIL just as other tools are currently made available (query writing tools or excel). Using the COL a user will be able to select the codes they need for their research question using a graphical interface, and the tool will then compose the appropriate SQL query to identify these records. This means that in the future research can be done using SAIL data without every project needing to have a SQL programmer within the team. Research queries defined using the COL can be saved and used again, or shared with other researchers</p> |

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| Dual Diagnosis | 18/12/2014 | <p>or the purposes of this study the definition of dual diagnosis is defined as follows: ◆An individual who presents with co-existing mental health (and/or Personality Disorder) and substance misuse problems (drugs and/or alcohol).◆</p> <p>The intention is to use SAIL to establish how many people in Wales are currently recorded as suffering with a Dual Diagnosis of Mental Health and Substance Misuse issues. Using Primary Care and Secondary Care data will help identify a cohort of patients in Wales. The project expects to encounter issues with the coding of both Mental Health and Substance Misuse. This information will be fed back to GP practices and Health Boards to hopefully inform and improve coding in this area.</p> |
| Bridgend Falls | 16/12/2014 | <p>The report will consider the factors which influence an individual's risk of a fall, specifically considering the impact of a pilot intervention designed to reduce the number of falls within the Bridgend area. The intervention is a two stage process. Stage one involves giving the patient advice on preventing falls and an assessment of their individual risk. If patients are deemed at high risk they are then offered further falls prevention strategies. Rates of events such as hospital admissions and primary care use will be compared in the intervention and control group. Factors such as pre-existing medical complaints and use of certain medications would be considered as part of the investigation. The analysis will be restricted to Bridgend residents that have received the first stage of a pilot intervention.</p> |
| Choose Pharmacy | 27/11/2014 | <p>Part A data request</p> <p>The Choose Pharmacy service aims to make the pharmacy the first port of call for patients seeking advice and treatment of common ailments, thereby reducing the number of patients who visit their GP and other health care services for the treatment of these ailments. The SAIL data will be used to help measure whether there is any change in the number of GP consultations for common ailments following the introduction of Choose Pharmacy in the pathfinder areas. If there are changes in the number of GP consultations, the SAIL data will also help to confirm whether these changes would have happened if the Choose Pharmacy service had not been available to patients.</p> <p>Part B data request</p> <p>The project will also identify whether there is any duplication of the services provided - ie do patients visit both the pharmacy and the GP for</p> |
| Neurological Needs Assessment for Hywel Dda | 24/11/2014 | <p>Hywel Dda is undertaking a Population Need Assessment as part of the required response to Together for Health ◆ Delivery of Neurological Services. As part of this we would like to obtain data to have a picture of the numbers of conditions among the population as recorded by general practitioners within the health board. This will be broken down by age category and county of residence. Only some GPs within the health board are signed up to SAIL, so we will assess whether the GPs in SAIL are representative of the health board. We will then estimate the numbers of conditions across the whole health board, adjusting for differences between SAIL GPs and all GPs if necessary.</p> |

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| Disability in the workplace | 04/11/2014 The aim of the project involving SAIL is to show the unique contribution data-linking can make to the evidence base. By investigating linked survey (NSW) and administrative (WDS, GP event data, PEDW, and A and E data) data we hope to compare the medical history between those who report disability and those who do not of patients with disabilities. |
| Interactive Health Visualisations - Demonstrator Phase | <p>23/10/2014 We Predict use complex big and small data to produce actionable insights. In this project, We Predict will adapt and apply their global expertise in predictive analytics to the health sector to benefit people in ABMU. We Predict are a local company who operate in Swansea.</p> <p>Objectives:</p> <ul style="list-style-type: none"> • Use sophisticated data linking and analysis methods on SAIL data to describe, evaluate and predict health and healthcare in ABMU. • Present this intelligence in a user friendly, interactive interface for use by lay people, health managers and clinicians to inform planning and evaluation of services. • Produce tables and views from SAIL for analysts to interrogate |
| Cost of reduction in Tonsillectomies to NHS | 10/10/2014 |
| Coagulation Biomarkers and acute illness | <p>29/09/2014 A biomarker of coagulation is a blood test that acts as an indicator of blood clotting in healthy individuals, in subjects with disease and is a measure of response to treatment. The Haemostasis Biomedical Research Unit (HBRU), in The College of Medicine, Swansea University, has developed a new biomarker of blood clotting, which is being tested against currently available biomarkers. We will investigate if this biomarker can detect early changes in clotting in critical illness, including stroke, heart disease, sepsis, and cancer. We will further investigate if this biomarker has greater sensitivity and specificity in the diagnosis of a range of critical illnesses and predict disease outcome. Our biomarker has the potential to replace and improve on existing methods for detecting clot structure that involves complicated preparation and expensive instrumentation. Therefore we require access to the SAIL database so that we can rigorously evaluate the biomarker against patient outcome data that is available on the SAIL database.</p> |

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| Clinical Concepts in Health Datasets | 29/09/2014 | <p>Data can be collected in many ways in different datasets. Data collected by GPs is entered into a number of different computer systems using codes which can either be typed in or entered from menus. GPs are also encouraged by the Quality Outcomes Framework (QOF) rules to record certain diagnoses or treatments with particular codes for financial reward. These rules change over time. Other datasets, such as diagnoses recorded and operations carried out in hospitals are entered into the computer system by specialist coders after the events have occurred. These coders work according to guideline which again can change over time and vary regionally.</p> <p>Numerical values (eg; laboratory tests, weights, heights, numbers of alcohol units) need to be checked for units and for unlikely values. Understanding of the data by specialists is important in interpreting it. We hope to develop sets of rules by which data checks can be made</p> |
| BP variability in primary care data | 28/08/2014 | <p>Raised BP is one of the most important treatable causes of stroke; a major cause of death and disability in the UK. Variation in BP - occasional high readings or fluctuation in readings over weeks, months or years - may also cause stroke (even if the average BP is normal). BP variation is not currently treated in the UK, but potential treatments already exist. My research will use data from the SAIL databank, a large population database, to explore methods of measuring BP variation in large populations. Developing these methods will be informative for large studies, enabling future investigation of the associations between BP variation and stroke. In the long run, this will guide the development of more personalised treatments for stroke prevention.</p> |
| Data linkage in social care a pilot project | 31/07/2014 | <p>Existing data linkage projects in Wales that utilise routinely collected administrative data have focussed on health datasets only. To build the complete picture of service provision there is a need to broaden this to include social service provision by Local Authorities, and provision of support by third sector organisations.</p> <p>The work proposed here is a pilot project to test the feasibility of linking datasets from a local authority, the NHS and third sector organisations. The focus of this work will be on individual level data from adults who are referred to social services in order to avoid admission to hospital or to facilitate their discharge from hospital. The data linkage will include data from statutory and third sector organisations and services which provide interventions and support in community settings</p> |
| Fractures in people with a diagnosis of epilepsy | 31/07/2014 | <p>Epilepsy is one of the most common neurological conditions affecting around 1% of the population. Fractures are serious, accounting for a significant proportion of emergency hospital attendances and causing pain and other complications to the individual as well as necessitating periods of time off work and school. It is thought that people with epilepsy have a higher risk of fractures due to injuries during and after seizures and side effects of anti-epileptic drugs. This project aims to record the risk of bone fractures in people with epilepsy when compared to people without epilepsy and identify possible factors involved with fractures e.g. certain types of anti-epileptic drugs. The results of the project would provide useful information in attempting to reduce the risk of fractures in the future.</p> |

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| ARBED | <p>29/07/2014 The SAIL data will be used to retrospectively to evaluate Arbed phase 1, aiming to evaluate the health impacts of ARBED interventions through using routinely-collected anonymised data held within the SAIL databank.</p> <p>Data from housing interventions will be linked with various medical records to support the analysis into the health comparison study to evaluate any derived health benefits. Analysis will concentrate on comparison of pre and post intervention data within the study cohort which will also be compared against two other comparator groups, details of each group are as follows:</p> <ul style="list-style-type: none"> - Study Cohort: 7,460 households subjected to interventions - Comparator Cohort: |
| Angiography and revascularisation procedures in Wales | <p>29/07/2014 To compare the primary and secondary care experiences of patients with Coronary Heart Disease for differences which might be associated with variations in emergency and elective revascularisation and angiographies. The investigation will consider factors influencing the provision of revascularisations and angiographies in a cohort of patients with CHD, recruited from GP data, secondary care data and mortality data. It follows on from the 2009 report Equity in the provision of angiography and revascularisation in Wales published by the National Public Health Service for Wales and utilises anonymised but linked primary and secondary care data stored in the Secure Anonymised Individual Linked (SAIL) databank at Swansea University.</p> |
| End of Life Care | <p>01/07/2014 The primary care team is central to the delivery of high quality end of life care. Primary care teams manage the worry and stress present at the end of life. Having open and honest conversations, where they are wanted, is essential to giving patients and their carers the time to adjust and make plans for death. This study is investigating how end of life care plan influence patients' place of death. The interest of the study is also to look at whether or not being on the palliative care register is an appropriate marker for having an end of life care plan in place.</p> |
| Self harm electronic cohort to further understand multiple aetiological factors | <p>11/06/2014 Self-harm is an important public health problem concerning a spectrum of behaviours and intents. People who self-harm are at an increased risk of suicide in both the short and long-term and assessing their needs could have important implications for informing suicide prevention strategies. Individuals who self-harm are typically managed in primary care or seek no help at all. However there is currently no monitoring of self-harm beyond emergency department attendance for planning service provision. This study aims to establish an anonymised electronic cohort of those with a diagnosis of self harm across multiple settings (general practice, hospital) based on routine electronic records from linked datasets available in SAIL. The establishment of the electronic cohort will allow for the monitoring of trends in self-harm over time, exploration of health contacts across different settings (primary and secondary care) and planning of appropriate service provision.</p> |

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| MSSA Bacteraemia in Wales | 19/05/2014 | <p>Staphylococcus aureus is a bacterium that is commonly carried on human skin and mucosa. The public are generally aware of the meticillin resistant variety (MRSA) through widespread media coverage. Both the sensitive (MSSA) and MRSA varieties can cause serious illness or death. If the bacterium enters the body through broken skin or an implanted medical device, for example an artificial hip, it can cause local or widespread infections. Bacteraemia is the term used for infection in blood that may develop into septicaemia, a very serious illness. With widespread preventive efforts in hospitals, the numbers of MRSA infections have steadily fallen in Wales over a number of years. However, there has been no equivalent decrease in MSSA bacteraemia and a recent increase in numbers has been identified and is a growing cause for concern. Public Health Wales have been asked to investigate the risk factors associated with this bacteraemia, in order to inform the revision and development of interventions to reduce the risk of infection. PHW has imported an anonymised set of laboratory data (DataStore) into</p> |
| Welsh Study of Mother and Babies - Renal disease | 13/05/2014 | <p>Long term kidney disease is one of the most common illnesses of childhood causing lifelong health needs. Babies born with abnormalities in the kidney are at risk of long-term kidney disease that may require treatment such as dialysis and kidney transplant as they grow older. Opportunities for early diagnosis and treatment of kidney disease may reduce the severity of illness over time. In some pregnancies, a marker (enlargement of the tubes that collect urine in the kidney, called pelvicalyceal dilatation) is detected in the baby's kidney at the antenatal ultrasound scan. The meaning of this marker for the future health of the baby (for example the risk of urine infections or hospital admissions for kidney problems) is not known. There are no consistent guidelines about how to treat babies with this condition and so the identification of this marker can lead to anxiety for families and additional tests during pregnancy and after birth. We were funded by NISCHR to study the meaning of markers of uncertain significance (Welsh Study of Mothers and Babies). The study has</p> |
| Secondary prevention strategies in patients with ACS | 30/04/2014 | <p>Acute Coronary Syndromes (ACS) are a major cause of morbidity and mortality in Wales. Patients surviving an ACS are at risk of developing a series of complications including heart failure, re-infarction, stroke and death within 5 years. Evidence-based, guideline recommended treatment has proven to be highly effective in preventing a secondary event however treatment is often underutilised due to under prescribing and lack of patient adherence to treatment. We will be looking at prescribing and risk factor management following an acute event to see if it follows the recommended treatment regime, which will enable us to identify any gaps in treatment provision/use and to assess the effects of these differences.</p> |
| Communities First | 24/04/2014 | <p>There is little evidence on the effects of area-wide regeneration projects on health. This in part is because randomised controlled trials, the gold standard of evaluative research, are often not possible. Recently, the Wanless Report and others have described the opportunities offered by 'natural experiments' to evaluate regeneration activities.</p> <p>The project aims to investigate whether the Welsh Government's Communities First regeneration programme improved mental health, enhanced social cohesion and reduced health inequalities.</p> <p>We will carry out a natural experiment to evaluate the Communities First programme in Caerphilly county borough, linking information from Caerphilly county borough council on defined areas which did and did not receive regeneration interventions to Caerphilly Health and Social</p> |

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| Pilot Study of patients with Eating Disorders | 07/04/2014 | <p>Eating disorders have the highest mortality of any mental disorder. Research suggests that only a minority of people with eating disorders receive help from mental health services. Current service data in Wales suggest referrals to secondary care are highly variable across regions as compared to projections based on population demographics.</p> <p>At present, we lack evidence of: how well eating disorders are recognised and diagnosed at the primary care level in Wales; what happens to patients with eating disorders after recognition at primary care, and how many or few enter Tier 2-3 care; and what happens to patients with eating disorders after entering Tier 2-3; and what inpatient admissions occur for these patients. Finally, we do not know what the trends have been over time. These are all concerns which need systematic exploration. This pilot research is intended to develop hypotheses for a large</p> |
| Comparing Graves' Disease Treatments | 03/04/2014 | <p>Graves hyperthyroidism is a condition characterised by thyroid gland overactivity and affects 05-1.0% of the population. Most sufferers are women, typically in their thirties to fifties. Three established treatment modalities are available for patients with Graves' disease, namely, (i) antithyroid drugs, (ii) radioactive iodine, and (iii) surgery (thyroidectomy). Untreated disease is associated with considerable morbidity including heart rhythm disorders, heart attacks, heart failure, strokes, and osteoporosis (thinning of the bones). Many of these complications occur long after the disease has been treated and there is evidence that patients who have been treated for Graves' disease suffer a higher mortality from cardiovascular disease than matched counterparts in the population. However, it is not known whether the treatment of Graves' disease has any relationship to the development of long term complications. This knowledge will be crucial in guiding clinical decisions on therapeutic choices. The study will address this by analysing the long term outcomes in a cohort of patients with Graves' disease who have</p> |
| Social Care and Health of Older People (SCHOOP) | 26/03/2014 | <p>There is a link between use of social care and use of health care by people aged 65 and over. Appropriate social care can maintain health and delay or avoid the need for health care such as hospitalisation. Conversely, a spell in hospital can mark the beginning of a need for social care.</p> <p>The Welsh Government's Chronic Conditions Management policy (2008) sets out a plan for improving care in the community and reducing demand for hospital care. Our study will examine the impact of the policy across Wales on emergency hospitalisations of people aged 65 and over and see how this varies with varying social care input.</p> <p>We will look in more detail at the same age group in Swansea. We will track health and social care use by individuals using linked anonymous</p> |
| Further costs of Head Trauma in a small Swansea cohort | 10/03/2014 | <p>The analysis will estimate the costs of head trauma patients for the NHS and personal social services (eg A&E attendances, inpatient admissions, length of stay, etc). Data on the use of the health service resources will be collected using SAIL extractions based on a detailed data items table. Costs will then be calculated using unit-costs estimated from current published sources. Costs per patient will also be calculated as well as frequency of service use multiplied by the relevant unit cost (also derived from current published sources) to produce a total cost per patient, with a segregation of costs in relation to the where they were incurred and the potential opportunity for cost shifting.</p> |

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| Cost Utilisation of patients on MS Register | 10/03/2014 | <p>This project is part of the work of the UK MS Register. It will estimate the costs due to people with MS visiting NHS services (such as GP visits, stays in hospital, etc.) and some further costs to society. Information about health service use will be found in SAIL datasets, and costs will then be calculated using unit-costs available in published sources for this type of work. We will be able to use this information to work out costs per person with MS. By taking into account the number of times people visit the GP and other healthcare settings, we will also see where the costs are incurred. This will give us a better picture of which services are most used by people with MS, and the associated costs, to add to the evidence for future planning and policy-making. The EQ5D is a general quality of life questionnaire, widely-used in health economic studies, and the MSIS-29 is an MS-specific questionnaire used to assess the impact of MS. Both these questionnaires are completed by people with MS as part of the UK MS Register. By linking the EQ5D and MSIS-29 responses to the SAIL data we will be able to model the</p> |
| Clinical Object Library (SBRI) | 03/02/2014 | <p>GPCSL will create a 'clinical object library' that describes each patients interaction with health services based on SAIL data, and allows unprecedented ease of access to understanding highly complex clinical pathways, interventions and outcomes.</p> <p>By defining the building blocks (or "objects") that make up this journey such as disease, interventions, pathways, services, guidelines (eg NICE) and outcomes it will allow users to rapidly visualise complex services and scenarios. In addition these building blocks will be modular and reusable allowing complex objects to be created by combining existing ones.</p> <p>Having created these objects users will interact with them using an 'Object Library Interface'. This interface uses modern swipe, touch and drag and drop techniques to select and combine objects to visualise current services , understand how interventions lead to outcomes and plan new services around predicting the impact of positive or negative outcomes.</p> |
| Support tool for health data analysis (SBRI) | 03/02/2014 | <p>Gesundheitsforen Leipzig (GFL) will provide an environment in which the analysis can be undertaken; this comprises: a data warehouse, a web portal, and an analytics platform. GFL will build a data warehouse which supports discrete data marts. Each data mart contains structured and cleansed data from a specific SAIL field. To provide performance and redundancy, these data marts are extendable. This approach will allow the solution to easily scale and retain required performance characteristics.</p> <p>To make these data accessible to the end-user we will provide an easy to use web application: SpagoBI.</p> <p>SpagoBI is written in Java it provides a high level of expandability and portability.</p> |
| Health Iris | 03/02/2014 | <p>The Abertawe Bro Morgannwg University (ABMU) Health Board has commissioned Digital Health Labs, a Welsh software company, to develop flexible web-based tools allowing rapid processing of health data held in the SAIL Databank by non-programmers. In addition to giving a general overview of health in Swansea, Neath, Port Talbot and Bridgend, these tools will enable ABMU health researchers to select any group of patients and gain a detailed understanding of the different ways in which their health is managed. This will help health managers to understand not only the best ways to treat and manage illness but also to understand factors that may predispose certain people to disease, providing targeted opportunities for keeping those people well.</p> |

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| Clarity Health (SBRI) | 03/02/2014 | <p>Data from the SAIL databank will be extracted onto a SQL Server environment, within the SAIL databank, where the data will be risk stratified and be made available to end users via a number of reports. These reports will initially focus on the following areas:</p> <ul style="list-style-type: none"> oGIS (Geographic Information System) oHealth planning and trend reporting oSOA comparison oDeprivation oCohort reporting for specific disease groups <p>Data modelling functionality will also be provided to end users. When data is presented to users via a secure portal, it will be done at an</p> |
| Interactive Health Visualisations | 03/02/2014 | <p>We Predict use complex big data to produce actionable insights. In this project We Predict will adapt and apply their global expertise in predictive analytics to the health sector to benefit people in ABMU. We Predict are a local company who operate in Swansea.</p> <p>We Predict will:</p> <ul style="list-style-type: none"> ◆ Use sophisticated data linking and analysis methods on SAIL data to describe, evaluate and predict health and healthcare in ABMU. ◆ Present this intelligence in a user friendly interactive interface for use by lay people, health managers and clinicians to inform planning and evaluation of services. ◆ Produce tables and views from SAIL for analysts to interrogate. |
| Anxiety and depression in children and young people | 30/01/2014 | <p>Research has suggested a change in the way GP's are recording depression in both adults and children. The recording of symptoms is increasing overtime with a parallel decrease in new diagnoses. Similar trends have been found with regard to anxiety diagnosis/symptoms in adults, however research has yet to be done with children and adolescents. Research has also shown a steady increase in antidepressant prescribing in both adults and children. The purpose of this research is to examine time trends in the incidence and sociodemographic variation in GP recorded symptoms and diagnoses of depression and anxiety in children and adolescents. We will also examine time trends in antidepressant prescribing for children and adolescents.</p> <p>To do this we will create a retrospective e-cohort of children and adolescents using routinely collected data available in SAIL. Data will be collected on new incidence of depression/anxiety symptoms/diagnoses and antidepressant prescribing for each year from 2003 to 2011</p> |
| Epilepsy - factors associated with A&E attendance | 22/01/2014 | <p>Epilepsy is one of the most common neurological conditions affecting around 1% of the population. People with epilepsy account for 2-3% of all emergency medicine department (Accident and Emergency) attendances. Whilst some of these attendances are appropriate-many of these emergency department admissions in people with epilepsy might be prevented by appropriate escalation of primary care/outpatient management. The project aims to identify factors associated with emergency attendances of people with epilepsy and identify any potential interventions that may reduce emergency department presentations in the future.</p> |

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| Using predictive models for unscheduled care | 22/01/2014 | <p>Emergency admissions are costly both to the individual and to the Health service. For some years there has been an attempt to quantify risk and produce risk stratification of patients to improve case management and avoid emergency admissions. Since April 2013 GPs in Wales are expected to risk stratify their patients and produce a list of the top 5% most at risk. The current model in Wales PRISM combines secondary care data and although compares well to other combination tools(PARR, SPARRA etc) it is several weeks out of date. Purely using SAIL data I would like to see if we can model a risk model based purely on primary care data and then compare this to the PRISM to see if this would be a possibility to develop. I also intend to see if there are other factors (e.g living alone) which are not currently included in models which may improve the accuracy of the model.</p> |
| Creation of Synthetic Datasets for SAIL Testing and Development | 22/01/2014 | <p>The SAIL Databank uses robust information governance to assure that medical data is not misused, as well as to prevent the disclosure of identity. Key safeguards include review of all projects by the Information Governance Review Panel, requiring all analysis to be conducted within a secure remote desktop environment, limiting access to only the data required for a particular project, and review of all outputs from the gateway. These procedures are essential for responsible use of anonymised health data. However, they also add a large amount of overhead to each project and are restrictive (by design).</p> <p>Certain types of work do not require access to the genuine data, only "SAIL-like" data. This includes some training, testing of software tools and developing new methods. By 'SAIL-like' data we mean data that have been changed so that they resemble the real data, but do not relate to anyone. For example, the columns for certain information e.g. disease codes, ages, prescriptions, etc. would be randomly reordered. In</p> |
| Investigating outcomes of Biventricular pacemaker implants | 26/11/2013 | <p>This project aims to investigate health outcomes for patients with severe heart failure after having a biventricular (biv) implant. BIV pacemakers cost approximately £15,000 and have shown reduction in the amount of healthcare required after having a BIV pacemaker. Outcomes we are interested in looking at are admissions to hospital and length of stay, cardiovascular drug management such as beta blockers/statins and mortality compared to a control cohort.</p> |
| Identifying the true cost of asthma in the UK | 15/11/2013 | <p>Identifying the true cost of asthma in the UK</p> <p>This work will provide the Wales's most detailed, comprehensive and up-to-date estimates of the true prevalence and costs from asthma. Asthma is now one of the commonest long-term conditions in the UK and it is therefore important to understand the costs of healthcare, social care and societal costs in order to inform decisions on care provision and planning.</p> <p>Welsh data will be integrated into a state-of-the-art overview for the UK and its member countries of how many people have asthma and the full cost of this. We will analyse a range of relevant data sources, including national health surveys, GP data, prescribing, emergency care, hospital and mortality data to estimate asthma frequency and to what extent the health service is used by people with asthma. We will need</p> |

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| Educational attainment at key stage 1 of children with epilepsy, and children of mothers with epilepsy | 01/11/2013 | This study aims to investigate the effect of epilepsy and epilepsy treatment on educational attainment of children at key stage 1 (age 7 years). We aim to investigate both whether there is an effect of the use of anti-convulsants and education in children who have epilepsy at key stage 1 (primary exposure) as well as seperately investigating if anti-convulsants or lack of anti-convulsants being taken by pregnant epileptic women (secondary exposure) has an effect on their childs' educational attainment. |
| Understanding the risk profiles and outcomes of Welsh patients with a diagnosis of ACS | 30/10/2013 | Broadly speaking there are two major types of heart attack. The first is the type were a plaque (narrowing) in the coronary artery (the vessel supplying blood to the heart muscle itself) ruptures and develops a clot that completely blocks the artery. These patients become very unwell and require immediate medical attention that will unblock the artery usually with a procedure called a coronary angiogram and angioplasty (removing the clot and restoring flow). Unfortunately a significant proportion of these patents die before they can get to hospital (30-40%). The second (and more common) type of heart attack is where the plaque ruptures but no clot forms. These patients have a brief episode of pain and then recover with minimal damage to the heart muscle (we call them small heart attacks or NSTEMI). NSTEMI are often seen prior to large heart attacks that are described above; and this is the main reasons we aggressively treat these patients, in order to stop them having a large heart attack which they may not survive or which may leave them severely debilitated. |
| Care and Repair | 18/10/2013 | Care & Repair complete housing improvement work for those people who live in owner occupied and private rented accommodation. They are generally older people who are eligible for benefits. We would like to assess the health service use of those people who have had repairs (before and after the work is completed) compared to those who have not had repairs. The intervention data set, including type of work and dates, will be brought into the SAIL databank and linked to demographic and health data. This project will investigate the time to move into old people or nursing accomodation using Residential Anonymous Linking Fields. We will also investigate hospital admissions for cardiovascular, respiratory conditions and injuries (burns and falls) using a hospital admission dataset. Outpatient attendances, GP events and A&E attendances will also be investigated. |
| Gwynedd Home Energy Certifications | 01/10/2013 | The main aim of the project is to investigate the usefulness and sensibility of linking EPC data into an anonymised dataset. The project will be a feasibility study as it will not be possible to know the size of any cohorts that can be flagged up until the linkage has happened. There are records of EPC data for 13,109 households in Gwynedd, therefore it is anticipated that the potential population size for the study will be approximately 28,840 individuals. The study will explore many different aspects of linking the EPC data into an anonymised dataset. Firstly, how effective can the address matching be in the anonymisation process, and will report on the success of linkage. Having anonymised properties, it would be possible to flag up the family groups living in the properties at the time of certification, therefore a correlation could be identified between the number of rooms and family size and structure. Another aspect that could be explored is migration by looking at the frequency of change of occupancy by housing type. A comparison between EPC certification and housing improvements data from the |

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| 2014 update of the Global Burden of Disease: UK | 01/10/2013 | <p>Policy makers increasingly use measurements of the health of the population to judge the effectiveness of policies. The Global Burden of Diseases was initiated in 1990 to calculate the burden of diseases, risk factors and injuries using a new metric - the Disability Adjusted Life Year (DALY). DALYs combine a measure of premature mortality with a measure of the impact of disability. The results of the GBD studies are used by policy makers to study the effectiveness of health policies. I have attached a Lancet paper showing the latest results for the UK amongst rich countries. There are a number of inaccuracies in the latest approach - mainly from insufficient data on how common diseases are and also in the impact these conditions have on peoples lives. This planned latest update of the GBD project will use improved measures of disease frequency for the UK and separately for Wales. We are applying to use the linked data in SAIL so that these calculations will be as accurate as they possibly can be.</p> |
| Cardiff Womens Aid | 02/09/2013 | <p>Victims of domestic violence and sexual abuse in the Cardiff area may approach a number of statutory health, local authority, voluntary organisations, or the police for help. These agencies form collaborative groups to ensure that information is exchanged to ensure the best possible help is available. This is highly sensitive information normally shared on a face to face basis by suitably appointed and authorised personnel, but currently there is no way to collate the information across these organisations to carry out general research on the underlying causes of these problems or the effectiveness of the various interventions.</p> <p>In order to explore the possibility of developing a linked dataset, this is a pilot study to process a sample of data from one of the partner organisations(Cardiff Womens Aid) into SAIL. This sample, which will include about 500 cases, is likely to include people who may move home frequently, particularly around the time they present to service providers, and in some cases may supply false information. The first aim of this</p> |
| Extracare -economic evaluation | 20/08/2013 | <p>Using retrospective longitudinal information to compare and contrast the utilisation of health and social services and their associated costs by those living in: Extra Care; in their own homes; in sheltered housing; and in residential care settings will provide a clear evidential base. Making use of local authority "supporting people and adult social care" information as well as information contained within the SAIL database at Swansea University a pragmatic cohort of older people will be identified from Swansea and their use of health and social care services monitored over a given time period. It is hoped that SAIL will provide access to information on individual use of health related services such as hospital admissions, medication usage and GP Events while social services departments will be able to provide access to information on individual use of services including assessment care management, day services, homecare provision, and respite. Similarly, supporting people services will be able to identify whether any housing related support is being provided.</p> |
| Smoke-free legislation and child health in Wales | 19/08/2013 | <p>Tobacco use kills over five million people each year worldwide. In addition, exposure to other people's tobacco smoke (second-hand smoking; SHS) is estimated to kill another 600,000 people, including 165,000 children. To protect people from harmful effects of SHS the World Health Organization (WHO) recommends that smoking be banned in public places. Among other positive effects, research now shows that deaths from cardiovascular disease among adults and hospital admissions for asthma among children are reduced following smoking bans in different countries. Despite this, only 10% of the world's population is currently protected by such bans. A better understanding of the range of effects that smoking bans may have can help policy makers worldwide to make well-informed decisions about the implementation and expansion of policies to further protect people from SHS.</p> <p>The current project aims to investigate whether the smoking ban that was introduced in Wales in 2007 has led to improvements of infant and</p> |

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| CALON (Cardiac Ablation: Linking Outcomes for NICE) | 13/08/2013 | <p>The two main aims of the CALON project are to:</p> <ul style="list-style-type: none"> ◆ Find out more information about how well cardiac ablation procedures work and how safe they are. ◆ Assess the value of using data linkage, a method of linking patient records, as a method for healthcare research. <p>Abnormal heart rhythms can cause very unpleasant symptoms such as chest pain, headache and tiredness. Cardiac ablation is a type of procedure which treats abnormal heart rhythms by destroying sections of tissue in the heart. The National Institute for Health and Care Excellence (NICE) recommend that some cardiac ablation procedures are only used in certain circumstances, as there is currently limited evidence on how well they work and/or how safe they are. We will look at existing health records to try to answer these questions. We will also evaluate the feasibility and usefulness of the method of linking patient records for the purpose of informing NICE guidance.</p> |
| Linking spatial accessibility of services to treatment of chronic health conditions | 02/08/2013 | <p>to health care has long been associated with health inequalities in Wales. Using the e-GIS (environmental geographic information system) and the SAIL databank we propose to test a methodology in which we can anonymously link residential level accessibility scores to an individual's health records.</p> <p>By using a GIS system we estimate a number of accessibility measures from residential addresses to health care providers (eg GP surgeries and clinics). So one measure may be the direct distance between the two points, another may use roads, and another may use footpaths. These calculated measures are saved in a file which is processed by NWIS to securely match and anonymise the residential addresses to a RALE (Residential Anonymised Linking Field (RALE). This process follows the same security protocols that are used in the matching and</p> |
| Colorectal polyp risk factors-Bowel Screening Wales | 21/06/2013 | <p>In Wales in 2010, colorectal cancer was the second most common cancer in men and third most common in women. The Bowel Screening Wales (BSW) programme began in 2008, aiming to reduce mortality from bowel cancer by 15% by 2020. Screening is available for men and women aged 60-74. Initial screening involves detection of faecal occult blood (FOB) in bowel stools. Sometimes FOB can be due to bowel polyps or cancer. Most bowel polyps are benign but some (e.g. adenomas) are pre-cancerous. Participants who test positive for FOB are offered colonoscopy. Colonoscopy aims to detect colorectal cancer and there is the opportunity to detect and remove polyps/adenomas before progression to cancer.</p> <p>This study aims to 1) investigate whether sleep disruption is associated with an increased risk of colorectal polyps/adenomas and 2) research modifiable risk factors for primary prevention programmes and secondary prevention of recurrence of screen-detected polyps. Data from an</p> |
| Predictive risk stratification: impact on care for people with or at risk of chronic conditions | 11/06/2013 | <p>The PRISMATIC research study is looking at the impact of a predictive tool available to general practices. Commissioned by the Welsh Government, the Prism tool assesses patients' risk of having an emergency hospital admission in the following 12 months, providing a score out of 100 for every patient (with 100 being the highest possible risk). The tool collates data from 37 primary care, hospital care and demographic variables to provide a secure web-based view for approved GP practice staff. These include the number of medications that a patient has received, the number of outpatient appointments over the past year, and the patient's age. Prism has been available and used in a number of practices across Wales since 2009, and appropriate governance and data security measures have been put in place by the NHS Wales Informatics Service.</p> <p>Prism is set to be made available in the ARMU area in late 2011 and the research team have received funding from the Department of Health</p> |

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| Cost of Wound Management to the NHS | 28/05/2013 | The analysis will estimate the costs of wound management for the NHS and personal social services (eg A&E attendances, inpatient admissions, length of stay, etc). Data on the use of the health service resources will be collected using SAIL extractions based on a detailed data items table. Costs will then be calculated using unit-costs estimated from current published sources. Costs per patient will also be calculated as well as frequency of service use multiplied by the relevant unit cost (also derived from current published sources) to produce a total cost per patient, with a segregation of costs in relation to the where they were incurred and the potential opportunity for cost shifting. |
| E. coli bacteraemia in Wales | 18/04/2013 | The increase in E .coli bacteraemia particularly in the elderly in Wales is a growing cause for concern. Public Health Wales have been asked to investigate the risk factors associated with E. coli bacteraemia, in order to devise population level interventions to reduce the burden of E. coli. |
| Impact of the NICE guideline recommending cessation of antibiotic prophylaxis for prevention of infective | 16/04/2013 | Infective endocarditis (IE) is a rare condition with significant morbidity and mortality. It may arise following bacteraemia in a patient with a predisposing cardiac lesion. In an attempt to prevent this disease, over the past 50 years, at-risk patients have been given antibiotic prophylaxis before dental and certain non-dental interventional procedures. Recent NICE guidelines suggest cessation of antibiotic prophylaxis in dental practices, and this study aims to determine the effects of these guidelines on incidence of infective endocarditis. |
| SAFER 2 (Support and Assessment for Fall Emergency Referrals). | 02/04/2013 | Sail data will be used to measure the outcomes of a structured trial in which some patients, who have fallen and been attended by an emergency ambulance, will receive the current standard treatment, whilst others will be processed according to a new protocol that allows referral by the ambulance crews to different services. The rates of further falls, subsequent 999 calls, A&E attendances for falls, fall related injuries, hospital admissions, quality of life, 'fear of falling', patient satisfaction and death will be compared and summarised for a period of time following the initial 999 event. Comparisons will be made between the group receiving standard treatment and those receiving the new treatment. Where possible this will be achieved in Wales by anonymising the study participants into SAIL so that their routinely collected data can be compared. A simultaneous process in England will be processed by the NHS Information Centre. |

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| Fforestfach fire incident public health impact follow-up | 21/03/2013 | On 16th June 2011, public health agencies in Wales were notified of a fire at an unoccupied warehouse on the Fforestfach Industrial Estate, Swansea. The fire generated a dense, dark smoke plume over the three week period for which it burned with fine particulate matter (PM10) being the emission of primary public health concern. It is considered plausible that those living up to 2km from the incident scene (estimated population 24,812) were exposed elevated levels of PM10 and may have suffered considerable anxiety. This project aims to assess whether there has been any measurable health impacts of this fire on population health in the 12 month period following the fire. |
| Journey mapping of patients with multiple chronic conditions | 20/03/2013 | Anonymised cohorts of people who had an emergency admission to hospital for: heart disease, chronic respiratory conditions, prostate, breast, lung and colorectal cancers, diabetes or stroke between 2007 and 2009 will be linked across primary care, secondary care, and Accident and Emergency care, to capture events before and after the emergency admission. Groups will be established according to what other complicating chronic conditions were also present, and the number and type of health service interactions and total length of stay in hospital, will be summarised for the period 2003 to 2011. The three groups of conditions that have required the most health service support overall will be examined for patterns of variation in the care, to see if good practice events, leading to better outcomes (e.g. shorter length of stay or less returns to hospital) can be observed. As a demonstration project the reporting will suggest hypotheses for further exploration and illustrate to WG colleagues some of the issues that arise when working with routinely collected data. |
| SID-Cymru project | 26/02/2013 | The information available on people who complete suicide in Wales is limited. This acts as a barrier to our understanding of their underlying problems and the effectiveness of efforts at preventing this tragic event. We know there are high levels of mental health disorders, substance misuse, previous self harm and contact with services. However much of this knowledge is based on small studies. More is required, to understand the health and wider social circumstances (short and long term) of those who complete suicide, in order to inform local and national policies. This study will look at possible risk factors for completed suicide from the whole Welsh population, whether known or unknown to mental health services. We will explore factors such as visits to the general practitioner, medication given, self harm, general hospital admissions, medical history and employment. It will highlight areas for intervention to prevent suicide in the general population of Wales. |
| Biobank - Phase II | 15/01/2013 | The study will use anonymised data linkage to bring together lifestyle, environmental and genetic information from Welsh resident volunteers in the Biobank project, and their continuing history of health service utilisation already accumulating in SAIL. This will allow the relationships between the biobank measured factors and the development of diseases to be examined by researchers who will be looking for patterns that might indicate associations between these factors and disease. Participants from the Biobank project have been linked in a previous project, which already received IGRP approval 0091. This study will update those records and add newly recruited participants. |

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| Quantifying the burden of electrical burn injuries | 22/11/2012 | <p>This project aims to quantify the burden of electrical burn injuries, by identifying electrical burn injury patients in the SAIL database and linking their health records together anonymously. The burden of electrical burn injuries in Wales and the UK will be expressed in terms of health service use, disability, fatality, and direct medical costs generated as a result of electrical burns. By assessing the burden of electrical burn injuries, this study hopes to raise the profile of electrical burns amongst the public and policy makers, and direct funding to support intervention/prevention activities.</p> |
| Quality Improvement Toolkits for primary care | 16/10/2012 | <p>PCQIS provides a national platform for the dissemination of quality improvement products specifically for primary care. PCQIS is advised by a national steering group which includes representation from, GPC Wales, RCGP, The Deanery, etc. This group outlines our work plan. There is a large range of products in our catalogue and general information found on our web pages.</p> <p>http://www.wales.nhs.uk/sitesplus/888/page/45127</p> |
| Understanding Healthcare utilisation of responders and non-responders to the bowel screening programme in Wales before and | 09/10/2012 | <p>We want to link the information routinely collected by the screening programmes to other health service data to gain new insights into reasons why people do or do not take up the offer of screening. We hope the results will give us ideas about how to improve both the screening programme and primary care to improve early detection of cancer.</p> <p>Through improved understanding of the differences in co-morbidities and health service usage we are also looking to inform professional training to support improved uptake and therefore to reduce inequities in mortality rates.</p> |
| Dynamic WECC | 03/10/2012 | <p>Research has shown that poor education is associated with ill-health. We propose a study to improve child health and education through the use of routinely-collected anonymised data held within the SAIL databank. We will convert the Wales Electronic Cohort for Children study into a dynamic e-cohort (D-WECC) capable of tracking individuals across datasets monitoring life events including health and education. We will include new births and flag migration. We will create novel links from D-WECC to a traditional cohort: the Millennium Cohort Study (MCS), to explore the effect that additional variables, such as socio-economic status and perceptions of the local environment, has on the well-being of children in Wales who overlap between the two cohorts. In this way we will be able to assess the robustness of using each data source alone compared with the increased power of using a hybrid design. Results will aid in assessing the ability of using routine data to identify health inequalities of children in Wales. This study offers a unique opportunity to inform policy and intervention studies to ensure limited resources</p> |

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| Fuel Poverty | 01/10/2012 Home improvements have been carried out for a number of years on the homes of people classified as being in fuel poverty. By anonymising these property details into the SAIL environment, the health service utilisation of those people effected can be compared before and after the intervention, and against the general population, to establish if the number or GP visits, illnesses, etc are affected by these home improvements to the extent that they might form the basis of a measure of effectiveness. |
| Using the SAIL databank, to develop a comprehensive tool for describing the epidemiology of orthopaedic care pathways in order to | 21/09/2012 The need for joint replacements to alleviate pain and dysfunction from hip and knee arthritis is increasing. Hip replacements are very successful but there is some variability in the success of knee replacements. There has been an enormous growth in knee replacements. The aim of this project is to better understand trends in the need for knee joint replacement in order to improve service planning. This will be undertaken by anonymised data linkage by studying the patterns of health service utilisation of people who have had joint replacements in the past and of those who might be suitable, such as those attending their general practitioners with knee pain |
| Social Deprivation and Epilepsy in Wales | 01/09/2012 Epilepsy is a common disease affecting around 1% of the general population. Epilepsy can possibly decrease quality of life due in part to factors such as the inability to drive and gain suitable employment. This project aims to investigate whether there is a link between social deprivation and the number of people with epilepsy. If any relationship is found it would highlight important areas for future spending decisions on epilepsy healthcare and research. |
| Evaluation of the Flying Start initiative | 30/07/2012 Flying start areas will be determined as a list of households translated from the school catchment areas designated as part of the initiative. These households will be processed into SAIL as a set of residential anonymised linking fields, which enables the existing health records of 0-3 year olds living in these areas to be established. When this group of children progress through education, the key stage achievements can be summarised. Changes in achievement, and in health service visits will be measured for the children in years leading up to the baseline date, 01st April 2009, and annual summaries will be produced from 2009 onwards to establish changes in health service utilisation and educational achievements in successive annual cohorts. Changes in flying start areas will be compared to the control areas to distinguish the initiative effects from general changes over time. |

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| Prescribing trends in Epilepsy | 01/07/2012 | Epilepsy is a common disease affecting around 1% of the general population. The majority of patients with epilepsy will have to take lifelong medication. It is very important therefore for doctors to prescribe the most appropriate medication for the patient. Over the last 10 years there have been several large drug trials in patients with epilepsy which have resulted in new guidelines for doctors when prescribing medications for people with epilepsy. We want to investigate trends in prescribing patterns for anti-epileptic medications in Wales to see if they follow the guidelines. If any differences are identified then this would be an important area for future work as it is very important that people with epilepsy in Wales get the best possible care by being prescribed the most appropriate medication for their condition. |
| GPC HINT Tool testing | 19/06/2012 | The concept of active case finding is to assist clinicians and case managers in identifying patients that may be more suitable for intervention and programmes of care. The objective of these programmes is to improve outcomes and efficiencies. Risk stratification is commonly used to predict patients at risk, for example those likely to be admitted. Gaps in care identifies possible clinical interventions based on established guidelines such as those published by NICE and WHO. Medicines optimisation recommends changes to prescribing that may lead to better outcomes or efficiencies. GP Commissioning have established a tool (HINT) that is able to combine these methods and wishes to explore whether this provides more accurate and useful recommendations for intervention. Anonymous SAIL data from primary and secondary care contains the required content and volume to achieve this. |
| UK MS Register | 31/05/2012 | MS is a complex neurodegenerative condition affecting an estimated 85,000 - 100,000 people in the UK. There is a lack of information about MS to support research and service planning. The MS Society has commissioned a project to develop a prototype MS Register in pilot sites that could be scaled-up to become a national Register. The prototype collects data from; neurology clinics in 5 pilot sites (2 in England, 1 in Wales, 1 in N Ireland and 1 in Scotland); directly from people with MS as they complete questionnaires via a secure internet site; and from routine data such as GP and hospital records. With consent of the people with MS and ethical approval we are able to link these data at the individual level and then remove personal details to create an anonymous MS Register as a rich resource for research and service planning. |
| Predicting the impact of HPV vaccination on cervical cancer: the interaction with screening | 30/05/2012 | In Wales and Scotland screening is initiated at age 20 years and women offered the HPV vaccine through the catch-up programme in Jan 2009 will be eligible for routine cervical screening from Jan 2011. We intend to perform a record linkage study in Wales to ascertain the uptake of screening in vaccinated cohorts. Vaccination status is recorded on the National Community Child Health Database (NCCHD), screening uptake and clinical results are held by Screening Division, Public Health Wales, NHS Trust. The Cervical Screening Wales (CSW) programme database contains records of all women who attended for cervical screening in Wales from 1999 onwards. It contains demographic information, NHS number, dates of cervical smears and results. The NCCHD consists of anonymised records of children who (since 1987) have been born, treated or resident in Wales. Overall data items are 95% complete and these data are used to monitor vaccination uptake. We will use this database to ascertain the cohort of women who were eligible for the catch-up |

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| Screening for Diabetic Retinopathy | 24/05/2012 | <p>Diabetic Retinopathy (DR) (damage to the back of the eye) is a major complication of diabetes, and a leading cause of blindness in the working age population. Screening for DR ensures early detection when treatment is most effective. Current recommendations are that screening for diabetic retinopathy should be carried out on an annual basis in all patients with diabetes. In the retinopathy screening database all patients have existing eye photographs and basic demographic data (age, sex, type and duration of diabetes). Data available via the HIRU databases will include more information on these patients (e.g. blood pressure, glycaemic control, treatment, etc). From this data we aim to devise a method, using modelling and statistical techniques, to predict patients who will or will not develop diabetic retinopathy. The health economic benefits of stratified screening will also be ascertained. The objective therefore is to determine a safe and more cost effective program of screening for diabetic retinopathy.</p> |
| Prognostic factors and outcomes for medical emergency admissions | 01/04/2012 | <p>There are often large differences in mortality following admission as an emergency across hospitals in the UK. Although some of this variation is linked to case mix (factors such as age and co-morbidities) the reasons for much of the variation in death rates is not known. It is also unclear whether this variation across hospitals extends to other outcome measures including lengths of inpatient stay, major hospital infections and high rates of readmission.</p> <p>We have designed a large record linkage study across England and Wales to gain important new insight into factors that are, increasingly, thought to have a possible influence on mortality after emergency hospitalisation. For example, we will establish the extent to which outcomes vary according to whether people are admitted at weekends rather than during the week, according to the size of the hospital, and the specialist services provided by the hospital. We will also establish whether outcomes have changed over time during following reductions</p> |
| Optimal methicillin-resistant Staphylococcus aureus (MRSA) response in Wales: a modelling framework for healthcare | 16/03/2012 | <p>We would like to find out how length of stay in hospital is related to the prevalence of MRSA in the hospital. For this we would need to know in each of 18 main hospitals in Wales, for each patient diagnosed with MRSA the number of days they have stayed in hospital and the number of days until diagnosis. We can then compare this data to other data we have regarding prevalence rates of MRSA, and use it to determine how well our models describe reality. Our models predict a rise in MRSA levels with longer stay in hospital on average. We would also like to see whether MRSA is spread locally (in a room or ward) or nonlocally (by transmission through HCW. For this we would need the ward where the patient was at diagnosis and during treatment.</p> <p>A promise has been made to Welsh Healthcare Appointed Infection Programme (WHAIP) to not use the names of hospitals in any report or publication. Due to the need to link PEDW data back to WHAIP data, hospital names would be needed but again the promise would be that</p> |
| Data Visualisation - Proof of concept | 16/03/2012 | <p>Dealing with vast amounts of data is a challenge and a new technique called Data Visualisation offers the ability to view such data in a different way, which could potentially highlight interesting aspects of the data that are not already known. This project is a proof of concept to understand the process required to work with the SAIL data and the data visualisation tools. To do this a subset of SAIL data will be identified for a group of randomly selected individuals aged 50 yrs + which will list all of their key health events for 12 months. These data will be displayed using Data Visualisation techniques to see if any underlying patterns of care are highlighted.</p> |

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| <p>Modelling risk pathways in coronary heart disease management: simulation of interventions to reduce inequality in</p> | <p>27/02/2012</p> | <p>It is well known that there exists an inequality in the rate of people dying as a result of coronary heart disease in Wales according to the level of deprivation of the population. Those individuals who are most deprived have a substantially greater rate of death from coronary heart disease compared to those who are less deprived. It is known that at least some of this difference relates to differences in the risk factors between the groups (for example it is known that those who are more deprived tend to smoke more), and there is some historical evidence that more deprived individuals receive less healthcare for the condition in situations where they have an equivalent need for healthcare. The primary aim of this project is to understand the extent to which these different possible causes are influencing the differences in death rates between more and less deprived groups.</p> <p>In order to answer this question, the intention is to use the anonymised data held on people in Wales relating to their attendances in primary</p> |
| <p>Comparison of prescribed incontinence drugs. Do patches lead to more consistent and sustained uptake of the medication than</p> | <p>24/02/2012</p> | <p>Oxybutynin is a common type of medication prescribed for incontinence. This is commonly prescribed over a long period of time. There are recognised risks of side effects when taking this drug, and so often patients get switched from one product to another over time. Eventually some patients may stop taking the drug altogether. We wish to explore if the prescribing of the drug by sticky patch reduces these problems, by comparing the prescribing patterns of the drug over time in the GP data routinely presented in SAIL.</p> |
| <p>Down's Syndrome: five year follow up</p> | <p>22/02/2012</p> | <p>This project aims to provide up to date information on the early years of a child with Downs syndrome in Wales. The purpose for the project is to inform decision making around the time of antenatal testing and to provide information for parents who continue with pregnancy.</p> <p>An informal search and review of the literature will form part of this project. Preliminary work has identified a series of papers based on data from the Metropolitan Atlanta Congenital Defects Program which seek to establish prevalence of Down syndrome, survival in infants and association with congenital heart defects.</p> <p>Work is also ongoing within the screening division of Public Health Wales to review and update the advice and information provided. This</p> |
| <p>An analysis of the clinical and environmental factors associated with onset and outcome in childhood type 1 diabetes: an</p> | <p>21/02/2012</p> | <p>Type 1 diabetes is a form of diabetes most commonly diagnosed in childhood that requires insulin injections for life. Careful control of blood sugar levels can reduce the risk of long term problems such as eye and kidney disease, but most patients do not manage to achieve this level of control. The Brecon group of paediatricians have kept records of all children newly-diagnosed with type 1 diabetes in Wales, dating back to 1995. This group (the Brecon Database) now comprises around 2500 children and young adults. Here we propose to link this dataset anonymously to GP and other health records. By studying records of insulin and blood testing kit use, average sugar levels and clinic attendances, linked to data on adverse outcomes such as hospital admissions, and eye problems, we can begin to understand what it is that makes good control difficult in diabetes and which patients are most at risk.</p> |

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| Change in alcohol outlet density and alcohol-related harm to population health | 17/02/2012 | <p>This is an evaluation of a natural experiment in the density of alcohol outlets. The hypothesis is that reduced accessibility is associated with less consumption and lower rates of alcohol related health problems. It is essentially an ecological study in which different area based measures of exposure are related to a series of potential health and social effects, including hospital admissions for diagnoses due to alcohol, evening and weekend emergency department attendances, alcohol consumption measured by the Welsh Health Surveys and alcohol or violence related crime obtained from the police. A list of all premises selling alcohol between 2005 and 2010 will be used to produce density maps at LSOA level. Network analysis of distance between all households and premises in Wales will be undertaken. All household level data will be anonymised using the RALF system operated by NWIS and all small areas (LSOAs) encrypted using the now standard SAIL approach. This system ensures that there is no risk of identifying any individual or household and now even the small areas are anonymised.</p> |
| Caerphilly Health and Social Needs electronic cohort study | 09/01/2012 | <p>Anonymously linking the CHSNS data to SAIL data will allow us to investigate whether common mental disorders are associated with admission to hospital and re-admissions and cause-specific mortality. We will examine whether these associations vary according to individual and neighbourhood social cohesion, household and area income, and socio-demographic characteristics (e.g. age, sex, socioeconomic status, educational achievement, employment, housing tenure). We will account for differences in illnesses at baseline (e.g. Physical and Mental Health), diabetes, arthritis, back pain, cardiovascular disease, cancer, respiratory diseases) and lifestyle factors (e.g. smoking, alcohol consumption, exercise, diet) in increasing the risk of hospital admission and mortality.</p> |
| Environments for Healthy Living | 09/01/2012 | <p>We would like to embed the study data into SAIL in order to give long term follow-up of the study participants. This will include validating data from patient recall and reducing the questionnaire burden by using routine data as much as possible. For example, we would like to examine treatment for depression in pregnancy and the affect this has on the weight and gestional age of the baby and the future health of the infant.</p> |
| COVID-19 Symptom Tracker Data Access - Bristol University | 05/01/2012 | <p>There is an urgent need to map the spread and impact of COVID-19 across the UK. Researchers will analyse data from the C-19 Symptom Tracker app, which is now used by close on 2m people, to understand the spread of the illness and present these data to key decision makers and public health officials to help them identify areas that need focused attention through, for example, more targeted social distancing campaigns or diagnostic testing. In support of this national response, this project is undertaking the following areas of work: - test for infection in schools and test whether staff and pupils have current or past COVID-19 infection; - conduct surveys of teachers to determine the effect of mitigation measures on reducing contacts within schools, and explore the consequence on transmission; - develop risk models of COVID-19 infection in schools that can be updated using data on community infection levels</p> |

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| Air Quality Alerting Pilot in NPT | 05/12/2011 | <p>Routinely collected health service utilisation data will be compared between a recruited cohort of residents with respiratory conditions who have agreed to receive air quality early warnings and a anonymous controls selected from the general population of asthma sufferers. Comparisons will be made, both before, during, and after a period of time when they will receive early warnings of poor air quality in terms of visits to GPs, A&E attendance and hospital inpatients spells. The identities of all those in the study will be anonymised so that researchers will not be able to identify subjects.</p> |
| Real-world Cholesterol Monitoring and Control: A Unique Study Involving EMR (SAIL) + PRO (MediGuard) | 02/12/2011 | <p>MediGuard will identify members with suspected high cholesterol and invite them to participate in the study. Interested subjects will be screened through a web-based survey tool; eligible and interested subjects will continue forward to complete an on-line questionnaire that contains questions related to: disease history; most recent cholesterol results; treatment satisfaction; adherence; health resource use; and demographics. Finally, patients will provide identifying information and an Electronic Signature of consent for their anonymised medical data to be utilised. Subjects will be compensated 20 upon receipt of the completed on-line survey and electronic consent. The resulting MediGuard dataset of consenting participants will be processed as a normal SAIL dataset (i.e., identifiable data will be sent to NWIS to be put through the ALF creation process). Participant response data will be processed into SAIL, and linked to the ALFs provided by NWIS, creating an anonymised linked dataset that includes routinely collected information from GP practice data. The latest available</p> |
| Proton pump inhibitors as a risk factor for campylobacter and other gastroenteitis infections,a cohort study using routine data | 16/11/2011 | <p>Currently several epidemiologic studies show that an increased risk of infections in hospitalised patients and in the general population are associated with the use of gastric acid suppressing drugs. However, conflicting data have been produced on the risk of bacterial infections associated with the use of acid-suppressing drugs. No research has evaluated the incidence of gastroenteritis (GE) among patients who take PPIs. Further research is required to more fully quantify the risk of enteric infections associated with the use of acid-suppressing drugs considering the evaluation of the incidence of GE. We thus assessed (addressing the incidence of GE among patients) whether the use of gastric acid suppressant drugs is associated with an increased risk of bacterial enteral infections.</p> <p>We would like to examine the incidence rate over a 12 month period before and after the prescription of PPI compared to controls</p> |
| GFL_AHI_Proof_of_Concept | 10/10/2011 | <p>To use routinely collected data available within the SAIL databank covering both primary and secondary care to achieve three things:</p> <ol style="list-style-type: none"> 1) Understand how well our existing software and models that originated in Germany will work with Welsh data 2) Stratify the available population data by using a clinical classification system to provide homogeneous groups based upon morbidity and prevalence 3) Accurately predict health events for anonymised individuals using longitudinal data |

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| Risk factor assessment for prevention of premature CVD in clinical practice | 06/09/2011 The aim of our study is to use the powerful SAIL database to explore how often CVD risk factors are NOT formally assessed and managed in patients presenting with heart attacks and angina at a young age. These data will be used in the future to identify and improve the detection and treatment of those at risk, to assist the development of strategies to reduce the burden of premature CVD as a major health problem in Wales. |
| Health impact, and economic value, of meeting housing quality standards | 17/08/2011 This is an NIHR funded evaluation of a natural experiment. The natural experiment is the substantial improvement of housing quality in 9,256 social housing homes in Carmarthenshire over a 5 year period. The evaluation aims to quantify the health and educational benefits of improving housing conditions. Using the standard SAIL methodologies of splitting files and multiple encryptions of individual, household and small area codes means that it is possible to track the health of residents without ever knowing who they are or where they live. This will allow us to quantify the expected benefits of living in homes meeting 21st century quality standards. Potential benefits include fewer deaths, heart attacks, improved mental health, and possibly improved educational attainment in children brought up in warmer homes. Injuries may be increased (unfamiliar lay outs) or decreased (fewer hazards). The health of residents before and after the intervention will be tracked and compared with the general population and a comparator group of social housing in Swansea. |
| Wales Electronic Child Cohort | 18/07/2011 An investigation into the associations between foetal echogenic bowel and perinatal and paediatric outcomes. Identification of babies diagnosed with foetal echogenic bowel on second trimester ultrasound through the CARIS database, and then an analysis of health care usage as compared to control babies. |
| Establishing the prevalence of certain rare neurological conditions as recorded in Primary Care using the SAIL databank | 15/05/2011 Long term conditions that are managed without regular hospital attendance tend to be recorded in GP systems. The condition may be noted by a GP at any point in the history of the patient, so that identification of patients requires searching the data over a long time span. The electronic recording of GP practice records has gone from limited recording to substantial recording from the late 1980s to the present day, during which time governmental initiatives have altered coding priorities. Diagnoses may be subject to general refinement or review over time, and for individual patients as they present to different GPs over time, Patients move and register with different GPs. GPs may retire and the patient registration is transferred. All these things lead to complications in the analysis of such data. Using a set of hereditary neurological conditions as an example, the study aims to document and address complications with an aim of establishing a robust methodology for completing such investigations |

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| Chronic obstructive pulmonary disease (COPD) prevalence, hospital admissions and deaths for patients registered with Abertawe Bro Morgannwg health | 01/05/2011 | GP practices in the ABM UHB area have been grouped into community networks. The Public Health Wales Observatory have been asked to determine COPD prevalence (using GP data), hospital admission rates and mortality rates for these community networks. |
| EUROmediCAT: Safety of Medication use in Pregnancy in Relation to Risk of Congenital Malformations. Project no 260598 | 25/03/2011 | A variety of complementary approaches are needed to evaluate safety of medicine use in pregnancy. To evaluate safety in relation to teratogenicity (capacity to cause malformations), population-based congenital anomaly registers, which are already networked across Europe (EUROCAT) with a common database, can provide a cost-effective mechanism which is as yet underexploited. The enormous population coverage of registers when combined gives sufficient statistical power for the identification of associations between specific drugs and specific malformations. This project will develop and test an efficient pharmacovigilance system for safety of drugs during pregnancy in relation to teratogenicity by (i) enhancing the information regarding drug exposure in the EUROCAT database, covering a total population of 3 million births 1995-2010, through linkage to electronic databases containing prescription information, and by linkage to chronic disease cohorts (ii) analysing the enhanced EUROCAT database in relation to four drug groups of public health concern - new antiepileptics, insulin analogs, SSRI |
| Multiple Sclerosis Case Ascertainment by querying the SAIL Databank | 01/03/2011 | An algorithm will be developed to ascertain the cases of Multiple Sclerosis from the records in the GP and Patient Episode Database Wales (PEDW) databases, as well as from the ONS Mortality records for Wales. The demographic characteristics of the records People With MS (PWMS) found through this method will be summarised and analysed. An anonymised PWMS cohort will be assembled from the extracted records and will be analysed for the following: <ul style="list-style-type: none"> • Age and sex distribution • Geographic distribution • Size estimation through the capture-recapture method • Number of mortalities in the cohort and demographic characteristics of the mortalities |
| SAFER (Support and Assessment for Fall Emergency Referrals) Trial | 11/01/2011 | The project involving HIRU is aimed at following up study patients who have had contact with an emergency department or been admitted as an inpatient, or have died, since their initial 999 call and inclusion in the study. This will be tracked and linked anonymously through SAIL, and output for analysis in SPSS |

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| The Epidemiology of Body Mass Index in the Welsh SAIL Primary Care Database | 07/01/2011 | <p>Obesity presents a major public health challenge to Wales over the coming decade and has been identified as a high priority area for health improvement by the Welsh Assembly Government. There is relatively little published literature on the epidemiology of obesity, particularly in relation to the Welsh population, and there is particularly poor information on trends in the severely obese (BMI of over 50 kg/m²).</p> <p>The aim of the study is to examine: The project aims to:</p> <ol style="list-style-type: none"> 1. Measure the completeness and validity of obesity data in the SAIL database 2. Measure changes in the pattern of severe obesity over time 3. Examine the association between obesity and co-morbidity |
| Do children who move frequently have poorer health and educational outcomes? | 07/01/2011 | <p>House moves are regarded as a stressful life event. Findings from a previous study from Swansea highlighted that children who presented with a burn before the age of three were more likely to move house before their sixth birthday compared to unburned control children. Another recent study has also suggested that children who move frequently are more likely to commit suicide. There has been little research however that has examined the effect of frequency of house moves on the long term health or educational outcomes of children. The proposed study will examine anonymised child health records within the Wales Electronic Cohort for Children to</p> |
| The Epidemiology of Open Tibial Fractures in Wales | 04/01/2011 | <p>Fractures of the tibia (shin bone) are particularly severe injuries when there is an open wound in the overlying skin. Combined surgery from specialised orthopaedic & plastic surgeons is required. This will mean that patients are often transferred to the hospital with these specialist services. Recently published standards of care aim to improve the outcome for patients by encouraging transfers to occur as soon as possible. However, our preliminary data shows that a significant number of patients remain under the care of the admitting hospital, and are only transferred once problems occur, sometimes weeks or months after injury. Presently it is impossible to know how large a proportion of patients sustaining open tibial fractures receive ortho-plastic care in the intended manner. The long term fate of patients who are never transferred remains unknown. This study will give us accurate numbers of recorded open tibial fractures for South Wales, and will also give us valuable information about the follow-up needed during the healing process. These data will help us develop the service we provide, and</p> |
| Prevalence and prevention of obesity and other risk factors for CVD among young people with a focus on high risk ethnic minority groups | 01/12/2010 | <p>This study examines growth rates and attendance at the GP for children who are categorised as high risk for diabetes and cardiovascular disease (CVD) compared to those categorised as low risk. This can help to identify early predictors of obesity and risk factors for CVD among children.</p> |

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| Population based ankylosing spondylitis cohort (PAS) | 19/10/2010 | This proposal is for a population based cohort of people with AS, utilising disease-specific data (rheumatology database, radiology imaging) and patient completed data, linked with existing electronic data from clinical, laboratory and administrative systems held by HIRU. All patients with a diagnosis of AS living in Wales will be approached to participate in the cohort and give a well characterised cohort with robust clinical data as its base. Question to be asked of the cohort will include: risk of adverse events such as myocardial infarction associated with AS, cost/burden of AS (cost of AS to the NHS and the patient), factors associated with a severe outcome (i.e. early life factors associated with need for surgery and/or need for anti-TNF medication). |
| Developing new risk models to improve targeting of the Fire and Rescue Services (FRS) Home Fire Safety Check (HFSC) | 13/10/2010 | As part of a major initiative to reduce the number of fire related deaths and injuries in the home, FRSs throughout the UK have been offering free Home Fire Safety Checkss. Although FRSs in Wales have developed area and household level risk models to target their free HFSC initiative towards higher risk households, many house fires still occur outside of these targeted areas. We propose to work with the FRS to help them improve their current risk models. By linking anonymised data from the FRS to anonymised health, education and environmental data stored within the SAIL databank, we will investigate whether certain health or environmental exposures (for example, having a smoker reside in the household, or people with chronic conditions, or those living alone) are at appreciably higher risk of house fires. The SAIL models cannot be used by the FRSs in an operational sense due to the anonymisation but if high risk |
| MINISAIL: Using routine data to estimate service need for Common Mental Disorders in Primary Care | 29/09/2010 | Common mental disorders (CMD), such as depressive and anxiety disorders, have serious costs to the individual and society. They account for over 30% of work days lost due to ill health and 20% of visits to the GP. At any time around 30% of people are affected. We have demonstrated in publications from an earlier WORD-funded project that the Mental Illness Needs Index (MINI), a score based on local area Census data collected every decade, is associated with the prevalence of CMD. We now plan to look at the relationship between levels of CMD in Wales, assessed using general practice diagnosis codes from the Secure Anonymised Information Linkage (SAIL) project, and a MINI-like score (MINISAIL), calculated from data more regularly available than Census data. We will then be able to compare actual levels of CMD currently diagnosed in general practice to levels predicted using MINISAIL scores, based on routine data collected by the SAIL project |
| An e-cohort study of serious adverse outcomes from antipsychotic drug use in older people with dementia in the community and care homes | 17/08/2010 | There has been concern for some years that antipsychotic drug use in older people with dementia is associated with poor outcomes and increased mortality. A recent Department of Health commissioned review highlighted the difficulties, emphasising that these medications are frequently inappropriately prescribed to treat behavioural symptoms of dementia. The report suggests that up to 1,800 extra deaths per year in the UK are attributable to these medications. This may be a conservative estimate as it is based on an extrapolation of short-term drug trial data that does not reflect true prescribing patterns. Our study involves a large-scale epidemiological review of the relationship between these medications and adverse outcomes for people with dementia. SAIL is an anonymised electronic database that allows researchers to anonymously identify patient groups and then investigate |

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| The development of an e-cohort for autoimmune diabetes in Wales. | 17/08/2010 | <p>Currently there are no published clinical guidelines to help health professionals manage and advise patients with latent autoimmune diabetes in adults (LADA). It is not clear within the literature what happens to the patient (patient pathway) once they have been classified as having autoimmune diabetes. For example;</p> <ul style="list-style-type: none"> (i) What treatments are prescribed in LADA and whether these treatments are adequate in maintaining blood glucose levels. (ii) Treatment by length of time to auto-antibody testing. (iii) The complications of diabetes incurred in LADA compared with other types of diabetes. (iv) The value of testing Thyroid function and other tests in LADA compared with other types of diabetes |
| Using anonymised routine data to Investigate the temporo-spatial patterns of suicide and other causes of death in Wales 2003 to 2008 | 26/07/2010 | <p>In Wales, suicide is one of the leading causes of death among young people. There is growing recognition that up to 5% of suicides may occur in clusters (i.e. close together in time/space) in people under 25 years. Our understanding of what triggers a suicide cluster, what influences its continuation and eventual cessation, and, critically, what advice to give to communities experiencing a suicide cluster, is limited. In 2007/08 a cluster of approximately 20 suicides occurred among young people living in the Bridgend area. In order to establish the context of the Bridgend suicide cluster we need to have a clear picture of the temporo-spatial patterns of suicide and other causes of death in Wales for the period before and during the cluster. The routine data on cause of death held in the SAIL data bank will allow us to do this.</p> |
| Dermatology service development for Hywel Dda Health Board based on a healthcare needs assessment | 19/07/2010 | <p>Data provided by HIRU will help establish the burden of skin disease in West Wales (Carmarthenshire, Pembrokeshire, Ceredigion). In addition it will be used to determine possible associations between type of skin disease and healthcare usage and area of residence, age, gender and level of deprivation. This information will then be used to better inform the development of dermatology services and resource allocation for the Hywel Dda area.</p> |
| Biobank UK: Improving the health of future generations | 23/06/2010 | <p>UK Biobank is a major UK medical research initiative, and a registered charity in its own right, with the aim of improving the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses, including cancer, heart diseases, diabetes, arthritis and forms of dementia. To do this vital work we need your help. We are now recruiting 500,000 people aged 40-69 from across the country to take part in this project. UK Biobank's Cardiff assessment centre has been opened and participants have given informed consent that their electronic health records can be used to augment the study data. The UK Biobank is currently investigating the best way to acquire electronic health records. HIRU has developed the SAIL databank that contains anonymised patient level data from routinely collected health and social care providers. This pilot study proposes to investigate the information governance, technical and logistical issues of supplying anonymised electronic health records to a research project of participants that have given informed consent</p> |

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| Environmental and socio-demographic factors associated with the incidence and outcome of serious asthma | 01/04/2010 | The SAIL data will allow us to investigate the hospitalised incidence (per 100 000 population) and case fatality at 30 days for serious asthma overall across Wales and according to socio-demographic factors such as social deprivation quintile, age group, sex, urban v rural residence, background air pollution, size of hospital, and distance to hospital. |
| NTEGRIS Work package 6: Integration of new technology to provide better estimates of injury related morbidity across Europe | 01/04/2010 | <p>juries are an important cause of disability and death in Europe. The European Injury Database (IDB) was implemented in 1999 and currently involves 12 member states. IDB is a standardised reporting system implemented in accident and emergency departments in a sample of hospitals.</p> <p>Different types of data are available in the IDB and in the routinely collected hospital discharge registers (HDR). Although HDRs may not always have all the desired detail, they are mplemented in all countries. INTEGRIS aims to link these two datasets to improve detail on the nature of injuries for admitted patients. This is pilot study towards a more comprehensive Europe-wide collection of anonymised injury surveillance data to support the development and evaluation of policies to prevent injuries. EU member states have accepted the World</p> |
| The Epidemiology of Harmful Algal Blooms and the Future Implications of Climate Change | 15/03/2010 | <p>The aim of the main project is to firstly asses the current state of the epidemiology of Harmful Algal Blooms in the North Atlantic Waters. This will be achieved by identifying the main species, which cause shellfish posioning. Secondly, to identify the climatic variables that affect each of the main toxic species, and to use ecological niche modelling to predict their future status.</p> <p>There are few published records of shellfish poisoning and we suspect that there is a high level of underreporting. Using the hopsital admissions and pathology records from the HIRU dataset, we aim to quantify the frequency of incidence of shellfish posioning, and identify which toxins are the most prevlevant. This will enable us to gain a good understanding of how often cases of shellfish posioning occur in Wales and assess the efficiency of shellfish toxin monitoring system</p> |
| Adiponectin Levels in People with Latent Autoimmune Diabetes A Case Control Study. | 25/02/2010 | The project team have conducted research investigating the adiponectin levels of patients with LADA matched with type 2 diabetic and non-diabetic controls. The work has been submitted to a peer reviewed journal and received a recommendation that the analysis should be controlled for BMI (Body Mass Index) as a cofounder. The project team do not have BMI data for the non-diabetic controls and would like to explore the potential of using SAIL data to supplement their study data. The project team has a list of all the NHS numbers for all of the participants and will securely send this to HSW for anonymisation. Once anonymised the data will be loaded into SAIL and for each of these anonymous individuals the GP data will be searched for weights, height & BMI measurements. These measurements will then be appended to the original study dataset (within the SAIL environment) and the statistical analysis will be repeated including the new BMI data as a cofounder |

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| Outcome measures from routine administrative data | 23/02/2010 | <p>Routine administrative inpatient and mortality held in SAIL will allow us to produce outcomes measures for all acute medical admissions - and for admissions for several subgroup conditions - at the hospital level across hospitals in England and Wales during a recent 12 month period (1st June 2008 to 31st May 2009).</p> <p>The subgroup conditions are COPD, MI, stroke, pulmonary embolism, DVT, cellulitis, and GI bleeding.</p> <p>The outcome measures would be length of hospital stay, mortality rates (irrespective of cause of death), readmission rates (irrespective of cause of readmission) and recorded c.difficile infection rates. They would be obtained via HES for England and PEDW and NHSAR for Wales.</p> <p>These crude, basic outcome measures will be at the hospital level not at the patient level.</p> |
| PsyCymru - A pilot study to establish the feasibility of an all Wales psychosis cohort with electronic linkage. | 08/02/2010 | <p>Patient databases such as PEDW and GPD contain information about patient diagnoses stored as ICD-10 and read codes respectively. We will search these databases for the codes corresponding to psychotic illnesses to arrive at a large prevalence cohort of people with Psychosis in Wales. The anonymised linkage field or ALF in each dataset will enable us to link the people with a psychosis read code across all the datasets. This will provide us with a large amount of data about medication, health outcomes and mortality for all people with psychosis in Wales. It would also provide the potential to incorporate a longitudinal perspective.</p> |
| Is capillary glucose testing associated with improved HBA1c? | 01/02/2010 | <p>Controversy exists on the prescription of glucose testing strips to patients with diabetes as the strips are costly and the current management algorithms (NICE, Wales Diabetes Guidelines) are based on HBA1c. The Swansea Diabetes Research Group (DRG) is interested in using the SAIL databank to investigate if there is an association between Hb1Ac levels and the number of glucose testing strips prescribed in the six months prior to the Hb1Ac test, for different treatment groups (diet only, those on oral agents only and those receiving insulin, which may be in combination with oral agents).</p> |
| Development & Evaluation of Prognostic Models in Breast Cancer | 01/02/2010 | <p>Protocol</p> <ol style="list-style-type: none"> 1. Submit dataset for breast cancer cohort to HIRU. Dataset will include patients who have been diagnosed for breast cancer in the 1990's. Variables in dataset will include patient forename, surname, NHS number, tumour grade, number of nodes positive, tumour size. This data has been collated and prepared by Dr Paul Lewis' group. 2. Request for anonymised data for all patients: date of death and cause of death if available. 3. Apply prognostic models to dataset. 4. Evaluate models for sensitivity and specificity using R |

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| Free School Breakfast Initiative Data Augmentation and Analysis | 27/01/2010 Anonymise components of the existing study data, incorporating this into SAIL and then linking to educational attainment data. Analysing relationships between the study data and educational attainment. |
| Welsh electronic cohort for children (WECC) | 10/11/2009 To improve understanding of the factors underlying the development of childhood obesity and inform the development of interventions to prevent or halt the increase in obesity. The purpose of this project is to develop a research platform capable of improving children's health through the generation of knowledge from analysis of routinely collected data from within and outside the health service in support of Welsh Assembly Government priority. It will utilize data that are routinely collected in Wales to answer specific questions about child health and well-being, with the aim of informing policy and practice in Wales, whilst also being internationally relevant. These datasets are publicly funded, and have already been incorporated into the Secure Anonymised Information Linkage databank. We propose to combine these datasets on children from health and social care to establish an anonymised Wales wide electronic cohort for children (WECC). Once established, WECC will serve as the platform for future work in translating information into child population health policy. |
| Hospital admissions of people with diabetes in Wales - the size of the problem | 14/10/2009 How many admissions and how many occupied bed days in hospital are the result of diabetes as a principal diagnosis and how many have diabetes recorded as a subsidiary diagnosis, how valid are the data and how have things changed since the 1980's? |
| Data Mining Approach to Identifying Impacts of Children's Health on Educational Outcomes Based on Linked Datasets with | 14/10/2009 A great deal of evidence from medicine, health economy, and social science has emerged that childhood health and socioeconomic status has significant long-term effects on future outcomes. Children who have poorer childhood health and socioeconomic care conditions tend to have lower educational attainment. However, traditional health statistics and socioeconomic research efforts on this topic focus on investigation at population level based on surveys. Currently, little research has been done on examination of effect of joint children's health and socioeconomic care conditions on educational attainment based on individual record level data. In this project, using the linked individual level data obtained via SAIL databank, we aim to develop novel data mining approach to tackling some challenging issues. |

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| Prevalence and prevention of obesity and other risk factors for CVD among young people with a focus on high risk ethnic minority groups | 28/08/2009 To develop growth curves of weight and height (IOTF BMI measures) for the children surveyed in the main study. These curves can be used to examine how growth in the first year of life predicts the development of risk factors for CVD and T2D at age 11-13. |
| How are pregnancy outcomes affected by intervention (colposcopy) following abnormal cervical smear? | 18/08/2009 The SAIL anonymised version of the Cervical Screening Wales database will be used to select anonymous individuals that have had a first episode colposcopy and also randomly select 2 controls (women who have had negative smears and no history of abnormal smears or colposcopy) match for age and GP practice. Data from April 2001 to March 2003 will be used for this project. These selected individuals will then be anonymously linked to the National Community Child Health Database and the All Wales Perinatal Survey to identify key measures, such as gestational age, stillbirths and perinatal deaths. From these databases, rates of preterm birth, low birth weight, perinatal mortality and time from intervention to pregnancy outcome can be calculated. |
| G & W Burden of Injury | 08/08/2009 This project is the Welsh/UK component of the Global Burden of Disease international study which aims to improve measurement and understanding of the magnitude and causal factors involved in injury related deaths. It is also an essential part of a Wales Burden of Injuries Study being carried out for the Public Health Wales NHS Trust and the Welsh Assembly Government. Current official statistics in most countries, including the UK, greatly underestimate the impact of injuries on society, as many injury related deaths are coded to unspecified causes or to other diseases. The purpose of the study is to provide better information on the size of the injury problem in the world and Wales to guide policy development on injury prevention. |
| A state of the art information-driven health care demonstrator: Combining advanced technologies in the gastro-intestinal | 14/04/2009 Clinical electronic information captured about patients with IBD (Inflammatory Bowel Disease), within gastroenterology clinics at Neath Port Talbot hospital, will be anonymised, securely transferred and loaded into the SAIL databank. These anonymous individual identifiers will be linked to existing data stored on the SAIL databank (general practice, hospital, pathology) producing a complex dataset of the IBD patients medical history. A machine learning algorithm, prepared by the Engineering department in Swansea University, will be installed on one of the secure terminals and will link to this anonymous dataset. The algorithm will then process the data exploring patterns/clusters within the data that Clinical electronic information captured about patients with IBD (Inflammatory Bowel Disease), within gastroenterology clinics at Neath Port Talbot hospital, will be anonymised, securely transferred and loaded into the SAIL databank. These anonymous individual identifiers will be linked to existing data stored on the SAIL databank (general practice, hospital, pathology) producing a complex dataset of the IBD patients |

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| Community Acquired UTIs and Community prescription of Antibiotics – the association for individuals and family members | 01/03/2009 'Resistant strains' of bacteria are those that cannot be treated fully by the normal course of antibiotics. There has been a lot of publicity recently about certain types of resistant bacteria, for example 'MRSA' or 'Methicillin Resistant Staph. Aureus'. Resistance occurs naturally through 'mutation' of bacteria, but can be greatly increased through prescription of antibiotics. This study aims to look at one type of common infection, urinary tract infection, or UTI, and then compare the prescriptions of antibiotics for people who have got a laboratory proven resistant bacteria to those who have got a none resistant or 'sensitive' strain. Then there will also be a comparison of all of the antibiotic prescriptions of household members in those with resistant strains compared to those who have the 'sensitive' type. This will tell us if there is an association between prescriptions to household members and another member of the family developing a resistant infection |
| Chronic obstructive pulmonary disease (COPD) for patients registered with Abertawe Bro Morgannwg GP practices | 01/01/2009 GP practices in the ABM UHB area have been grouped into community networks. The Public Health Wales Observatory have been asked to determine COPD prevalence (using GP data), hospital admission rates, mortality rates and COPD outcome measures (e.g. flu vaccination uptake) for these community networks. |
| SAIL Databank | 01/01/2009 The SAIL Databank is a world-class complete solution to sourcing, accessing, linking and analysing health and population data all within a governed infrastructure that is safe and secure. Researchers can access a broad range of routinely collected data spanning up to 20 years from an entire population. The SAIL Databank provides you with linkable, anonymised datasets ready for analysis that can be accessed remotely via our unique SAIL Gateway platform, complete with analysis tools. |
| Development of pathology informatics data analysis platform | 02/09/2008 The key objectives of the study are to (i) evaluate middleware and tools for mining of free text pathology reports; (ii) evaluate and develop middleware for heterogeneous clinical and pathology data integration and multivariate data analysis. We wish to utilise anonymised free text pathology reports, obtained from Morriston Hospital data, to evaluate a number of available tools for text mining. The tools will allow us to build a vocabulary of terms useful beneficial for research metadata. We are also developing middleware and user interfaces for multivariate analysis of clinical and pathological datasets. We (via Phil Verplancke and Nathan Hill) have previously deposited anonymised data from the US SEER database to serve as a test dataset for this project. |

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| Can routinely collected health related data be used to monitor the prevalence of depression and post traumatic stress disorders in patients | 15/06/2008 | <p>1- monitor the prevalence of depression and post traumatic stress disorders in patients admitted to hospitals due to burn injuries.</p> <p>2- Identify the risk factors in order to predict the patients with high risk of developing mental health disorders after burn injuries.</p> |
| Calculating the electoral ward prevalence of asthma in the Swansea area using linked Primary Care data | 11/06/2008 | <p>Asthma is a hereditary condition affecting the bronchial tubes leading to the lungs, which become inflamed, mucous filled and constricted, making the flow of air to the lungs very difficult. There are two types of asthma, non-allergic or intrinsic and allergic or extrinsic. The difference between the two types is that intrinsic asthma is present without any known trigger whereas extrinsic asthma is triggered by some external antagonistic substance. There are many such triggers including dust and chemical fumes.</p> <p>As with all chronic conditions that are well managed in the primary care setting, historically it has not been possible to determine an accurate figure for the prevalence of the condition at a small area level, as records for each individual diagnosed with the disease have been retained by their General Practitioner, and independent contractor governed by strict codes of confidentiality. The SAIL project, however, has allowed</p> |
| Measurement of the Global and Wales Burden of Injuries | 03/05/2008 | <p>This project is the Welsh/UK component of the Global Burden of Disease international study which aims to improve measurement and understanding of the magnitude and causal factors involved in injury related deaths. It is also an essential part of a Wales Burden of Injuries Study being carried out for the Public Health Wales NHS Trust and the Welsh Assembly Government. Current official statistics in most countries, including the UK, greatly underestimate the impact of injuries on society, as many injury related deaths are coded to unspecified causes or to other diseases. The purpose of the study is to provide better information on the size of the injury problem in the work and Wales to guide policy development on injury prevention.</p> |
| Folate Augmentation of Treatment Evaluation for Depression (FolATED): a randomised controlled trial | 05/03/2008 | <p>Recruitment to clinical trials can be challenging. The purpose of this study was to test a new method of identifying suitable participants using routinely collected data (housed in the SAIL databank) that would make it easier for practices to identify potential subjects for a clinical trial and consequently reduce their workload, whilst potentially maximising recruitment and reducing costs.</p> <p>Stage 1: Methods</p> <p>Swansea Universities Health Information Research Units Secure Anonymised Information Linkage (SAIL) database of routinely collected health records was interrogated, using Structured Query Language (SQL). The folATED inclusion/exclusion criteria were translated into read codes which were used in the algorithm to identify suitable anonymous participants. Two independent clinicians rated the eligibility of the</p> |

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| Incidence and case fatality for upper gastrointestinal (GI) bleed in Wales | 18/02/2008 | The SAIL data will allow us to investigate the hospitalised incidence (per 100,000 population) and case fatality at 30 days overall across Wales and according to socio-demographic factors such as social deprivation quintile, age group, sex, geography, size of hospital, and day of admission (weekday v weekend) for upper GI bleed. The SAIL data will also enable investigation of any trend over time in the incidence and case fatality for upper GI bleed in Wales from 1999 to 2007. |
| Non-conveyance of 999 callers: risk, views and decision making | 08/05/2007 | Patient clinical records (PCRs) completed by emergency ambulance crews based at three Swansea ambulance stations for patients that they attended but did not convey between 01/07/2006 and 31/12/2006, were collected (n=827) through a manual sorting process within the ambulance service. The PCRs were entered into an electronic database and uploaded to the SAIL databank through a process involving file splitting, matching and anonymisation, enabling linkage of each PCR to other health service routine data without identification of individuals. These data relate to GP out of hours calls, NHS Direct calls, GP contacts, accident and emergency attendances, hospital admissions, outpatient appointments and deaths. All health service contacts made within six months of the 999 call were identified and time from call to first contact was noted. |
| Common infections, their complications, antibiotic prescribing and resistance: moving away from simple correlations | 28/03/2007 | Where antibiotic prescribing has reduced in general practice, there is concern that it may have fallen too much, putting patients at greater risk from complications from infections. To our knowledge no studies have measured in patients presenting to practices with an respiratory tract infection (RTI), individual exposure to antibiotics and serious or complicated common infections presenting in secondary care as well as general practice, therefore underestimating the number of complications. Using individual data arising from general practices, we plan to explore this relationship, with the aim of understanding whether patients who do not receive antibiotics for a RTI have a higher risk of developing a serious or complicated common infection (in general practice or in secondary care). We further plan to explore the impact that other factors may have on the occurrence of a serious or complicated common infection, such as prior antibiotic use and patient characteristics such as co-morbidity. |
| Reducing clinical risk in the management of alcoholic re-attenders in Emergency Departments | 00/01/1900 | Alcoholic A&E mortality linkage This study is for an MD thesis in the College of Medicine, Swansea University, which is investigating the clinical management and clinical risks for alcohol-related re-attenders at Emergency Departments in Swansea and Newport. The study patients are 74 from Morryston Hospital Swansea and 97 from the Royal Gwent Hospital, Newport The SAIL data will enable us to investigate how mortality rates and hospital admission rates (for alcohol-related causes including liver cirrhosis, acute and chronic pancreatitis, upper gastrointestinal bleeding, etc) among the study patients compare with those in the corresponding age-group and sex matched general population. This will help enable the project to assess the degree of clinical risk in the |