2021/2022 Applications approved by HSC-PBPP to 31st March 2022

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Application Reference	Applicant	Applicant Organisation	Title of Study	Approved/ Approved with conditions	Level of Approval	Clocked Time (days)
2021-0035	Dr Martin Johnson	NHS Golden Jubilee	Mortality data for the Scottish Pulmonary Vascular Unit	Approved	Tier 1 Panel Meeting	9
2021-0248	Fiona Wee	University of Edinburgh	Cervical Ripening at Home or In-Hospital - prospective cohort study and process evaluation (CHOICE Study)	Approved	Tier 1 Review	31
1920-0176	Dr Michael Fleming	University of Glasgow	Investigating the relationship between health and educational outcomes in children	Approved with conditions	Tier 1 Review	88
2021-0307	Professor Helen Colhoun	Public Health Scotland	Record-linkage to estimate risk of Cerebral Venous Thrombosis associated with COVID-19 Vaccine exposure	COVID19 Approved with recommendations	COVID19 rapid review panel	6
2021-0243	Professor Irene Higginson	King's College London	CovPall-Connect. Evaluation of the COVID-19 pandemic response in palliative and end of life care: Connecting to boost impact and data assets.	COVID19 Approved	Tier 1 Review	13
1819-0286	Dr Rosemary Hollick	University of Aberdeen	RHEUmatic and musculoskeletal conditions: geographical MApping of Prevalence and outcomeS (RHEUMAPS)	Approved with conditions	Tier 1 Review	18
1920-0229	Dr Jasmeet Soar	Royal College of Anaesthetists	The 7th National Audit Project (NAP7) of the Royal College of Anaesthetists (RCoA): Perioperative Cardiac Arrest	Approved with conditions	Tier 1 Review	15
2021-0291	Dr Andrew McAuley	Public Health Scotland	Enhanced Surveillance of COVID-19 in Scotland: population-based seroprevalence surveillance	COVID19 Approved with recommendations	COVID19 rapid review panel	9
2021-0036	Dr Hester Ward	NHS NSS	Cost-effectiveness analysis of the living donor transplant program	Approved with conditions	Tier 1 Review	15

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2021-0138	Dr Diane Lindsay	Glasgow Royal Infirmary	Genomic epidemiology of Legionella pneumophila in Scotland	Approved with conditions	Tier 1 Review	19
1920-0228	Professor Fiona Gilbert	University of Cambridge	BRAID- Breast Screening – Risk Adaptive Imaging for Density	Approved with conditions	Tier 1 Review	46
2021-0067	Mark Danton	University of Glasgow	Impact of COVID-19 pandemic on Scottish Congenital Heart Population	COVID19 Approved with recommendations	Tier 1 Panel Meeting	6
2021-0308	Dr Linda Fiaschi	University of Nottingham	COVID-19: PROphylactic ThErapy in Care homes Trial	COVID19 Approved with recommendations	COVID19 rapid review panel	16
1920-0194	Dr Emily Adrion	University of Edinburgh	The Elimination of the Prescription Charge in Scotland: Understanding the short- and medium-term impact of prescription charge removal and examining future directions	Approved	Tier 1 Review	24
2021-0264	Dr Annemarie Docherty	University of Edinburgh	HEAL-COVID	COVID19 Approved with recommendations	Tier 1 Panel Meeting	8
2021-0154	Joe Schofield	University of Stirling	Exploring the utility and safety of benzodiazepine prescribing among people receiving Opiate Replacement Therapy in Scotland (the BENZORT study).	Approved with conditions	Tier 1 Review	24
2021-0059	Dr Kuan Ken Lee	University of Edinburgh	High-sensitivity troponin in the evaluation of patients with acute coronary syndrome (HighSTEACS): A randomised controlled trial (this includes the substudy known as HiSTORIC)	Approved with conditions	Tier 1 Panel Meeting	20
2021-0131	Dr Ryan Wereski	University of Edinburgh	Myocardial Injury in elective Coronary Angiography	Approved	Tier 1 Panel Meeting	9
1920-0225 SR296	Andrew McNally	National Haemophilia Database (NHD) / UK Haemophilia Centre Doctors'	Haemophilia Mortality Study	Approved	Tier 1 Panel Meeting	14

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		Organisation (UKHCDO Ltd).				
1819-0356	Colin Angus	University of Sheffield	Evaluating the impact of Minimum Unit Pricing for alcohol on harmful drinkers	Approved with conditions	Tier 1 Panel Meeting	9
2021-0135	Dr Niamh Mclennan	University of Edinburgh	Impact of Covid-19 Clinical Care Pathway Changes on Gestational Diabetes Prevalence and Pregnancy Outcomes, UK data study	COVID19 Approved with recommendations	Tier 1 Review	27
1617-0269	Julie Landsberg	Scottish Government	Scottish Health Survey (SHeS)/SMR data linkage	Approved with conditions	Tier 1 Panel Meeting	8
2021-0200	Dr Rachel Rowe	University of Oxford	The UK Midwifery Study System (UKMidSS)	Approved	Tier 1 Review	19
1920-0021 SR281	Dr Helen Harris	Public Health England, National Infection Service	Hepatitis C National Register	Approved with conditions	Tier 1 Panel Meeting	14
1920-0126	Dr Jayne Digby	University of Dundee	Intelligent use of quantitative faecal immunochemical testing for haemoglobin in screening populations	Conditions Met	Tier 1 Panel Meeting	8
2122-0042	Fiona Murdoch	NSS National Services Scotland	Further Analysis of Hospital Onset COVID-19 Cases in Scotland through data linkage	COVID19 approved with recommendations	Tier 1 Review	14
1920-0199	Dr Michelle Williams	University of Edinburgh	Secondary image analysis research using anonymised imaging	Approved with conditions	Tier 1 Review	19
2122-0018	Dr Anna Santarsieri	Addenbrookes Hospital, Cambridge	Toxicities and strategies to reduce them in blood cancer patients treated in the non-trial setting	Approved	Tier 1 Review	17
1920-0257	Julie Landsberg	Scottish Government	Scottish Health Survey (SHeS)/SMR data linkage – Legal basis change	Approved with conditions	Tier 1 Panel Meeting	6

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2021-0236	Hazel Dodds	Public Health Scotland	Scottish National Audit Programme (SNAP), Clinical & Protecting Health Directorate, Public Health Scotland (PHS) - approval for rolling access to patient level data for quality assurance to improve the quality and credibility of clinical audit data	Approved	Tier 1 Panel Meeting	10
2122-0091	Professor Bijay Vaidya	Royal Devon and Exeter NHS Foundation Trust	Antithyroid Drug Study	Approved with conditions	Tier 1 Review	20
2122-0006	Dr T'ng Kwok	University of Nottingham	British Paediatric Surveillance Study of Neonatal Stroke in the United Kingdom and the Republic of Ireland presenting / diagnosed in babies in the first 90 days of life.	Approved	Tier 1 Review	24
2021-0162	Nanisa Feilden	Healthcare Improvement Scotland	National Hub for Reviewing and Learning from the Deaths of Children and Young People	Approved with conditions	Tier 1 Review	23
2021-0185	Andrew McNally	UK Haemophilia Centre Doctors' Organisation (UKHCDO Ltd).	National Haemophilia Database (NHD)	Approved with conditions	Tier 1 Review	28
2021-0063	Dr William Whiteley	University of Edinburgh	Whole population automated reading of brain imaging reports in linked electronic health records (WARBLER)	Approved with conditions	Tier 1 Panel Meeting	12
2122-0071	Professor Richard Colquhoun	Imperial College, London	National Neonatal Research Database	Partial approval	Full committee	46
2122-0100	Dr Donald Maciver	Queen Margaret University	National Autism Implementation Team (NAIT) RETROSPECTIVE NOTES REVIEW: waiting times for assessment and diagnosis in autism and neurodevelopmental pathways for adults and children	Approved with conditions	Tier 1 Review	17
1920-0204	Elizabeth Thomson	University of Glasgow	IRONMAN (Effectiveness of Intravenous iron treatment vs standard care in patients with heart failure and iron deficiency: a randomised, open-label multicentre trial)	Approved with conditions	Tier 1 Review	18

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2021-0228	Calvin Down	Royal College of Paediatrics and Child Health	National Neonatal Audit Programme (NNAP) data flow	Approved with conditions	Tier 1 Review	18
2021-0096 SR289	Professor Diana Eccles	University of Southampton	Prospective Study of Outcomes in Sporadic Versus Heredity Breast Cancer	Approved	Tier 1 Review	42
1819-0127 SR274	Dr Jatinderpal Kalsi	University College London	Whitehall II Study	Approved with conditions	Tier 1 Panel Meeting	10
2021-0190 SR295	Amy Taylor	University of Oxford	FUTURE-GB	Approved	Tier 1 Panel Meeting	8
2021-0160	Magdalena Jurczuk	Royal College of Obstetricians and Gynaecologists (RCOG)	OASI2: a hybrid effectiveness implementation RCT to inform scale up of care bundle to reduce obstetric anal sphincter injury (OASI) caused during childbirth	Approved with conditions	Tier 1 Review	27
2122-0051	Dr Kyle Gibson	NHS Lothian	Clinical Frailty in Scottish Intensive Care Units	Approved	Tier 1 Review	17
1920-0121	Dr Claire Tochel	University of Edinburgh	The Scottish Clinical Optometry and Ophthalmology Network e-research (SCONe) project – proof of concept	Approved	Tier 1 Review	26
1920-0232	Dr Linda Fiaschi	University of Nottingham	The clinical and cost-effectiveness of testing for group B streptococcus in pregnancy: a cluster randomised trial with economic and acceptability evaluations (GBS3)	Approved with conditions	Tier 1 Review	17
2021-0221	Professor David Newby	University of Edinburgh	SCOT-HEART – long term outcomes	Approved	Tier 1 Review	22
2122-0078	Anna Morton	NHS GGC	International Staging Project - Mesothelioma	Approved	Tier 1 Panel Meeting	14
2021-0050	Professor Gillian Reeves	University of Oxford	The Million Women Study	Approved with conditions	Tier 1 Review	29
2021-0312	Dr Jan Savinc	Edinburgh Napier University	Deaths at home during COVID-19 in 2020 in Scotland	COVID19 Approved	Tier 1 Review	17

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1819-0107	Dr Richard Feltbower	University of Leeds	Paediatric Intensive Care Audit Network (PICANet)	Approved with conditions	Full Committee	47
2021-0072	Professor Maggie Cruickshank	University of Aberdeen	Impact of human papillomavirus (HPV) immunization on adverse obstetric outcomes: A data linkage study	Approved	Tier 1 Review	20
2021-0199	Daniel Bradford	University of Glasgow	Health of young looked after children in Scotland	Approved with conditions	Tier 1 Review	17
1920-0223	Dr Anne-Helen Harding	HSE Science and Research Centre	The Prospective Investigation of Pesticide Applicators' Health Study (The PIPAH Study)	Approved	Tier 1 Panel Meeting	12
1920-0162	Dr Ewelina Rydzewska	University of Glasgow	Suicide attempts and deaths in people with autism in Scotland: secondary data analysis and data linkage of administrative and health records	Approved with conditions	Tier 1 Panel Meeting	13
2122-0142	Dr Rebecca Shakir	University of Oxford	Correlation of PET-CT with organ at risk (OAR) dose from radiotherapy	Approved	Tier 1 Review	17
2021-0282	Katrin Metsis	University of St. Andrews	Health inequalities among adolescents and young people in Scotland: an analysis linking the UK Censuses and the Scottish Longitudinal Study to health data	Approved	Tier 1 Review	26
2122-0165	Professor Colin Palmer	University of Dundee	SHARE Biobank – Use of e-Health data in anonymised way for Research within the Trusted Research Environment (TRE) at Health Informatics Centre (HIC)	Approved	Tier 1 Review	29
2122-0004	Dr David Henderson	University of Edinburgh	Individual-level analysis of the Health and Care Experience Survey	Approved with conditions	Tier 1 Panel Meeting	8
2021-0229	Professor Simon Davies	Keele University	BioImpedance Spectroscopy To maintain Renal Output Trial: the BISTRO Trial	Approved	Tier 1 Review	10
2021-0290	Jodie Westhead	University of Manchester	Suicide in former service personnel: rates, antecedents, and prevention	Approved with conditions	Tier 1 Panel Meeting	17
1819-0325	Professor James Walters	Cardiff University	Large scale linkage of genetic and health informatics data in schizophrenia to investigate the impact of copy number variants	Approved with conditions	Tier 1 Review	13

			on physical and mental health and response to treatment (CLOZUK Scotland)			
2122-0141	Dr Omar Kouli	NHS Greater Glasgow and Clyde	Cardiovascular OutcoMes afteR AbDominal surgery (CASCADE)	Approved	Tier 1 Review	40
2021-0313	Professor Susan McVie	University of Edinburgh	Understanding the relationship between health-related and other vulnerability and compliance with the Coronavirus Regulations	Approved with conditions	Full Committee	69
1819-0347	Nermine Basta	Newcastle University	National Relapsed Neuroblastoma Study	Approved	Tier 1 Panel Meeting	16
2122-0054	Andrew McEwan	Scottish Government	Equality Protected Characteristics Dataset	Approved with conditions	Full Committee	32
2122-0101	Miguel Souto	British Thoracic Society	BTS Interstitial Lung Disease (ILD) Registry Programme	Approved	Tier 1 Panel Meeting	14
1819-0348	Nicola Starkey	PHS	Rape and Sexual Assault: National Dataset	Approved with conditions	Tier 1 Review	15
2021-0062	Victoria Hall	UK Health Security Agency	The impact of detectable anti SARS-CoV-2 antibody on the incidence of COVID-19 in healthcare workers (SIREN)	Approved with conditions	Tier 1 Review	26
2021-0293	Carole Morris	PHS	CO-CONNECT (COvid - Curated and Open aNalysis aNd rEsearCh plaTform)	Approved with conditions	Tier 1 Panel Meeting	13
2122-0003	Professor Adrian Martineau	Queen Mary University of London	COVIDENCE UK	Approved	Tier 1 Review	18
2122-0118 SR293	Ian Evans	University of Manchester	BADBIR – The British Association of Dermatologists Biologic Interventions Register	Approved with conditions	Tier 1 Panel Meeting	9
2122-0114	Nicholas Bradley	University of Glasgow	Sarcopenia in Vascular Surgery	Approved	Tier 1 Review	40

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2122-0030	Dr Janet Hanley	Edinburgh Napier University	Hypertension management and outcomes during the COVID-19 Pandemic (HoCo)	Approved	Tier 1 Panel Meeting	13
2122-0182	Dr Katherine Forrester	Scottish National Blood Transfusion Service (SNBTS)	Infected Blood Inquiry: transfusion recipient follow-up, Scotland	Approved	Tier 1 Panel Meeting	21
2021-0103	Ivy Wanjiku	Royal Free London NHS Foundation Trust	Phenotyping individuals with elevated mean pulmonary arterial pressure and elevated pulmonary vascular resistance in the United Kingdom	Approved with conditions	Tier 1 Review	19
2122-0195	Dr Rita Perry	University of Birmingham	TRANSFER – ThReatened preterm birth, Assessment of the Need for in utero transfer between 22+0-23+6 weeks' gestation	Approved	Tier 1 Panel Meeting	18
2122-0072	Wendy Saywood	University of Dundee	Febuxostat vs Allopurinol Streamlined Trial (FAST) – retention of datapost-study	Approved	Tier 1 Panel Meeting	20

Lay summaries for approved applications

1617-0269 Julie Landsberg Scottish Government
Scottish Health Survey (SHeS)/SMR data linkage

The Scottish Health Survey (SHeS) provides a detailed picture of the health of the Scottish population in private households and is designed to make a major contribution to the monitoring of health in Scotland. It was established in 1995 and was repeated in 1998 and 2003 and has been carried out annually since 2008. More information about the survey can be found at: Scottish Health Survey - gov.scot (www.gov.scot)

Approval to carry out the survey was obtained by the Scottish Government from the Wales Research Ethics Committee (REC) 3 and does not form part of this application. The survey is undertaken for statistical and research purposes only.

This proposal is to continue to hold and update a linked minimum dataset for respondents to SHeS who did not opt out of linkage in all years of the survey up to 2014 and to further link the respondents of the 2015 onwards surveys. SHeS responses are linked will be linked to the following health records from 1981 to date:

- SMR01 – inpatients and daycases,
- SMR04 – mental health inpatients and daycases,
- SMR06 - cancer registrations and
- NRS death records
- ECOSS – COVID19 test positive results

Health record data back to 1981 is required to provide information on admissions and registrations both prior to and after the SHeS interview. This substantially increases the value of the linked datasets and their potential for research. For example, the linkage with the 2021 survey data can be used to analyse the impact of past admissions on the likelihood of hospitalisation following a positive COVID test.

This linkage is updated annually so for each subsequent year of the survey, the SMR extraction is re-run and any new health events in that year for the participants are added to the linked dataset for each survey year.

SG analysts within the Health and Social Care division would access the minimum linked dataset to complete analysis on the health of the population. Further, the dataset will be made available to approved academic researchers who apply for specific years of data.

The SHeS series now has trend data going back 20 years; providing the time series is an important function of the survey and increases the utility of this powerful resource.

1819-0107 Dr Richard Feltbower University of Leeds
Paediatric Intensive Care Audit Network (PICANet)

The Paediatric Intensive Care Audit Network (PICANet) is an international clinical audit of paediatric intensive care (PIC) activity in the UK and Republic of Ireland (ROI). Established in 2001, with the aim of providing a secure and confidential, high quality clinical database of PIC activity, PICANet is now part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and recognised as the definitive source for PIC data in the UK and ROI. It collects data from NHS and private Paediatric Intensive Care Units (PICUs) providing level 3 care, and data pertaining to referral and transport to them.

Level 3 care denotes invasive and non-invasive means of aiding vital organ functions through the aid of clinical interventions that require close monitoring and 1:1 care.

Data is collected on patient demographics; referral, transport and admission details; diagnosis; interventions received and outcomes.

Customised data collections are sometimes carried out which collect additional clinical data items specific to an area of care or in response to local or national policy requirements.

Data collected from PICUs and Specialist Transport Services is used to:

- define the supply, demand and outcomes for current PIC services and the patient population using the service
- measure and improve the quality of care provided to patients as part of PIC services (clinical audit)
- extend the available knowledge with a view to ultimately providing benefits to patients (research)
- ensure that transport services provided reflect and meet the geographical diversity and location that are challenging to the Scottish population

1819-0127 SR274 Dr Jatinderpal Kalsi University College London Whitehall II Study

The Whitehall II study (WHII) is a longitudinal cohort study established in 1985 to investigate the relationship between socioeconomic status, stress and cardiovascular disease. The study recruited civil servants working in London who underwent a clinical examination and completed questionnaires covering a wide range of topics. Since its initiation, 12 phases of data collection have been completed (for further information see https://www.ucl.ac.uk/epidemiology-health-care/research/epidemiology-and-public-health/research/whitehall-ii/data-collection). The study has been expanded to include new measures of cardiovascular function (eg pulse wave velocity) and also captures information about other morbidities, physical and mental health, cognitive functioning and death. As with previous phases self-reported data have certain limitations, we are seeking to ascertain participant health through linkage to electronic health records in NHS Scotland. This involves obtaining regular updates on cancer and death registrations, participant hospitalisations and outpatient clinic visits. These data together with the research data allow the primary objectives of the study to be fulfilled.

1819-0286 Dr Rosemary Hollick University of Aberdeen RHEUmatic and musculoskeletal conditions: geographical MApping of Prevalence and outcomeS (RHEUMAPS)

The rural population is older and growing at a faster rate compared to urban areas. Rheumatic and musculoskeletal diseases (RMDs) are the commonest cause of disability in the elderly. Delays in diagnosis and treatment are associated with poorer outcomes, and many people with RMDs are older and have other complex health care needs. Most specialist services are located in urban areas, but around one third of the UK population live in rural areas. This creates a significant challenge in delivering timely and equitable access to care.

Furthermore, the COVID-19 pandemic has resulted in significant disruption to usual health and social care and is impacting differentially on different subgroups of the population and different parts of the country. The impact of the healthcare system changes that have happened as a result of the pandemic on the ability to meet the care needs of this group of people is unclear.

We aim to understand how many people living in rural areas have an RMD (prevalence), their health outcomes and patterns of healthcare use compared to those living in urban settings in Scotland. We

will use population level routine health care data from general practice, outpatient and hospitalised care to explore this. We are conducting similar work in Wales (not part of this application).

Our findings will be critical to support vital service planning and decision-making for rural populations to meet immediate and future health and care needs. It will also provide a basis to understand the long-term impacts of the COVID-19 pandemic on people with long-term conditions and the health care system changes that have happened as a result.

1819-0325 Professor James Walters Cardiff University
Large scale linkage of genetic and health informatics data in schizophrenia to investigate the impact of copy number variants on physical and mental health and response to treatment (CLOZUK Scotland)

Scotland is part of a broader project that seeks to link the world's largest genetic sample of those with schizophrenia (CLOZUK; a cohort of individuals with a diagnosis of treatment-resistant schizophrenia on Clozapine treatment) with health informatic strengths across three UK countries. The project will link genetic data from individuals with schizophrenia with health informatics resources across Scotland (SAFEHAVEN), Wales (SAIL), and South London (CRIS). This will lead to a unique resource that will enable us to ask many research questions of clinical relevance to those with schizophrenia and psychosis.

The CLOZUK-Scotland project envisages linkage of samples within the CLOZUK study (N~2500) to electronic health records, using Safe Haven. 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 genetic variants that may affect physical health outcomes in schizophrenia, as well as adverse effects and treatment response in the clozapine sample.

People with schizophrenia have high levels of physical comorbidity and a 20 year decreased life expectancy than the rest of the population; worryingly the mortality gap is increasing over time. Therefore, it is important to discover and target the causes of this premature mortality. The linkage of genetic data from the CLOZUK Scotland cohort with physical health outcomes in routinely collected data within Safe Haven will provide insights into the physical health of a particularly high risk patient group. Furthermore, this research has the potential to inform the development of novel approaches in genetic counselling and testing in psychiatry and more targeted intervention.

1819-0347 Nermine Basta Newcastle University
National Relapsed Neuroblastoma Study

Neuroblastoma is a type of cancer that mostly affects children less than 5 years of age. It most often develops in the adrenal gland, but can occur anywhere from the neck to the groin. It is one of the most difficult childhood cancers to cure with around 40% five-year survival in high risk cases (50% of all cases). Despite advances in neuroblastoma treatment, relapse still occurs in 50% of high risk cases and only around 1 in 10 of such cases can then be cured. Knowledge of factors which influence whether the tumour will shrink after relapse and length of survival following relapse in neuroblastoma are important to determine which, if any, treatment at relapse is appropriate in individual cases. These factors may affect the results obtained when testing new therapies for neuroblastoma in early clinical studies. Recent studies report an increased frequency of recurrent, genetic changes at relapse including gains and losses of chromosomal parts and mistakes in genes (mutations). The present study looks at patient case notes to identify clinical and genetic factors

associated with neuroblastoma relapse and length of survival following relapse. The outcomes from this study will be used to help design future clinical trials for children with neuroblastoma.

We are seeking approval from the PBPP to allow the identification of cases and data extraction at the 3 Scottish children's hospitals that treat children's cancer and then removing personal identifiers from the data before sending it on to the research team in Newcastle.

1819-0348 Nicola Starkey PHS
Rape and Sexual Assault: National Dataset

Following the publication in March 2017 of HM Inspectorate of Constabulary in Scotland report on the Strategic Overview of Provision of Forensic Medical Services to Victims of Sexual Crime, the Scottish Government was asked to provide national leadership by way of forming a

Chief Medical Officer's (CMO) Taskforce for the improvement of healthcare and forensic medical services for adults, children and young people who have experienced rape, sexual assault and child abuse. To support and inform the CMO Taskforce, a Quality Improvement (QI) Working Group was established. The role and remit of this group is to maximise the use of IT systems and the data generated by these systems to support service delivery and quality improvement in healthcare and forensic medical services for victims of rape, sexual assault and child sexual abuse.

In order to provide evidence to inform improvements of healthcare and forensic medical services Public Health Scotland (PHS) were requested by the CMO Taskforce to develop a national dataset to collect data about adults, children and young people who have experienced rape, sexual assault and child abuse. PHS have developed two national datasets, one for adults and one for children and young people. These two datasets will allow (pseudonymised) patient level data to be collected by PHS for analysis and reporting with the aim of providing the CMO Taskforce and the Scottish Government evidence for quality improvement and performance measurement to ensure the timely delivery of person centred, trauma informed services for people of all ages, in line with the Taskforce vision and the Healthcare Improvement Scotland Standards.

Currently Public Health Scotland do not routinely collect these data from NHS Boards.

1819-0356 Colin Angus University of Sheffield
Evaluating the impact of Minimum Unit Pricing for alcohol on harmful drinkers

This project will use primary care records to identify a group of individuals for whom their GP/practice nurses have recorded information suggesting that they were drinking at a harmful level in the period prior to 1st May 2018, when Minimum Unit Pricing for alcohol was introduced in Scotland. We will then look at these people's subsequent health records (hospital admissions, A&E attendances and, where relevant, mortality records) to assess whether the introduction of Minimum Unit Pricing was associated with an improvement in their health. This analysis will contribute to the Scottish Government's evaluation of whether Minimum Unit Pricing has been a successful policy and help to inform their decision whether to retain the policy beyond the initial 6-year period set out in the current legislation.

1920-0021 SR281 Dr Helen Harris Public Health England, National Infection Service
Hepatitis C National Register

The National Hepatitis C Register is an ongoing national public health surveillance programme established in 1998 to provide epidemiological information on the natural history and clinical outcomes of hepatitis C infection in the UK. It contains data for one of the largest cohorts of patients in Europe who acquired their hepatitis C virus (HCV) infections on a known date.

Data provided by NHS National Services Scotland and the National Research Services for each Scottish case enrolled in the HCV National Register will include members and postings, death and cancer information. The members and postings data will enable PHE to contact the current clinician for each Scottish case to obtain clinical information on the patient's current clinical status. The death and cancer information are required to enable us to: (i) establish whether the patient has a cancer registration, and if so to determine whether it is HCV-related, and (ii) be notified of any deaths so we can ascertain whether they died of an HCV-related cause or not.

These data will be linked to data held in the HCV National Register and used by PHE to learn about the clinical course of the disease from the time of infection to the present. Survival and other analyses will be undertaken to investigate any excess mortality among transfusion recipients exposed to HCV and to inform the future burden of HCV infection in the UK to help inform national policy/healthcare planning.

1920-0121 Dr Claire Tochel University of Edinburgh
The Scottish Clinical Optometry and Ophthalmology Network e-research (SCONe) project – proof of concept

Scotland has a unique system of eye care delivery, with better integration of primary and secondary ophthalmic services than the rest of the UK including well-equipped and skilled community optometrists. Retinal images have been obtained as part of routine NHS-funded eye examinations since 2006 when a new General Ophthalmic Services contract was introduced, including the provision of all optometrists in Scotland with high resolution fundus retinal cameras. The large number of images taken in practice since then constitutes a rich, longitudinal, population-based resource which could support research into how the retina changes in ocular and systemic diseases. However, at present the images are stored in practice according to local procedures.

SCONe's aim is to collect, classify and curate these community-acquired images in a responsible and secure manner, making them accessible for research for public benefit within the eDRIS National Safe Haven. The linkage of these images with routinely collected eye health data will facilitate many streams of research and enable development of technologies such as artificial intelligence for aiding early detection of common blinding conditions including age-related macular degeneration, glaucoma and diabetic eye disease; tools to improve accuracy of referral from primary to secondary care; and tools for improved predictions of risk of systemic diseases with retinal manifestations.

In our first two years, we aim to acquire fundus photographs from a group of motivated community optometry practices. Members of the SCONe team will then demonstrate the feasibility of using the images and linked healthcare data to undertake research.

1920-0126 Dr Jayne Digby University of Dundee
Intelligent use of quantitative faecal immunochemical testing for haemoglobin in screening populations

A quantitative test for blood in faeces, known as Faecal Immunochemical Testing (FIT) has been introduced into the Scottish Bowel Screening Programme. The amount of blood in faeces, measured by faecal haemoglobin concentration (f-Hb), is determined not only by disease but also by age, gender and levels of deprivation. A positive test is defined by the level of f-Hb exceeding the agreed threshold for the screening programme. The threshold used in Scotland is high relative to many other countries, and so a substantial number of cancers will not be detected. There is therefore an urgent need to refine the use of FIT in order to maximise early detection of bowel cancer without overwhelming colonoscopy services.

This research will be carried out by utilising the database generated by the Scottish Bowel Screening Programme. By taking FIT results and adjusting them for age, gender and deprivation and adding in other variables, including screening history, it will be possible to develop estimations of risk of bowel cancer or pre-cancer. Because of the very large amount of data that is available it will be possible to use part of these data to develop the risk scores and the other part to validate them.

1920-0162 Dr Ewelina Rydzewska University of Glasgow
Suicide attempts and deaths in people with autism in Scotland: secondary data analysis and data linkage of administrative and health records

Despite the overall decrease in the suicide rates in the UK in the past 10 years, the rates increased markedly by 15% in Scotland last year in 2019. Living with or developing an impairment or long-term condition is known to contribute to higher suicide risk. Existing evidence shows that suicide attempts and deaths are more common in people with autism than in the general population, but studies of whole-country populations are lacking, with none yet conducted in the UK. The recent policy brief of the International Society for Autism Research and Autistica on autism community priorities for suicide prevention emphasises that there is little research into why suicide is more common in autism, how it could be prevented or what risk and protective factors and barriers in seeking help autistic people experience. The top ten research priorities for autism developed by James Lind Alliance and Autistica also both strongly emphasise the importance of research into mental health of adults with autism. This study will bring together routinely collected data from different sources to investigate the incidence of suicide attempts and deaths and explore the extent to which mental health comorbidities (e.g., anxiety, depression, substance use disorders), contact with healthcare services and socioeconomic factors mitigate or compound the risk of suicide in people with autism in Scotland.

1920-0176 Dr Michael Fleming University of Glasgow
Investigating the relationship between health and educational outcomes in children

Many factors can influence children's educational and health outcomes including maternal antecedents, outcomes at birth, neonatal and childhood morbidity, socioeconomic and parental factors, early life events, childhood chronic disease and medication used through childhood. Whilst health factors can influence educational outcomes, improved educational performance can in turn impact future health, wellbeing and quality of life via increased prosperity and opportunity. Therefore, it is important to investigate factors affecting both.

Aims:

1. What factors (maternal and obstetric, early life, chronic conditions and multimorbidity, health behaviours) are associated with poorer health and educational outcomes in children
2. What factors (maternal and obstetric, early life, chronic conditions and multimorbidity, educational) are associated with children's health behaviours
3. Develop a risk prediction tool for onset of neurodevelopmental conditions and neurodevelopmental multimorbidity.

Educational outcomes include special educational need and reason for need (including autism and intellectual disability); absence, truancy, and exclusion; examination attainment; school leaver destination. Health outcomes of interest include all cause and cause specific acute hospital admissions, mental health admissions, prescribing for chronic conditions, cancers, and cause specific and all-cause mortality. Health behaviours are as recorded on the Health Behaviours in School Aged Children (HBSC) Survey. Maternal and obstetric factors include maternal age, birthweight, gestational age, congenital anomalies etc. Early life factors include neonatal and early life hospitalisations, breastfed, developmental milestones etc. Chronic conditions include diabetes, asthma, epilepsy, ADHD, depression, mood disorders, skin disorders, autism, learning disability and neurodevelopmental multimorbidity.

1920-0194 Dr Emily Adrion University of Edinburgh
The Elimination of the Prescription Charge in Scotland: Understanding the short- and medium-term impact of prescription charge removal and examining future directions

NHS prescription charges were fully eliminated in Scotland on 1 April 2011. This policy was widely promoted as an effort to end the 'tax on ill health' by reducing cost-related access barriers to prescription medicines for the Scottish population. However, in the 9 years since the elimination of prescription charges, no comprehensive assessment of the impact of this policy has been produced. With prescription drug spending in Scotland growing 25.7 percent over the past decade, addressing the rising costs and utilisation associated with medicines has become an urgent priority. Given recent calls for the re-introduction of prescription charges as a means of raising revenue and reducing unnecessary utilisation, a timely review of the impact of prescription charge elimination is critical in order to better inform policy debates. The purpose of this project is to contribute to Parliamentary Health Committee discussions around prescription charges. The work will be carried out as part of a Scottish Parliament Academic Fellowship with the Scottish Parliament Information Centre (SPICe).

1920-0199 Dr Michelle Williams University of Edinburgh
Secondary image analysis research using anonymised imaging

At Edinburgh Imaging (University of Edinburgh) we perform radiology tests such as computed tomography, magnetic resonance imaging and positron emission tomography as part of research studies, including participants from NHS Lothian and throughout Scotland. The research studies may also involve radiological imaging which was initially performed as part of NHS care. We have an established system for pseudonymising imaging studies for use in research, which has previously been approved by NHS Lothian Caldicot Guardian and has undergone rigorous audit and testing. The team have a track record of successful anonymising scans and have robust standard operating procedures, quality systems and validation checks. We would like to use these pseudonymised images to create a research database to support secondary image analysis research. These new ways of analysing images will provide important additional information on a variety of health conditions including diseases of the heart, blood vessels and lungs. These new techniques were not developed when the images were originally obtained, so this research database will enable us to test out these

techniques without new participants having to undergo imaging or be exposed to potentially harmful radiation. Participants who have consented to undergo imaging as part of research studies will have provided informed consent for participation in the primary research study. This may or may not have discussed the use of pseudonymised images in future image analysis research. Many current research studies include discussion of this in the information sheet and consent form, but this may not have been discussed in historic research studies. The earliest imaging will be from 2009, when Edinburgh Imaging opened. Approximately 1000 imaging studies are performed for research at Edinburgh Imaging per year. After the initial incorporation of historic images into the research database, we update the research database on a six monthly or yearly basis as appropriate following the above process.

1920-0204 Elizabeth Thomson University of Glasgow IRONMAN (Effectiveness of Intravenous iron treatment vs standard care in patients with heart failure and iron deficiency: a randomised, open-label multicentre trial)

IRONMAN is a randomised clinical trial of intravenous (IV) infusions of iron versus no additional treatment on top of standard care, in patients with heart failure and iron deficiency, powered to detect with sample size chosen to detect effects on morbidity and mortality. The trial will inform clinical management and international guidelines in the treatment of heart failure. The trial will look at whether there is evidence that the addition of IV iron to standard care impacts on the primary outcome (cardiovascular mortality and heart failure hospitalisation) and a range of other cardiovascular outcomes and is safe (requiring the collection of data on all Serious Adverse Events (including deaths, cancers and hospital admissions)) during the randomised period of the trial and in the longer term. We will also examine the cost-effectiveness of the intervention. It is an investigator-designed and initiated study. It will utilise a PROBE (prospective, randomised open-label, blinded endpoint) design. Patients will be assigned to receive IV iron or not, in addition to guideline-indicated care. Patients assigned to IV iron will receive repeated doses sufficient to ensure iron repletion for the duration of the study. Many patients with heart failure are iron deficient, and do not absorb oral iron. Evidence from smaller studies suggests that patients feel better if given IV iron treatment. However, a trial establishing the longer term safety of this intervention and evidence of benefit on life events such as deaths and hospital admissions is needed to provide the evidence required for the widespread use of this treatment. IRONMAN is an event-driven (meaning that the study will stop once a target number of heart failure hospitalisations or cardiovascular deaths have been reached) trial with a primary focus on cardiovascular death and hospitalisation for heart failure. It is expected that participants will be treated for between six months and 5.5 years or possibly longer depending on the observed event rate. We will use record linkage to support the collection of serious adverse event data and study endpoints during the randomised portion of the study and also in the longer term.

Written consent was and is being sought from patients to access their electronic health records. As recruitment is ongoing, the cohort to be linked will increase with time until the target sample size has been reached Recruitment will be completed soon and is likely to be complete by the time record linkage is achieved. It is expected that the initial cohort will consist of approximately 370 385 Scottish patients. Patient identifiable information will be used to link to datasets available in eDRIS.

1920-0223 Dr Anne-Helen Harding HSE Science and Research Centre The Prospective Investigation of Pesticide Applicators' Health Study (The PIPAH Study)

The PIPAH study is an occupational cohort of approximately 6,000 men and women in Great Britain who use pesticides as a part of their job. In 2013 the Health and Safety Executive established the study to monitor the health of these workers, and to gain a better understanding of the relationship between long-term exposure to pesticides and health. HSE continues to recruit new professional pesticide users into the study on an annual basis.

The specific aims of the study are:

- To compare morbidity and mortality among the pesticide users with the general population and between different groups within the cohort study.
- To investigate the associations between occupational exposure to pesticides and chronic ill health, and to investigate changes in health status over time, including the development of new chronic health conditions.
- To investigate the association between occupational exposure to pesticides and all-cause mortality, cancer incidence and health care utilisation.

Professional pesticide users are invited to participate in the study. If they consent to taking part, they are asked to complete a questionnaire on joining and annual questionnaires during the follow-up period. Their health status will also be followed-up through the National Health Service Central Registers in England, Scotland and Wales. The information collected on the study participants will encompass:

- Self-reported information on their exposure to pesticides,
- Self-reported information on other factors that may affect their health, and
- Health outcomes, including self-reported health outcomes and those recorded by the NHS, and health care utilisation.

1920-0225 SR296 Andrew McNally National Haemophilia Database (NHD) / UK Haemophilia Centre Doctors' Organisation (UKHCDO Ltd). Haemophilia Mortality Study

UK National Haemophilia Database (NHD) holds information on people registered with a bleeding disorder within the United Kingdom. It contains details of more than 40,000 people, both alive and deceased. The NHD is managed by the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO), who work with practitioners based within the Haemophilia Centres in the UK and have an interest in the care of people with inherited bleeding disorders. Since its inception, the database has monitored treatment trends and morbidity and mortality associated with bleeding disorders and changes in life expectancy. UKHCDO have published extensively on the epidemiology of bleeding disorders, life-expectancy and causes of death. The database is essentially conducting an open-ended cohort study

Data is collected from haemophilia centres and from the Haemtrack home therapy recording system. The NHD serves two purposes: non-research activity; regular reporting to the NHS to facilitate disease monitoring and healthcare planning, for example, current and future needs, safety, and efficacy of treatment. Secondly, research into bleeding disorders and their complications to understand the natural history of these conditions and the outcomes of treatment.

The NHD is required to provide annual cyclical reporting on Bleeding Disorder Statistics to assist with national strategic healthcare planning, disease monitoring and requires death certification data to allow us to study trends in causes of death and in life expectancy as improvements in treatment

are introduced. This would help us to evaluate and justify therapeutic developments. The benefits will be measured in terms of reduced morbidity, mortality and treatment costs.

1920-0228 Professor Fiona Gilbert University of Cambridge
BRAID- Breast Screening – Risk Adaptive Imaging for Density

On mammograms dense breast tissue can hide, mask, or obscure small cancers which the screening programme aims to detect. The BRAID study is investigating the ability of different types of medical imaging to detect these small cancers in women with dense breasts who have normal mammograms.

Women with normal mammograms who have dense breast tissue will be invited to join the trial. Eligible, consenting participants are randomized to one of four study arms and will be imaged with either abbreviated MRI, whole breast ultrasound, or contrast-enhanced mammography or have no additional imaging. Women will be imaged again, using the same modality, 18 months after their first visit. Cancer detection rate and recall rate will be measured for each imaging technique.

Women will be asked to provide saliva samples and complete a 'CanRisk' questionnaire to calculate the participant's risk of developing breast cancer based on their lifestyle and medical profile. At the end of the study the predictive power of the questionnaire, the genetic material and breast density will be analyzed to determine if this can be used to offer risk stratified screening in the future.

1920-0229 Dr Jasmeet Soar Royal College of Anaesthetists
The 7th National Audit Project (NAP7) of the Royal College of Anaesthetists (RCoA): Perioperative Cardiac Arrest

The RCoA National Audit Projects (NAPs) examine rare events in anaesthesia that are incompletely studied, important to patients and important to anaesthetists. Previous NAPs – NAP3-NAP6 have taken place in Scotland since 2007. NAP7, will examine perioperative cardiac arrest. Surveys show that people worry they may not wake up from their anaesthetic at the end of their operation. Our knowledge of how often this actually occurs, why and when it occurs is limited.

NAP7 will have three parts:

1. Case registry of cardiac arrests: All cases of perioperative cardiac arrest during a one-year period will be included. The general criteria for inclusion will be 'chest compressions and/or defibrillation in a patient having a procedure under the care of an anaesthetist'. Anonymised details of these cases will be reported by local coordinators and reviewed by the NAP7 Stakeholder Panel. It will not be possible to reverse identify patients as we will not collect unique identifiers, the identity of location of the patient, hospital, or Local Coordinator, as has been the case in previous NAP cycles.
2. National survey of anaesthetic activity: Details of every anaesthetic case over a 4-day period will be collected to create a snapshot of anaesthetic activity in the UK and collect information about critical events pertinent to perioperative cardiac arrest.
3. A baseline experience survey: An online survey will be sent to all anaesthetists, including those in training, in the UK to investigate their previous experiences of perioperative cardiac arrest, resuscitation training and facilities in their workplace.

The information gathered during NAP7 will lead to expert consensus opinion on many service aspects of caring for patients with perioperative cardiac arrests, including training standards, resuscitation facilities and resuscitation protocols.

1920-0232 Dr Linda Fiaschi University of Nottingham
The clinical and cost-effectiveness of testing for group B streptococcus in pregnancy: a cluster randomised trial with economic and acceptability evaluations (GBS3)

Group B Streptococcus (GBS) is a bacterium presents in the vagina of approximately 1 in 4 pregnant women. Giving women antibiotics in labour reduces the risk of their babies developing GBS infection. Current UK practice is to offer antibiotics when the baby is at higher risk of developing the infection based on maternal risk factors. This “risk-factor” screening is imperfect: some babies born to mothers without risk factors still develop an infection and many women with risk factors do not carry GBS but receive antibiotics unnecessarily. A potential solution is “routine testing” of every pregnant woman, and offering antibiotics in labour only to those who are carrying GBS.

80 maternity units will be randomly allocated to the “risk factor” approach or the “routine testing” approach that will test women using a vaginal-rectal swab either at 35-37 weeks of pregnancy, or in labour. In order to compare the number of babies who develop serious infection, as infections are relatively rare, we will need to collect information on 320,000 women to be able to conduct the analysis.

We will use routinely collected data from national systems. Moreover, we will collect individual level detailed data (through eCRF) for 100 women at each of the 80 sites to inform the economic evaluation of the trial and for monitoring purposes. We will also interview women and healthcare professionals about the acceptability of the testing approaches. Finally, we will compare the overall costs of each strategy to ascertain which represents the best value for money for the NHS.

1920-0257 Julie Landsberg Scottish Government
Scottish Health Survey (SHeS)/SMR data linkage – Legal basis change

This project plans to use the CHI database to identify current contact details for previous participants of the Scottish Health Survey (SHeS) who consented to their survey data being linked for research. This is to allow past participants to be contacted and informed of a change in legal basis for the collection and linkage of the survey and what this means for them. SHeS is commissioned by the Scottish Government (SG) and provides a picture of the health of the Scottish population. To increase the utility of the survey, responses have previously been linked to routine administrative health records and made available for research. This linkage was completed for participants in the 1995 – 2014 surveys and is planned to be refreshed and continue for SHeS respondents from 2015 onwards (see HPBPP application 1617-0269), meaning participants from 1995 onwards will have their survey responses linked to present-day health records and continue to be linked on an annual basis.

Prior to 2019, the legal basis for collection of the SHeS, and subsequent linkage to health datasets, was consent. However, the most appropriate basis for the survey and linkage of the data has changed to a task in the public interest.

2021-0035 Dr Martin Johnson NHS Golden Jubilee
Mortality data for the Scottish Pulmonary Vascular Unit

The Scottish Pulmonary Vascular Unit (SPVU) is a national service funded by the National Services Division (NSD) Scotland for the provision of care to patients with pulmonary hypertension from all Scottish health boards. On an annual basis (May of each year) we provide data on our performance to the NSD in our annual report and nationally to NHS England as part of the National Pulmonary Hypertension Audit (NPHA). This enables both longitudinal review of our performance by NSD and

benchmarking with the other UK pulmonary hypertension units. One facet of the data provided is survival analysis which requires access to accurate and timely mortality reports. In NPHA, NHS England check these data with mortality results from the Office of National Statistics. The fact that Scottish PH mortality is not checked against national sources is recognised to be a deficiency of our data contribution. The aim of this proposal is to establish an annual check using central records on the survival status of all patients actively attending the Scottish Pulmonary Vascular Unit together with accurate data on cause of death in patients who have died.

2021-0036 Dr Hester Ward NHS NSS
Cost-effectiveness analysis of the living donor transplant program

NHS National Services Scotland's National Specialist Division (NSD) commissions specialist services on behalf of the Scottish Government and NHSScotland's Boards. This includes the Scottish Renal Transplantation Service which is responsible for providing kidney transplantation services to patients across Scotland. The planning and operation of the service is guided by NSD's 'Commissioning Transplantation to 2020 Plan' which detailed arrangements up to 2020. An update to this plan is now needed.

An overarching aim of the new plan is to increase rates of living donor kidney transplantation. This is when a kidney is transplanted from a donor who is alive, and differs from a deceased donor kidney transplant, wherein the donor is clinically dead. One of the main advantages of living donation is that more transplant patients could potentially receive a viable kidney. There are also other advantages such as better health outcomes and fewer long-term complications for the transplant patient.

In order to assess just how beneficial living donation could be to the NHS, Healthcare Improvement Scotland (HIS) has been asked to develop an economic model to measure the anticipated costs and health benefits of implementing the Living Donation program over the coming years. To do this, HIS will examine the data from kidney transplant patients over the previous ten years. This data will be used to predict how the implementation of living donation will impact on healthcare service costs in the future, as well as the health benefits to kidney transplant patients when compared to more traditional deceased donor transplantation. This information about the cost-effectiveness of living donation will be used by NSD to aid decision-making and planning about how the service is run in the future.

2021-0050 Professor Gillian Reeves University of Oxford
The Million Women Study

The Million Women Study (MWS) is a national study of women's health funded by Cancer Research UK. The study involves 1.3 million women in England and Scotland, recruited through NHS breast screening clinics in England and Scotland between 1996 and 2001. Signed consent for follow up of participant's health via medical records was taken at the time of recruitment. While the initial stimulus of the study was to investigate use of different types on menopausal hormone therapy and risk of breast cancer, from its inception the study was designed to investigate the role of other factors (such as smoking and obesity) and other health outcomes. The overall aim of the study is to investigate risk factors for serious and common diseases in women. As the study has progressed, and the cohort has aged, different conditions have become of greater relevance: eg. Dementia, other neurodegenerative and neurological conditions, mental health, cardiovascular disease and stroke, as well as other cancers. The research agenda is peer-reviewed every few years as part of the applications for renewed funding and developments and are determined by the MWS Principal Investigators at the University of Oxford, taking into account the importance of age-appropriate research questions, in relation to new evidence and to public health priorities; the availability of

sufficiently long follow-up and number of cases for less common diseases; and additional information which becomes available for linkage and which may allow new analytic approaches.

2021-0059 Dr Kuan Ken Lee University of Edinburgh High-sensitivity troponin in the evaluation of patients with acute coronary syndrome (HighSTEACS): A randomised controlled trial (this includes the substudy known as HiSTORIC)

The High-STEACS trial (High-Sensitivity Troponin in the Evaluation of patients with suspected Acute Coronary Syndrome) evaluated the impact of implementing a highly sensitive test to measure troponin, a protein released into the bloodstream when the heart muscle is damaged, in patients with suspected heart attacks across 10 hospitals in Scotland. Implementation of this test resulted in an increase in the diagnosis of heart attacks and the provision of effective treatments but patient outcomes did not improve at 1 year.

In this study, we wish to evaluate the impact of the highly sensitive troponin test on patient outcomes beyond 3 years. Better provision of preventative treatments may be beneficial for patients over the longer term.

Secondly, we wish to evaluate how the sex of the treating clinician affects patient care, and in particular how this is affected when the patient is of the opposite sex to their clinician. We think that when the sex of the clinician is different to the patient, this could lead to differences in diagnosis and treatment.

2021-0062 Victoria Hall UK Health Security Agency The impact of detectable anti SARS-CoV-2 antibody on the incidence of COVID-19 in healthcare workers (SIREN)

- The SIREN study is a UK wide study investigating whether healthcare staff who have had a previous COVID-19 infection, detected by a positive antibody test, are protected from future infections compared to those who have negative antibody tests. The study will also examine the short-term, the next year and long-term protective effect of COVID-19 vaccine against future infection. To do this data is collected from healthcare staff in England, Scotland, Northern Ireland and Wales and transferred to the lead organisation, UKHSA, to be analysed to answer the research questions.

- The SIREN study team at UKHSA want to analyse the severity of COVID infections in healthcare staff participating in the study. PHS will facilitate this by extracting hospitalisation data on SIREN Scotland participants from the national hospitalisation data set (SMR01). Extracted data will include have these SIREN participants been hospitalised due to COVID-19 and if they have been hospitalised; how long did they stay in hospital and were they admitted to an intensive care unit? This data will be securely transferred to UKHSA for analysis.

- Healthcare staff when they enrolled into the study were informed in the study Privacy Notice that the information they provided to the study would be linked to information about their health and care which is held centrally.

2021-0063 Dr William Whiteley University of Edinburgh
Whole population automated reading of brain imaging reports in linked electronic health records (WARBLER)

Brain scans (CT or MRI) could give important information about people's subsequent health status. Scans show that some brains are smaller ('atrophied'), or have damage to small blood vessels or from old strokes. People with these brain appearances might be more likely to have strokes, develop dementia or mental health conditions, or to die early. For people with existing illnesses, scan appearances can help identify disease subtypes, suggest how conditions will progress, and help make treatment decisions.

To show brain scan appearances are important for predicting subsequent health status, we need to know the brain scan appearances of a very large number of people. Research studies like this are difficult to do because brain scanning is expensive and keeping in touch with people over many years is hard.

NHS Scotland data includes the written reports of all brain scans done during routine healthcare, and also data about the health of all patients. Using NHS Scotland's data is an excellent opportunity to study the relationship between brain appearance and subsequent health at a low cost, with excellent follow up, and would be of great relevance to people in Scotland.

We want to use a computer program ('natural language processing') to read the brain scan reports of a large number of patients and link these findings to patient's subsequent health. We will use these findings to determine the risk of dementia, stroke and other brain diseases in people with different brain imaging findings, to help inform disease prevention and prediction.

2021-0067 Mark Danton University of Glasgow
Impact of COVID-19 pandemic on Scottish Congenital Heart Population

Currently there are estimated to be 10-16,000 people with congenital heart disease (CoHD) residing in Scotland ranging in age from infancy to late adulthood. As a consequence of their heart condition, these people have compromised heart and lung functioning that renders them vulnerable to additional challenges to the cardiovascular system including infection and sepsis. Thus, it is anticipated that people with CoHD are potentially vulnerable to the complications of SARs-CoV2. Although these risks are fully anticipated by the CoHD community, no study to date has investigated the COVID-19 risk within this population. It is also recognised that the clinical course of CoHD can be complex and unpredictable, requiring regular follow-up and timely intervention when appropriate. Thus, the restrictions on healthcare delivery imposed by the pandemic may have an indirect and disproportionate influence on the clinical outcome of people with CoHD.

This study seeks to determine the impact of the COVID-19 pandemic on people with CoHD living in Scotland. The CoHD population will be identified from paediatric and adult clinical databases held within nationally designated CoHD hospitals and from eDRIS, who can identify people with a diagnostic code for CoHD.

The effect of the COVID-19 pandemic on outcomes in the CoHD population in 2020/21 will be compared with the effect on the general population. It will also be compared with outcomes in the CoHD population in the years prior to COVID-19 (2015-19).

COVID-19 datasets made available by eDRIS via the COVID-19 Research Database will provide health outcomes of interest, including incidences of COVID-19 testing/positivity, mortality, hospital/ITU admission rates, and planned/unplanned NHS access. These data will be linked to our CoHD clinical databases, with the information held on secure servers in the Robertson Centre for Biostatistics (University of Glasgow), where they can be accessed only by approved experts to conduct analyses

2021-0072 Professor Maggie Cruickshank University of Aberdeen Impact of human papillomavirus (HPV) immunization on adverse obstetric outcomes: A data linkage study

Human papillomavirus (HPV) vaccination aims to prevent cervical cancer and precancerous cells of the cervix, called cervical intraepithelial neoplasia (CIN) caused by HPV. Cervical treatment for these abnormal cells is expected to reduce in vaccinated women. CIN and its treatment are associated with a higher risk of adverse obstetric outcomes, including preterm birth. The aim of this study is to investigate if obstetric outcomes have improved following introduction of HPV vaccinations.

This study will use routinely collected data in Grampian area. There are five relevant datasets: AMND (Aberdeen Maternity and Neonatal Databank) and local BadgerNet electronic pregnancy data containing information on obstetric outcomes in Grampian area from 2006-2020, SIRS (Scottish Immunisation & Recall System) containing HPV vaccine data and NCCIAS-Grampian (National Colposcopy Clinical Information and Audit System-Grampian) containing colposcopy attendance, examinations, definitive histology diagnosis and treatment associated information). These datasets contain the Community Health Index (CHI) number and so can be linked to enable this work.

Women who were delivering between January 2006 and July 2020 in Grampian area, with singleton pregnancies and spontaneously delivery at 20 to 30 years old will be identified. Within the Safe-Haven, records will be linked to any previous HPV vaccine status in SIRS and colposcopy, definitive histology diagnosis and treatment information in NCCIAS-Grampian.

The primary outcomes are preterm birth (PTB), low birth weight (LBW) and pre-labour preterm rupture of membranes (pPROM). The proportion of primary outcomes in HPV vaccinated women will be compared with the proportion in unvaccinated women.

2021-0096 SR289 Professor Diana Eccles University of Southampton Prospective Study of Outcomes in Sporadic Versus Heredity Breast Cancer

PICO (Population, Indicator (gene info), Comparison (carrier v non-carrier of breast cancer susceptibility gene), Outcome (survival, second caner) summary

Population: UK

Participants: female breast cancer patients diagnosed aged 40 years or younger. Interventions / Indicators: Observational cohort study with no active intervention with treatment or follow up. Gene carriers identified from stored DNA to enable comparison of outcomes between carriers and controls

Comparator / Control: carriers of hereditary genetic predisposition to breast cancer compared to sporadic non-carrier

Outcome: 1) overall survival; 2) distant disease free survival; 3) new primary cancer diagnosis

NB. The study aims and design are outlined on the study website which also provides access to all study documents and publications

https://www.southampton.ac.uk/medicine/research/posh.page

2021-0103 Ivy Wanjiku Royal Free London NHS Foundation Trust
Phenotyping individuals with elevated mean pulmonary arterial pressure and elevated pulmonary vascular resistance in the United Kingdom

The aim of the study is to understand the Pulmonary Arterial Hypertension (PAH) patient population. We anticipate that this will mean better surveillance/screening and earlier interventions for patients who require it to promote better outcomes.

PAH is a lethal, debilitating, rare condition and is diagnosed where a pulmonary arterial pressure (mPAP), above 25mmHG is measured on right heart catheterisation. Phenotyping individuals with elevated mean pulmonary arterial pressure and elevated pulmonary vascular resistance in the UK is an observational, multi-center study, collecting data on patients with elevated mean pulmonary arterial pressure (mPAP) i.e the average blood pressure in main pulmonary artery. This study is being conducted across 7 UK Pulmonary Hypertension centres and sponsored by the Royal Free London NHS Foundation Trust.

We will be collecting and comparing data from patients that fall into three mPAP ranges:

i. <21mmHg, (Control group)
ii. between 21-24mmHg
iii. >25mmHg (control group)

We will also compare clinical characteristics, biomarkers, therapies, quality of life and prognosis with particular interest in borderline cases, to better understand the natural progression of this disease.

This study will provide a UK perspective on patients who are deemed to have mild Pulmonary Hypertension currently described as having a mean pulmonary artery pressure between 21-24mmHg. This study may influence guidelines on how to screen and manage this population.

The study has been on-going since December 2020, the study report is due to be completed by March 2022. We aim to submit the study report to the European Society of Cardiology for publication.

2021-0131 Dr Ryan Wereski University of Edinburgh
Myocardial Injury in elective Coronary Angiography

We have recently found that in people who come to the cardiology clinic with chest pain, a protein in the blood called troponin is a very good marker of a type of heart disease seen on a CT-scan. This type of heart disease is known as coronary artery disease, and occurs when there is a build-up of fatty tissue plaques in the vessels of the heart. These plaques can cause people to experience chest pain on exertion, and can also lead to heart attacks.

Currently we do not know if this troponin blood test can be used in other settings to predict the severity of coronary artery disease. We may be able to use a blood test like troponin when patients come to the hospital for other reasons to help identify those who are most likely to have severe coronary artery disease. This could allow us to avoid doing unnecessary procedures in patients who have a very low risk, and help prioritise tests treatments in patients who will benefit the most. To investigate this, we will look at troponin levels in every patient who attends hospital for an angiogram (dye test) of their heart arteries, and see if this blood test can predict the severity of heart disease seen on the angiogram test. We will also look to see if troponin can predict risk of heart attacks and strokes in the future.

2021-0135 Dr Niamh Mclennan University of Edinburgh
Impact of Covid-19 Clinical Care Pathway Changes on Gestational Diabetes Prevalence and Pregnancy Outcomes, UK data study

Gestational diabetes (GDM), diabetes that develops during pregnancy, is the commonest pregnancy complication. GDM can lead to pregnancy complications, including having a large baby but risks are reduced by tight blood glucose (sugar) control.

In the COVID-19 pandemic, pregnant women are considered a vulnerable group. This has led to major changes in the way GDM is diagnosed and managed. Care pathways have been modified to limit face-to-face contact and 'virtual' clinics have been rolled out where a woman's blood glucose levels and pregnancy are reviewed remotely.

These changes were implemented quickly and women and Health care professionals' had to rapidly adapt. We plan to investigate the effect that these changes have had on women and their babies across Scotland. We will capture data from health records to see if the changes have altered the number of women diagnosed with GDM and their pregnancy outcomes. Our research will be used to inform the best care pathways for women with GDM in Scotland in the short and long term.

2021-0138 Dr Diane Lindsay Glasgow Royal Infirmary
Genomic epidemiology of *Legionella pneumophila* in Scotland

An increase in the use of man-made water systems has resulted in an increase in a form of pneumonia called Legionnaires' disease (LD) over the last 40 years. The infection is caused by inhalation or aspiration of a Legionella contaminated water source. A rapid response to LD outbreaks is critical to minimise further cases and requires the identification of suspected water source and comparisons made to the Legionella bacteria isolated from infected individual/s.

This project aims to use data generated from the whole genome sequencing (WGS) of Scottish patient and environmental isolates to identify links within Scotland and compare these to publicly available WGS information from isolates from around the world.

The data generated will lead to a greater understanding of the diversity in patients and the environment and will allow the identification of a definitive source of infection.

However this can only be achieved when we have access to epidemiological data on the patient. The aim of this study is to merge the lab and epidemiological data to get a better understanding of prevalence and persistence of certain Legionella in the environment and why they cause disease

2021-0154 Joe Schofield University of Stirling
Exploring the utility and safety of benzodiazepine prescribing among people receiving Opiate Replacement Therapy in Scotland (the BENZORT study).

Drug-related deaths (DRD) are a significant and increasing public health problem in Scotland. Benzodiazepines (BZD) and other drugs that suppress breathing Central Nervous System Depressants (CNSD) are increasingly implicated involved in DRD. In 2018, BZDs were implicated involved in 67% of DRD, often in combination with other illicit and prescribable substances including Opiate Replacement Therapies (ORT) such as methadone and buprenorphine which are used to treat heroin addiction.

Illicit BZD use and dependence is higher among people with other drug problems substance use disorders. 29% of patients presenting to Scottish addiction services report current illicit BZD use. There are differences in is widespread variance in approaches to the clinical management of BZD dependence among people on ORT with opioid use disorder in Scotland. Some addiction clinicians

are reluctant to prescribe BZD to people on ORT, some will prescribe BZD for a short period only with the primary aim of dose reduction and detoxification, others will consider longer-term maintenance prescribing whilst patients stabilise on ORT.

Previous research has identified increased risks of death mortality among people taking BZD and ORT. Other work suggests that co-prescribing both BZD and ORT increases patient engagement and retention in addiction treatment.

This multi-centre retrospective cohort study will analyse anonymised, linked data on a cohort of group of Scottish ORT patients from across Scotland to explore any relationships between exposure (co-prescribing of being prescribed ORT plus BZD and other central nervous system depressant medications) and harms including: mortality death (all-cause and DRD), hospitalisation, emergency healthcare, and early cessation of leaving addiction treatment early.

2021-0160 Magdalena Jurczuk Royal College of Obstetricians and Gynaecologists (RCOG)

OASI2: a hybrid effectiveness implementation RCT to inform scale up of care bundle to reduce obstetric anal sphincter injury (OASI) caused during childbirth

Up to 9 in 10 women who have a vaginal birth experience some sort of tear or graze of their perineum (area between the vagina and anus). First and second degree tears are the most common and are unlikely to cause long term problems. Third or fourth degree tears, also called obstetric anal sphincter injuries (OASI), can result in complications such as anal incontinence with significant psychosocial consequences to women, and long-term financial consequences for the NHS.

A tripling in detected OASI rates was identified in primiparous women giving birth for the first time in England between 2000-2012, which led to the development of the OASI Care Bundle. Care bundles are defined as ‘a small set of evidence-based practices that, when implemented together, will result in significantly better outcomes than when implemented individually.’ The OASI Care Bundle has four components: discussion with women about OASI during pregnancy, manual perineal protection (clinician uses their hands to support the woman’s perineum during birth), episiotomy (a small cut made at the vaginal opening) at 60° (well away from the anus) if there is clinical need to for it, and systematic examination of the perineum, vagina and ano-rectum after vaginal birth to assure immediate diagnosis and treatment where necessary. which aims to standardise practice and address inconsistencies in clinicians’ training, skills and prevention strategies. In 2016-2018, the OASI Care Bundle was rolled out in 16 units across England, Scotland and Wales as part of in the OASI1 project, demonstrating the bundle’s clinical effectiveness and feasibility of implementation.

This project—OASI2-- will evaluate more sustainable scale-up methods of the OASI Care Bundle through its implementation in 20 additional maternity units across England, Scotland and Wales. Both clinical and implementation outcomes will be measured.

Implementation outcomes are adoption, acceptability, appropriateness, feasibility, and coverage of the care bundle and the scale-up method. These will be assessed using data collected from surveys and focus group discussions.

The main clinical outcome is rates of OASI as this is the condition targeted by the care bundle. Rates of episiotomy and caesarean birth will also be monitored. Clinical outcomes will be measured through analysis of routinely collected data from participating hospitals’ maternity information systems.

2021-0162 Nanisa Feilden Healthcare Improvement Scotland
National Hub for Reviewing and Learning from the Deaths of Children and Young People

Scotland has a higher mortality rate for under 18s than any other Western European country, with over 300 children and young people dying every year1. Around a quarter of those deaths could be prevented2. Every death of a child or young person deserves a review and by reviewing and learning from these deaths we may reduce the chances of future deaths.

There is currently no national system to support reviewing and learning, or to share national learning, and not all deaths are reviewed. We also know that the quality of reviews varies across services, and across Scotland. To address these issues a National Hub has been set up at the request of Scottish Government, co-hosted by Healthcare Improvement Scotland and the Care Inspectorate.

The programme will use a multidisciplinary and multi-agency approach, focused on using evidence to deliver change, and ultimately aim to reduce deaths and harm to children and young people. We want to ensure the death of every child and young person is reviewed to an agreed minimum standard. We have worked with key stakeholders to develop a core review data set, with associated methodology and guidance, for use by NHS boards and local authorities, when reviewing deaths of children and young people. Reviews will be conducted on the deaths of all live born children up to the date of their 18th birthday, or 26th birthday for care leavers who are in receipt of aftercare or continuing care at the time of their death.

2021-0185 Andrew McNally UK Haemophilia Centre Doctors' Organisation (UKHCDO Ltd).
National Haemophilia Database (NHD)

UK National Haemophilia Database (NHD) holds information on people registered with a bleeding disorder within the United Kingdom. It contains details of more than 40,000 people, both alive and deceased. The NHD is managed by the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO), who work with practitioners based within the Haemophilia Centres in the UK and have an interest in the care of people with inherited bleeding disorders. Since its inception, the database has monitored treatment trends and morbidity and mortality associated with bleeding disorders and changes in life expectancy. UKHCDO have published extensively on the epidemiology of bleeding disorders, life-expectancy and causes of death. The database is essentially conducting an open-ended cohort study. Data is collected from haemophilia centres and from the Haemtrack home therapy recording system. The NHD serves two purposes: non-research activity; regular reporting to the NHS to facilitate disease monitoring and healthcare planning, for example, current and future needs, safety, and efficacy of treatment. Secondly, research into bleeding disorders and their complications to understand the natural history of these conditions and the outcomes of treatment. The NHD is required to provide annual cyclical reporting on Bleeding Disorder Statistics to assist with national strategic healthcare planning, disease monitoring and requires death certification data to allow us to study trends in causes of death and in life expectancy as improvements in treatment are introduced. This would help us to evaluate and justify therapeutic developments. The benefits will be measured in terms of reduced morbidity, mortality, and treatment costs.

2021-0190 SR295 Amy Taylor University of Oxford FUTURE-GB

For patients with a brain tumour called Glioblastoma (GB), prolonging survival whilst ensuring quality of life is key, but remains challenging. GB is incurable and the most frequent and aggressive form of brain cancer, with a poor prognosis.

Patients experience a decline in Health-Related Quality of Life (HRQoL), and caregivers report high levels of distress and carer burden. The main treatments for GB are surgery, radiotherapy, and chemotherapy, used in various combinations. For patients where surgery will benefit, a surgeon often removes as much as possible, whilst limiting the risk of causing problems, (e.g. weakness, speech or cognitive difficulties). However, it is unclear as to which techniques a surgeon should use to remove the tumour safely. This influences when the cancer returns, what symptoms the patient has, and how a patient feels.

Ultrasound (US) (high frequency sound waves which create an image) is one of the tools a surgeon can use during the operation to find the tumour and assess how much is being removed during the operation. Another technique, Diffusion Tensor Imaging (DTI) allows important fibres involved in specific functions (e.g. speech/language, vision, and movement) to be seen during surgery. This means that potential damage to these functions might be avoided during the procedure.

This study aims to see if surgery to remove a GB with additional imaging added to present standard techniques improves HRQoL. This will be assessed through participants and their proxies completing HRQoL questionnaires before and after surgery for up to 2 years.

2021-0199 Daniel Bradford University of Glasgow Health of young looked after children in Scotland

Children that require formal looking after by local authorities have poorer health than similar children that don't need formal care. The term `looked after' in Scotland can include children living with their parent(s) but receiving additional input from health and social services, children living with other members of their family such as grandparents, children that need specialist healthcare and must live away from their parents to get it, children living with foster parents, and children in secure accommodation.

Poor health and development outcomes in childhood can have negative consequences on health and wellbeing over the entire lifetime, so it is important to act early. NHS Scotland carries out scheduled health reviews of every child from birth through to the age of five. One such review happens at age 27-30 months. Using data from this review from April 2013-March 2022 we will look at the health and development of young children that are formally looked after and compare it to children that are not.

Deprivation is also associated with poorer health so this study will also investigate health differences by level of deprivation. This will also help clarify if any potential differences in health between children that are looked after and those that aren’t are due to a higher proportion of children that are looked after living in more deprived areas. We will also consider the effects of age, sex, ethnicity, and parent/guardian smoking to better understand the independent association between being a child being looked after and their health.

2021-0200 Dr Rachel Rowe University of Oxford
The UK Midwifery Study System (UKMidSS)

The UK Midwifery Study System (UKMidSS) is a national system for carrying out observational research studies in midwifery units, co-ordinated from the National Perinatal Epidemiology Unit (NPEU) at the University of Oxford. UKMidSS was set up in 2015, using the same approach as the UK Obstetric Surveillance System (UKOSS), which was established at the NPEU in 2004. To date, four national observational studies have been carried out using UKMidSS and further studies are planned. All Scottish NHS Health Boards with alongside midwifery units (i.e. those co-located with hospital obstetric units) have been contributing data to UKMidSS studies since our first study started in 2016, and all freestanding midwifery units (community maternity units) are now also involved.

Each study investigates a different condition or event occurring in midwifery units. For example the first study investigated outcomes for women with a high body mass index (BMI>35kg/m2) admitted to a midwifery unit, and the most recent study is looking at how severe bleeding immediately after birth (postpartum haemorrhage) is managed in midwifery units and what the outcomes are for women. Each month, midwife 'reporters' in each unit identify and report the number of 'cases' meeting the study inclusion criteria, and the overall number of admissions or births, to the NPEU co-ordinating centre. They then enter selected anonymised data about cases and ‘controls’ or comparison women directly from medical records using the secure online system, OpenClinica.

2021-0221 Professor David Newby University of Edinburgh
SCOT-HEART – long term outcomes

We are looking to see what happened to participants who took part in the SCOT-HEART trial. The main aim of the SCOT-HEART trial was to see if a CT scan of the blood vessels of their heart (called a CTCA) in patients attending a rapid-access chest pain clinic changed the diagnosis of angina and improved clinical outcomes. A CTCA scan uses x-rays looks at the blood vessels of the heart. These arteries supply blood to the heart muscle, and disease of these vessels (atherosclerosis) is responsible for most heart attacks. The trial found that the CT scan did change diagnosis and improved outcomes at 5 years. Now we are looking to see if using a CTCA had longer-term benefits to participants beyond 5 years. In particular, we wish to determine whether there is a reduction in death related to the heart and also a reduction in heart attacks in the longer term (up to 10 years).

2021-0228 Calvin Down Royal College of Paediatrics and Child Health
National Neonatal Audit Programme (NNAP) data flow

The Royal College of Paediatrics and Child Heath (RCPCH) is currently was previously funded by the Scottish Government, NHS England and NHS Wales to deliver the National Neonatal Audit Programme (NNAP), commissioned by the Healthcare Quality Improvement Partnership (HQIP), for the period 1 April 2017 to 31 March 2021. The RCPCH has received an extension to its contract with HQIP until March 2022, however this does not include Scottish services. Therefore the RCPCH has sought a direct agreement with the Scottish Government. This application relates to the period 1 April 2021 to 31 March 2022 and the flow of data from Scottish Health Boards via Clevermed to the RCPCH, which would be underpinned by a contract directly between the RCPCH and the Scottish Government. It is hoped that in the future the Scottish Government could enter into an overarching agreement with HQIP again for inclusion of Scottish data in NCAPOP audits.

The reason for this is so that the RCPCH-based NNAP team can process data that is solely required for care quality and service improvement in relation to the aims and scope of the NNAP. Setting up this new data flow will allow the NNAP project team within the RCPCH to improve the

responsiveness and utility of NNAP reporting and therefore allow for timely comparisons of unit and network performance, help to rapidly identify variation and facilitate improvements in the quality of care for the benefit of neonatal units and networks and the babies and families that they care for.

2021-0229 Professor Simon Davies Keele University
BioImpedance Spectroscopy To maintain Renal Output Trial: the BISTRO Trial

The BISTRO Trial, (BioImpedance Spectroscopy To maintain Renal Output), is a randomised controlled trial funded by the National Institute for Health Research, the research funding arm of the NHS.

Its purpose is to find out whether using a device that measures the amount of fluid in the body, called bioimpedance, can help to guide clinicians in deciding how much fluid to remove from people having dialysis for kidney failure. Specifically, BISTRO is establishing whether using bioimpedance can stop removing too much fluid, so preventing dehydration at the end of a dialysis treatment which could result in a more rapid decline in their own remaining kidney function. Keeping this going for as long as possible has survival and quality of life benefits for dialysis patients.

In addition to finding out whether bioimpedance is helpful clinically, when commissioning this research, the NIHR requested that a full health economic analysis was undertaken. This has not been done before for bioimpedance technology and will help the National Institute for Health and Care Excellence (NICE) to develop its recommendations once the research is completed. To do this we have measured the quality of life as reported by the trial participants themselves, but we also need to know what else happened to them during the trial, such as hospital admissions, visits to A&E, medical procedures and appointments. A significant number of the trial participants were in Scotland, and for them, these data are reliably captured by the Electronic Data Research and Innovation Service held by Public Health Scotland.

2021-0236 Hazel Dodds Public Health Scotland
Scottish National Audit Programme (SNAP), Clinical & Protecting Health Directorate, Public Health Scotland (PHS) - approval for rolling access to patient level data for quality assurance to improve the quality and credibility of clinical audit data

PHS has legal powers to produce National and Official statistics with obligations to ensure that its statistics are based on accurate data and demonstrate that it takes active steps to evidence the quality of the data behind the published statistics. Data are collected for national clinical audits/ registers follow strict protocols/ definitions. They are entered/ supplied by health boards to PHS and are the basis of the datasets held for national audits/ registers within SNAP which are analysed to produce real-time management reports via Tableau/ annual national reports.

To evidence data quality, SNAP have two QAMs who, in collaboration with either a local audit coordinator or other identified individual within the health board, e.g. specialist nurse, check the quality of samples of the data held in SNAP against the equivalent data held locally. SNAP produces national reports and bespoke detailed local reports which are used by local health boards to drive improvement in the provision of care for patients. SNAP also provides data entry training/ advice to local audit coordinators and others to help them improve the accuracy of their data collection. This is usually done by the NCC or RC attached to each national audit/ register who also in most cases accompanies the QAMs on their quality assurance CNV visits.

The aim of this proposal is to seek approval for the small team of authorised and well trained QAMs, NCCs/ RCs and Senior Nurse for continued and open ended access to local health board data which

are used to facilitate the validating of national data held by SNAP and the continued provision of training and advice to local audit coordinators and others associated with the audit/ register in individual health boards.

2021-0243 Professor Irene Higginson King's College London
CovPall-Connect. Evaluation of the COVID-19 pandemic response in palliative and end of life care: Connecting to boost impact and data assets.

Palliative care is the medical approach aimed at helping wellbeing, and easing pain of people at the end of their life. COVID-19 has had a large impact on health care services.

1-4% of people have died from COVID-19, with over 10000 UK deaths. Vulnerable groups that palliative care helps, are those most affected by COVID-19. Symptoms can be painful and stressful, but most are not well understood, making it hard for palliative care workers to change how they work in response to COVID-19.

2021-0248 Fiona Wee University of Edinburgh
Cervical Ripening at Home or In-Hospital - prospective cohort study and process evaluation (CHOICE Study)

Induction of labour (IOL) is offered when risks of continuing a pregnancy are thought to outweigh risks of birth. The first part of IOL, cervical ripening, is usually performed in hospitals to allow detection of potential maternal and fetal complications. Some maternity units offer home cervical ripening, where women attend hospital to start cervical ripening and then return home for 24 hours. Home cervical ripening may be more acceptable to women, and reduce the numbers of women admitted to maternity units.

Nevertheless, there is a lack of evidence about the safety of home cervical ripening, its acceptability to women and their families, and its cost effectiveness. The CHOICE study will address these evidence gaps. Changing maternity policies in response to the pandemic means that more maternity units have started offering home cervical ripening, (to reduce footfall in hospital, and to reduce the amount of time mothers and partners spend in maternity units). The CHOICE study is therefore urgently needed.

We will use data from electronic maternity and neonatal records from 25-30 UK hospitals to assess the safety of home cervical ripening. Information that might easily identify women or their babies (e.g. name; date of birth) will be removed before using the data for research (pseudonymised). We aim to collect data from all women having IOL so findings can be put into context and are generalisable. It is not practical to seek consent from all women, and doing so would inevitably lead to an incomplete and potentially biased sample. Women will instead have the option of opting out of contributing data, and clear details of how to do this will be given to women in the study information sheets.

2021-0264 Dr Annemarie Docherty University of Edinburgh
HEAL-COVID

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 participants, alongside collection of remotely entered patient reported data (telephone or smartphone app), resource use and quality of life assessments.

Formal feedback from the Long COVID Support Group identified non-acute treatment as a key question to be addressed, both to aid recovery and as an early intervention to prevent patients developing longer-term problems. Previous patient engagement in convalescent treatment in lung infections has underlined the importance of prevention of readmissions to hospital and prolonging life.

2021-0282 Katrin Metsis University of St. Andrews
Health inequalities among adolescents and young people in Scotland: an analysis linking the UK Censuses and the Scottish Longitudinal Study to health data

This proposal covers the third part of the PhD project, which examines health inequalities among young people (aged 10-24) in Scotland and investigates whether these are related to the uptake of prescription medicines in their adulthood. Adolescence (ages 10-19) is a formative life stage when health is established. Young people are exposed to unequal conditions that contribute to the formation of health inequalities. Determinants of adolescent health and their impact in later life are not well understood - most research concentrates on younger children and adults, and studies linking health measures in adolescence with adult health outcomes are scarce.

I am proposing to link data from the Prescribing Information System (PIS) to the Scottish Longitudinal Study (SLS). The SLS links data from the 2001 and 2011 Censuses and includes variables that describe self-reported health (SRH) and household-and individual-level socioeconomic (SE) status. This allows me to investigate whether SRH at ages 10-24 predicts adult health outcomes and whether these outcomes differ by SE status. Prescribing data was chosen because other health measures such as mortality and hospitalisations are not common among 18-42-year-olds. Prescription medicines are one of the main tools in treating health problems. Medicines prescribed for depression, anxiety, substance dependence, neck and lower back pain were chosen based on the Scottish Burden of Disease Study. Diabetes and asthma medication were chosen because of their increasing overall prevalence and higher prevalence among deprived population groups. This project will also demonstrate how existing data can be used in health inequalities research.

2021-0290 Jodie Westhead University of Manchester
Suicide in former service personnel: rates, antecedents, and prevention

UK Armed Forces veterans are potentially a highly vulnerable group due to prior adverse life events, the difficulties associated with the transition to civilian life and high rates of homelessness and substance misuse. Previous work by the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) examined the rate, timing and risk factors for suicide in veterans who had left the Armed Forces in 1996-2005, compared to the general and serving populations. We identified that young male veterans were at increased risk of suicide and made recommendations for suicide prevention. As far as we are aware, there has been no detailed UK study since this research was published in 2009.

The main aim of the proposed study is to again examine rates of suicide and characteristics of individuals who had left the UK Armed Forces, but to update our earlier work – firstly, by examining a 20 year (1997-2018) compared to a 10 year (1996-2005) period. We will also build on earlier findings by collecting coroners' and police death report data on approximately 200 veterans who have died by suicide. This is a new data source compared to our previous study, and will allow us to examine factors related to suicide in veterans in detail. It is envisaged that the findings of our proposed study will provide an estimate of the burden of suicide in UK veterans and will identify key characteristics that could be the focus of preventative efforts in the veteran population.

2021-0291 Dr Andrew McAuley Public Health Scotland Enhanced Surveillance of COVID-19 in Scotland: population-based seroprevalence surveillance

COVID-19 is caused by the new coronavirus known as SARS-CoV-2. When the body is infected with coronavirus, it produces antibodies to help fight the virus, and these may be detected by blood tests. The detection of antibodies provides an indication that someone has had COVID-19 or has been vaccinated for COVID-19. We use serology methods to detect these antibodies. The Public Health Scotland (PHS) serology surveillance programme uses residual (leftover) blood samples within community healthcare and other settings to estimate the proportion of people who have antibodies to coronavirus ("seroprevalence") in the general population of Scotland and to see if this changes over time. This surveillance programme currently has permissions to operate using pseudonymised data (i.e. the data that we get back with the antibody result is limited to the age and sex of the individual). We are proposing to link these individuals to other nationally held datasets in order to: monitor the proportion of the Scottish general population who have already been exposed to the virus or have been vaccinated; monitor the proportion of the Scottish general population who are still susceptible to the virus; and support evaluation of the COVID-19 vaccination programme.

2021-0293 Carole Morris PHS CO-CONNECT (COvid - Curated and Open aNalysis aNd rEsearCh plaTform)

The current COVID-19 pandemic has caused hundreds of thousands of deaths, severely strained health systems and damaged economies across the world. For those that have had COVID-19 and have antibodies, we don't know if or for how long they are protected from being infected again. By understanding who is immune and why, will help protect vulnerable individuals, manage the spread of COVID-19 and allow population-based interventions such as lockdowns, mask wearing, and social distancing to be safely scaled back.

Across the UK, different healthcare teams have been collecting data that can help answer these questions. As this is a new disease, the way the data on antibodies is collected is also new. This means different research teams might collect different pieces of information or they might record it in different ways. With all the data being held in different places and in different ways, it makes it difficult for public health groups and researchers to find and access the high-quality data they need.

CO-CONNECT stands for: "COVID - Curated and open analysis and research platform". CO-CONNECT is led by the University of Nottingham and University of Dundee and working with the University of Edinburgh and Public members.

Working together we will:

- Standardise antibody data collection across the UK
- Create a system which enables trustworthy, fast, de-identified, secure analysis of data sets from across multiple sources

- Answer key questions about immunity to COVID-19 and what this means for patients' health

CO-CONNECT is funded by funded by the Medical Research Council (Part of UKRI) and the Department of Health and Social Care (part of NIHR).

We have created a CO-CONNECT explainer video that covers all aspects of the project in layman's terms. It can be found here and we suggest you watch this to give a higher-level understanding of the CO-CONNECT project.

This application covers the inclusion of Scottish data in the UK wide federated CO-CONNECT platform.

Fundamentally this project will allow researchers to undertake early feasibility checks for a potential research project or public health analyses which they will then discuss with the data controllers and seek the appropriate permissions to get access to a full set of data needed to answer the questions. For NHS Scotland data this will be through the NHS Scotland Public Benefit and Privacy Panel.

2021-0307 Professor Helen Colhoun Public Health Scotland Record-linkage to estimate risk of Cerebral Venous Thrombosis associated with COVID-19 Vaccine exposure

COVID-19 vaccination has been shown to be highly effective. Its broad safety has also been demonstrated. However sometimes rare side effects are not detected in trials and need to be carefully monitored in the population. This monitoring has raised a questions about bleeding and clotting problems that have occurred in some people after vaccination including a certain kind of brain clot. We don't know yet if this is really a side effect or a chance finding or how common it is or how much vaccines may increase the risk and in whom. So we need to look into this urgently to understand it.

In this project we will bring together radiology reports on brain scans from NHS Boards where the scan has been done to identify a certain kind of clot in the brain called a cerebral venous sinus thrombosis. These data will be imported securely into Public Health Scotland and will be combined with other routine health data including vaccination data. We need to collect data from both before the COVD-19 epidemic and the vaccination programme so as to get an accurate estimate of the background rate of these clots in the population as well as analyses that will estimate risks if any associated with vaccines.

2021-0308 Dr Linda Fiaschi University of Nottingham COVID-19: PROphylactic ThErapy in Care homes Trial

The COVID-19 pandemic has had a devastating effect in care homes. COVID-19 causes illness and death in care home residents and staff. Measures to reduce viral spread into care homes such as limiting family visits, impact on residents' health and wellbeing. Beyond public health measures to prevent infection, we urgently need treatments to minimise these impacts on residents.

We will set up a large clinical trial platform that will test several treatments intended to reduce the spread of COVID-19 within care homes and reduce the risks of hospitalisation and death. A trial platform allows multiple treatments to be tested in parallel, with results analysed regularly. As soon as a treatment is shown to be effective or ineffective, it is removed from the platform. This makes space for new treatments, tested and chosen by government advisors, to be added and rapidly evaluated.

We will recruit more than 400 care homes from across the UK and approximately 12,000 residents. Representativeness of the trial cohort will be assessed against demographic characteristics (such as age and ethnicity). Care homes will be allocated to a treatment or standard care (no additional treatment). We expect most of the treatments to be given for two months before we can see whether they have worked, and whether the treatments are cost-effective. For care home staff we will develop training materials. For residents (or their legal representative) we will provide information on the study and the treatments to help them make an informed decision on whether to take part.

2021-0312 Dr Jan Savinc Edinburgh Napier University
Deaths at home during COVID-19 in 2020 in Scotland

There has been a sustained increase in the number of people who died at home in Scotland during the COVID-19 pandemic compared to 2015-2019, raising questions about the quality of care received and implications for end-of-life care policy. This project will use linked administrative and health data to investigate the demographic, clinical and service use data to compare people who died at home during the pandemic to those who died in 2015-2019, as well as those who died in an institutional setting. The aim is to describe the population of people who died at home, find out why the shift to death at home occurred, and estimate the quality of care they received at the end of life.

2021-0313 Professor Susan McVie University of Edinburgh
Understanding the relationship between health-related and other vulnerability and compliance with the Coronavirus Regulations

The project will explore the association between health-related (and other) vulnerabilities and compliance with the Coronavirus Regulations (using FPNs as a proxy measure of compliance), with a view to understanding the likely efficacy and fairness of the Emergency Health Regulations on those with conditions that may have prevented people from complying.

It has been proposed that the restrictions introduced to deal with the pandemic impacted most severely on those with underlying vulnerabilities and this may explain greater levels of non-compliance amongst some people. This research will use linked health and police data to generate plausible hypotheses about whether or not this was the case.

Comparing FPN recipients to a matched sample of Scottish residents, we will investigate whether underlying health-related vulnerabilities (e.g. mental health problems, alcohol dependence, drug misuse or history of violent victimisation), and other household or neighbourhood measures of vulnerability (e.g. over-crowding and deprivation) may have been associated with non-compliance with the Emergency Health Regulations.

The aim of the Regulations was to 'reduce the spread of the virus and save lives'. Therefore, this research will also link FPN data to Covid-19 testing data to explore the possibility that people who received FPNs for not complying with the Regulations posed a greater risk in public health terms than other similar individuals.

This project will help generate hypotheses about the potential impact of people's health vulnerabilities on their ability to comply with strict public health restrictions; identify possible health inequalities in the impact of the Public Health Regulations (measured using justice sanctions) during the pandemic; and improve collaboration between health and policing organisations in terms of public service delivery and policy development.

2122-0003 Professor Adrian Martineau Queen Mary University of London COVIDENCE UK

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 medical records, 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 interested in taking part in future clinical trials, and to invite selected people to participate in those trials.

The results of the research will help identify potential risk factors and help develop strategies to reduce the risk of coronavirus disease.

2122-0004 Dr David Henderson University of Edinburgh Individual-level analysis of the Health and Care Experience Survey

The Health and Care Experience Survey (HACE) collects views of patients receiving care from General Practitioner services every 2 years. It is collected by the Scottish Government and asks questions about satisfaction and experience with general practices and associated services, ability to access care and other questions related to carers and health and wellbeing.

Although results are freely available on the Scottish Government website, these only describe overall patterns and limited comparisons over time. We would like to delve deeper into the results and investigate changes in patient satisfaction and experience over the last ten years, especially the views of older people and those living in poorer areas of Scotland.

In order to do this robustly, we need access to pseudonymised data of individuals' responses so that we can apply suitable statistical techniques that will help identify whether differences over time are meaningful.

This is one piece of work in a much larger project funded by the Economic and Social Research Council which is investigating transformation of primary care in Scotland and China. Results will be one piece of a larger jigsaw of research findings that we will combine to form an overall evaluation of recent policy changes.

2122-0006 Dr T'ng Kwok University of Nottingham British Paediatric Surveillance Study of Neonatal Stroke in the United Kingdom and the Republic of Ireland presenting / diagnosed in babies in the first 90 days of life.

We are seeking approval for a new British Paediatric Surveillance Unit facilitated study.

The BPSU facilitates active surveillance of rare health conditions affecting children across the UK and Republic of Ireland. The unit was established in 1986 and is based at the Royal College of Paediatrics and Child Health in London. At any one time, the Unit facilitates active surveillance of a range of rare paediatric conditions/events. Surveillance of each condition is led separately by an independent Principal Investigator, although standard BPSU processes apply to all studies.

In this application we are seeking approval for a new surveillance study of neonatal stroke, to be run jointly by the BPSU and University of Nottingham. Stroke in babies is rare and different from those of older children and adults. Presently, we have insufficient information about the number of babies with neonatal stroke, which babies are most at risk and what problems they will likely face. There is also no agreed guidance on how we should investigate and treat babies with stroke. The study aims to answer these questions and raise awareness of neonatal stroke amongst clinicians, as it is often under-reported.

Clinicians will notify the research team, through the BPSU, if they care for a baby with stroke. Online questionnaires will be sent to notifying clinicians. All study data is stored securely for at least 20 years within the University of Dundee–Health informatics Centre safe haven (https://www.dundee.ac.uk/hic/hicsafehaven/). It is ISO 270001 certified with the highest level of data security possible.

2122-0018 Dr Anna Santarsieri Addenbrookes Hospital, Cambridge
Toxicities and strategies to reduce them in blood cancer patients treated in the non-trial setting

Most patients with blood cancer are treated outside of clinical trials. In routine clinical practice, many patients receive chemotherapy regimens that diverge from standard treatment because there is a need to reduce the toxicity of the chemotherapy (e.g. in older patients or those with other illnesses). However, often there are no studies to show whether the modified treatment is as effective as standard treatment and whether it does in fact reduce toxicity to patients.

We will use real world data to investigate three strategies that are used to reduce toxicity in the treatment of lymphoma. 1) Modified protocols, 2) Non-chemotherapy approaches, 3) Targeted small molecule cancer therapy.

The study will be performed retrospectively. Patients will be selected at Addenbrooke's and at collaborating centres in the UK based on specific treatments they have received for blood cancers. Data will be collected from the patients' medical records and all personal identifiers will be removed at the point of collection. The information will be transferred securely to Cambridge where we will collate the data.

We will analyse the data to compare patient survival and the side effect profile of modified treatment and standard treatment. We will publish the results of our analysis so that Haematologists in the UK and internationally are provided with the evidence for any treatment regimens that are effective and less toxic to patients. We aim to improve care for lymphoma patients by making the treatment more tolerable.

2122-0030 Dr Janet Hanley Edinburgh Napier University
Hypertension management and outcomes during the COVID-19 Pandemic (HoCo)

In Scotland, as many as 30% of adults have high blood pressure (BP) accounting for 1.2 million primary care appointments annually. Scale Up BP is a self-monitoring service that allows patients to measure their own BP and electronically report it back to practice. NHS Scotland are in the process

of embedding BP telemonitoring within primary care and evaluation is ongoing as the service expands across Scotland.

The effects of COVID-19 on a hypertension population are currently poorly understood however they are potentially severe both due to an estimated doubled risk of death from COVID-19 and by altering the way people with hypertension have been able to access healthcare. The pandemic shifted services to remote delivery and appeared to cause a reduced willingness to present to hospitals for major cardiovascular events such as stroke or myocardial infarction potentially worsening clinical outcomes.

Therefore, this proposal aims to explore the immediate impact of COVID-19 on the hypertensive population in Scotland and compare outcomes between those with and without access to BP telemonitoring. Patients for inclusion would be identified through prescription of first line anti-hypertensive drugs on the Prescribing Information System (PIS). This would be linked to Scottish Morbidity Records (SMR) data held by PHS and BP telemonitoring data held by NSS and NHS Lothian. The use of pseudonymised data from five Scottish health boards aims to analyse 650,000 records (25% of the adult population within these health boards) to ensure adequate power to identify changes to hypertension management and outcomes across Scotland due to COVID-19.

2122-0042 Fiona Murdoch NSS National Services Scotland
Further Analysis of Hospital Onset COVID-19 Cases in Scotland through data linkage

Nosocomial transmission of SARS-CoV-2 contributes significantly to the overall burden of infection within these settings. Deaths occurring in patients with COVID-19 are an important measure of patient outcome. Therefore, monitoring COVID-19 mortality in hospital patients and publishing the data is critical in the development and monitoring of local and national improvement plans to improve patient outcomes, inform the development of infection prevention and control measures, shape policy and guide research.

To understand the association between hospital-onset (HO) COVID-19 cases and their healthcare needs it is necessary to describe the epidemiology of hospital-onset COVID-19 cases in relation to other healthcare factors involved in their care before or during their first positive COVID-19 isolate (e.g. frequency of hospital care, co-morbidities, types of operations conducted).

This study will aim to describe the epidemiology of HO COVID-19 cases in relation to other healthcare factors involved in their care before their first positive COVID-19 isolate from March 2020.

The study will link HO COVID-19 cases with Scottish Morbidity Records (SMR00, SMR01, SMR01 (Long-stay Geriatric), SMR02, SMR04), National Records of Scotland (NRS) deaths, Electronic Communication of Surveillance in Scotland (ECOSS) and Scottish Intensive Care Society Audit Group (SICSAG) data.

2122-0051 Dr Kyle Gibson NHS Lothian
Clinical Frailty in Scottish Intensive Care Units

Frailty is a state of increased vulnerability which results from age-related decline in physical reserve. As the population ages, frailty will become more common. When those with frailty become severely unwell, the healthcare team looking after them may discuss their case with Intensive Care specialists. This audit seeks to understand those patients with frailty who are admitted to Intensive Care Units in Scotland, the organ support they receive, the decision-making about their treatment, consequences and complications of Intensive Care and their overall outcomes. It is anticipated that

greater understanding of this will improve future care, conversations and decision-making with patients and their families when they become severely unwell.

2122-0054 Andrew McEwan Scottish Government
Equality Protected Characteristics Dataset

Lay summary not yet available

2122-0072 Wendy Saywood University of Dundee
Febuxostat vs Allopurinol Streamlined Trial (FAST) – retention of datapost-study

FAST was a European Medicines Agency (EMA) requested study to assess the relative safety of febuxostat and allopurinol in patients over the age of 60 years suffering from gout. It was sponsored by the University of Dundee and run by MEMO (Medicines Monitoring Unit) Research within the School of Medicine. The study was active from December 2011 until the end of December 2019. Over 7000 participants were recruited from Scotland, England, Denmark and Sweden. The study was closed in August 2020 with a final report being published in The Lancet in November 2020. Data is currently being retained for audit purposes and for further analysis to ensure best use is made of the information gathered. We recognise that with so many participants the further analysis could further aid with better treatment of the disease for the future, not just within the UK but more widely across Europe. All reports and resulting articles published will be posted on the FAST study public website.

2122-0071 Professor Richard Colquhoun Imperial College, London
National Neonatal Research Database

Lay summary not available

2122-0078 Anna Morton NHS GGC
International Staging Project - Mesothelioma

The International Association for the Study of Lung Cancer (IASLC) Staging Project is a global effort to investigate and improve the current tumor, node, metastasis (TNM) staging system for lung cancer, mesothelioma, esophageal, and thymic cancers. Over the past two decades, the IASLC Staging Project has provided evidence-based recommendations for the TNM classification for lung cancer, which are published and adopted by the Union for International Cancer Control (UICC) and the American Joint Committee on Cancer (AJCC). These TNM stagings are the international basis used for the staging of mesothelioma. The project is now entering the third cycle, with the goal of developing recommendations for the ninth edition of TNM. The project outcomes are used as the standard TNM staging for lung cancer and this is the first time that scottish data has been submitted. Scotland has some of the highest incident globally so it is important to be involved in the study.

Staging lung cancer and other thoracic malignancies accurately is critical in deciding treatment regimens and ensures best standardized care for patients worldwide. New data elements such as genetic biomarkers, protein alterations and copy number alterations (CNAs) will be added to the staging project for the first time, and such additions and enhancements to the system may significantly improve the current staging system leading to more precise treatment decisions and improvement in patient survival.

This decision-making becomes more complex as emerging treatments enter clinical use. Refinement of staging systems by the addition of real-world patient data allows more informed decisions to be made by clinicians and patients, and represents progress towards a goal of personalised cancer treatment. The inclusion of data from Scottish patients ensures that staging systems are derived from datasets that represent a wide range of populations, and are thus directly applicable to patients with these cancers in Scotland. Despite the long-running nature of the staging project, inclusion of data representing the local population will increase the accuracy of staging systems with lasting benefit for patients and clinicians.

Scotland has some of the highest incidents of mesothelioma worldwide due to its industrial history and it is only since the introduction of the Scottish Mesothelioma Network in April 2019 that there has been a dedicated pathway and resource to audit mesothelioma specific information from Scotland.

2122-0091 Professor Bijay Vaidya Royal Devon and Exeter NHS Foundation Trust
Antithyroid Drug Study

Antithyroid drugs (ATDs) are the primary treatment for most patients with hyperthyroidism (a condition where the thyroid gland produces too much of the hormone thyroxine). Of the 15,000 new UK patients treated each year, 1/500 have a drug reaction causing a very low white cell count leading to inflammation of the throat, mouth and lips, fever and sepsis. If treatment is stopped quickly a patient will usually recover after 5-10 days but up to 10% of cases are fatal. Another potentially life-threatening effect is liver injury and 1/1000 patients taking the ATD Propylthiouracil will get this. Of these, 10% will have liver failure resulting in liver transplantation or death. As these side-effects are rare, each doctor will only see a small number of cases. Therefore, important patterns or information about who is affected and the best way to manage them could be being missed. This is a UK-wide study to collect information from 150 adult patients who have had a reaction. Data will be collected from medical notes only. Those willing will provide a blood sample will have their DNA stored for future research to identify genetic variants that predispose patients to develop severe adverse events. The results will be published in a scientific journal and will be available for participants and the public as a lay summary on the Society for Endocrinology public facing website 'You and Your Hormones'.

2122-0100 Dr Donald Maciver Queen Margaret University
National Autism Implementation Team (NAIT) RETROSPECTIVE NOTES REVIEW: waiting times for assessment and diagnosis in autism and neurodevelopmental pathways for adults and children

The National Autism Implementation Team (NAIT) are a team of health and education practitioners funded by Scottish Government and they have a remit to Improve autism and neurodevelopmental diagnostic pathways across the lifespan.

The team are primarily a resource for practitioners to support them to implement up to date and inclusive, evidence informed, multi-disciplinary practice which takes account of priorities for people who access support for their own or their family member's neurodevelopmental differences.

Documentation and a range of materials are published online www.thirdspace.scot/NAIT

Neurodevelopmental disorders have a significant impact on individuals and their families. Early assessment and diagnosis is crucial. Diagnostic assessment can be complex and time-consuming. Covid-19 has brought forward the issue of waiting for assessment.

Data collection is part the work of NAIT. Government ministers have regularly asked for information about:

- Which diagnostic services are where?
- What are the main issues diagnostic services face?
- What are wait times for diagnostic assessment?

This data is not currently routinely or consistently reported in Scotland. Some work is underway through pre-existing projects but this is anticipated to take several years.

NAIT seeks to rapidly establish information about wait times for Neurodevelopmental Disorders assessment and diagnosis across Scotland. Some Individuals may wait for more than 2 years for a diagnosis. Service development will be needed to address issues.

Prior to COVID, assessments were carried out face to face. Many more appointments will take place remotely now. It will be important to understand the impact of this.

2122-0101 Miguel Souto British Thoracic Society
BTS Interstitial Lung Disease (ILD) Registry Programme

The BTS Lung Disease Registry is an ongoing programme which was conceived and developed by the British Thoracic Society (BTS). Through the Registry, data on demographics, treatment and outcomes of patients with lung disease are collected from clinics across the UK. These data are stored and analysed to enable a greater understanding of the epidemiology and care provision for lung disease, with the aim of improving diagnosis and treatment for patients. The BTS Lung Disease Registry currently covers two disease areas: Idiopathic Pulmonary Fibrosis (IPF) and sarcoidosis, and may cover all ILD within five years. The Lung Disease Registry does not involve any intervention – it merely records the intervention chosen by the clinician and the outcome of that intervention.

The aim of the Registry is to provide a means of reviewing UK-wide data, to increase understanding of epidemiology, and ultimately to help improve patient care.

Data on demographics, method of diagnosis, markers of disease severity, and details of treatment and outcome are collected. It is anticipated that the database will provide the foundation for greater clinical research into these diseases in the UK and ultimately facilitate the delivery of improved care for patients.

Intended outcomes include refinement of the clinical characteristics, burden of disease (including impact on health status and quality of life), and the course of the diseases in the British population. Outcomes would also include provision of information which will allow clinicians to reduce delays in diagnosis and to make more informed decisions on the best management strategies.

2122-0114 Nicholas Bradley University of Glasgow
Sarcopenia in Vascular Surgery

Sarcopenia is a condition where patients, typically older patients or those with certain chronic conditions, develop wasting of certain muscle groups. This is associated with people being increasingly frail, and is linked with higher rates of death and complications following some surgical procedures.

Abdominal aortic aneurysm (AAA) is a condition where the aorta (main blood vessel in the body) becomes dilated and can lead to rupture of the aorta. This is treated by either an operation, or by placement of a stent under x-ray guidance.

There is a growing amount of evidence that patients with AAA and patients with sarcopenia share common risk factors, such as poor nutrition and long term inflammation. These factors are not well studied, however there is some early evidence that many patients with AAA may also have undiagnosed sarcopenia due to these shared risk factors.

Very little is known about the effect of sarcopenia on patients who undergo aneurysm procedures. It may be that it leads to very high chance of complications following the procedure, and that in patients who have sarcopenia doing the procedure is not appropriate.

This study aims to use data from patients at 5 health boards across Scotland who had procedures performed to treat aortic aneurysms to identify if patients with sarcopenia are at higher risk of death and post-operative complications.

2122-0141 Dr Omar Kouli NHS Greater Glasgow and Clyde Cardiovascular OutcoMes afteR AbDominal surgery (CASCADE)

The aim of this study is to better understand how to reduce heart-related complications (i.e. postoperative cardiovascular complications) after major abdominal surgery across the UK and Ireland, conducted by STARSurg collaborative. This broadly includes heart attacks (i.e. myocardial infarction), heart rhythm problems (e.g. Atrial Fibrillation), and clot-related complications (e.g. strokes, pulmonary embolism, and deep vein thrombosis). Any hospital in the UK and Ireland can take part as long as they perform major abdominal surgery on a routine basis. A parallel version of the study across the rest of Europe will be done by a collaborative group (EuroSurg).

We will achieve this aim by auditing compliance to quality standards outlined by the Royal College of Anaesthetists (RCOA) and Enhanced Recovery After Surgery (ERAS) guidelines for reducing the risk of postoperative cardiac complications (PCC). Most complications occur in the first 30 days of surgery – so we will focus on this time frame.

We will include all patients who undergo surgery in the study period at each participating hospital. The study will run from Monday 10th January 2022 to Sunday 6th March 2022 (with the last follow-up period ending on 5th April 2022). Data will be collected on all patients receiving their initial surgery during the time-period with follow-up to 30-days after their operation. This will include all adult patients undergoing emergency or elective abdominal surgery (including complete or partial abdominal organ removal, reversal of stoma, open vascular surgery, anterior abdominal wall hernia repair, or transplant surgery) through any operative approach.

2122-0118 SR293 Ian Evans University of Manchester BADBIR – The British Association of Dermatologists Biologic Interventions Register

Psoriasis is a common long-term skin condition with severely affected patients requiring lifetime systemic therapy. Biologic therapies are a new addition to the available treatment options. Biologics have been evaluated for short-term safety in clinical trials but in a relatively small group of patients. Thus, long-term safety in the "real world" is unknown. We do not know whether powerful but toxic biologic interventions lead to a net benefit or a net adverse effect for patients.

BADBIR is an observational pharmaco-surveillance study established in 2007 with the aim of monitoring the long-term safety of these biologic treatments in the U.K. and Republic of Ireland. When agreeing to join BADBIR, psoriasis are followed via their dermatologists with any adverse events or illnesses being reported to the study team directly. The relative safety will be established against a reference group of psoriasis patients on conventional therapies who are followed in the same way.

With safety the main study outcome, accurate recording of adverse events is key (with particular interest in serious infection and malignancy). However, there is scope for adverse events not to be reported as despite the best efforts of the clinical teams, it is not uncommon for patients to receive treatment at another health care facility and this data may be missed.

Therefore, linkage to mortality, malignancy and inpatient admission data in Scotland will help ensure all serious adverse events are captured providing a more comprehensive understanding of safety of these new treatments in the long-term.

2122-0142 Dr Rebecca Shakir University of Oxford
Correlation of PET-CT with organ at risk (OAR) dose from radiotherapy

Hodgkin lymphoma (HL) is a malignancy of the lymphatic system. Lymph nodes affected by HL take up a radiolabelled form of glucose, named FDG. PET-CT scans taken after a person has an injection of FDG identify the areas of the body affected by HL, and are used routinely for diagnosing HL, and monitoring response to treatment.

The treatment of HL is chemotherapy, which may be followed by radiotherapy. Over 85% of people are cured, so there are concerns about the long-term risks of treatment. Radiotherapy used to treat HL has been shown to cause long-term side-effects that are related to the radiation dose to critical organs.

Currently, it is not possible to use individualised risks of radiotherapy when discussing treatment options with patients. This is because risk estimation uses the dose to organs, which are not known until after the decision to use radiotherapy has already been made and a radiotherapy plan produced.

This study will document the distribution and extent of lymph nodes involved with HL from PET-CT scans from patients treated with radiotherapy. The doses received by the critical organs, such as heart and lungs, will be determined from their radiotherapy plans.

From this data, we will develop models to predict the radiotherapy dose the organs would receive using measures from the patient's diagnostic PET-CT scan. These predicted organ doses could then be used to estimate individualised radiation-related risks for people being treated for HL. This data would improve shared-decision making in the context of HL.

2122-0165 Professor Colin Palmer University of Dundee
SHARE Biobank – Use of e-Health data in anonymised way for Research within the Trusted Research Environment (TRE) at Health Informatics Centre (HIC)

The Scottish Health Research Register and Biobank (SHARE) is a database of volunteers consenting to be contacted by SHARE and invited to participate in research projects.

Registrants give permission for their health records to be interrogated using disease diagnostic codes and prescribing information, to see if they are eligible for a particular project. Permission is also given for any spare blood left over after routine clinical tests to be used for anonymised genetic research.

SHARE Biobank currently has over 280,000 registered volunteers and the Biobank has over 100,000 samples / DNA.

The SHARE database is managed by the NHS Safe Haven Health Informatics Centre (HIC) and receives regular health updates from Public Health Scotland (PHS), relating to SHARE registrants.

HIC is supported by trained staff and agreed processes whereby health data is processed and can be made available in a de-identified form, for secure analysis within their Safe Haven / Trusted Research Environment (TRE) to facilitate research.

SHARE seeks permission to use this existing data for research as specified in the consent of the SHARE registrants.

The data for research will be de-identified and made available to researchers. No individual will be identified at any stage.

2122-0182 Dr Katherine Forrester Scottish National Blood Transfusion Service (SNBTS)
Infected Blood Inquiry: transfusion recipient follow-up, Scotland

Note: here "transfusion" means transfusion of blood and blood components (red cells, platelets and fresh frozen plasma) and not infusion of blood products e.g. clotting factor concentrates.

The proposal is to examine transfusion-recipients to identify changes in the use of, and survivorship after, transfusion in Scotland. The Inquiry considers this application an essential backdrop to informing its work and it will demonstrate how transfusion performance monitoring can evolve effectively.

Four distinct calendar-year cohorts (1999, 2004, 2009 and 2014) of transfusion-recipients in Scotland will be defined. The 5-yearly cohorts will be analysed separately to describe jointly the demography of recipients by number of type-specific units transfused and ICD10 (International Classification of Disease Version 10) chapter for discharge diagnoses.

Minimal other demographical information about the recipient will enable lifetable analyses, and dates of emigration and/or death terminate survivorship. ICD10 code for underlying cause of death allows documentation of the main reasons underlying death in recipients' 1st post-transfusion year versus 5th year of follow-up, and comparison with ICD10 discharge code at the time of recipients' cohort-qualifying transfusion. Log-linear modelling and/or Poisson regression are options for multifactorial analyses, and comparison of regression coefficients across cohorts will inform how to conduct further modelling. Analysis is by recognised statistical techniques.

To discover if and how ("like-for-like") survivorship post-transfusion has changed during 5-years follow-up we shall conduct formal multifactorial survival analysis, adjusting for demographical and transfusion-related covariates. Finally, we shall address major ICD10-chapter causes of mortality insofar as the four 5-yearly cohorts are powerful to do so.

2122-0195 Dr Rita Perry University of Birmingham
TRANSFER – ThReatened preterm birth, Assessment of the Need for in utero transfer between 22+0-23+6 weeks' gestation

The TRANSFER project will find out how many women come into hospital with threatened preterm birth soon after their 20 week scan and may need to be moved to another hospital which can care for extremely preterm babies. Senior doctors who look after pregnant women and babies have started this project after recommendations by the British Association of Perinatal Medicine, to consider offering life support to babies who are born extremely early (babies born between 22 weeks' to 23 weeks' and 6 days gestation). Before this new guidance, life support was only offered to babies born after 24 weeks' gestation. We have information on the number of babies born

extremely early who survive to be admitted to specialist baby units, but we do not know the number of women who go to hospital with threatened preterm birth in the UK. To offer the best care to women and their babies we must know how this recommendation will affect maternity services as more women will need to be transferred to hospitals able to look after extremely preterm babies. We are collecting information to work out how many women go to hospital with extremely early threatened preterm birth in England, Scotland, Wales and Northern Ireland and record the number needing transfer to hospitals with a baby unit able to look after babies born extremely early. We must have this information to ensure we have services to keep women and their babies as safe as possible.