

2022/2023 Applications approved by HSC-PBPP to 31st March 2023

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Application Reference	Applicant	Applicant Organisation	Title of Study	Approved/ Approved with conditions	Level of Approval	Clocked Time (days)
2021-0259	Christine Menzies	NIHR	Removal of deceased Scottish residents from JDR Registry	Approved	Tier 1 Review	21
2021-0187	Dr Nathaniel Quail	NHS GG&C	How does advance care planning and palliative care input affect the place of death of motor neurone disease patients in the West of Scotland?	Approved	Tier 1 Review	29
1819-0094 SR267	Professor Eve Roman	University of York	United Kingdom Childhood Cancer Study	Approved	Tier 1 Panel Meeting	16
2122-0158	Professor Ewan Pearson	University of Dundee	GoDARTS Scotland	Approved	Tier 1 Review	32
1718-0218 SR164	Dr Michael Jones	Institute of Cancer Research	A cohort study of morbidity and mortality in people with cytogenetic abnormalities in Great Britain	Approved	Tier 1 Panel Meeting	14
2122-0238	Nanisa Feilden	Healthcare Improvement Scotland	National Hub for Reviewing and Learning from the Deaths of Children and Young People	Approved	Tier 1 Review	25
2122-0068	Dr Robert Porter	University of Strathclyde	Growing up in Kinship Care	Approved with conditions	Tier 1 Review	32
2021-0297	Dr Fabien Puglia	Royal College of Surgeons of England	Quality and Outcomes in Oral and Maxillofacial Surgery (QOMS)	Approved	Tier 1 Review	42
2122-0132	Michelle Oliver	NHS Forth Valley	An exploration of the experiences of identity and resilience in adolescents assigned female at birth (AFAB) with Autism Spectrum Disorder (ASD) and Gender Dysphoria (GD) who have not surgically transitioned: An Interpretative phenomenological analysis (IPA) study	Approved with conditions	Tier 1 Review	40

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2122-0023 SR311	Karen Dennison	University College London	The Early Life Cohort Feasibility Study (ELC-FS)	Approved with conditions	Full Committee	68
2122-0120	Dr Amy Chandler	University of Edinburgh	Suicide Cultures WP1	Approved	Tier 1 Review	40
2021-0205	Claire Lawrie	NHS NSS	Admission to Psychiatric In-Patient care of Women within one year of child's birth	Approved with conditions	Tier 1 Review	35
2021-0046	Dr Tom Clemens	University of Edinburgh	Change in alcohol and tobacco availability, population health and the lived experience	Approved with conditions	Tier 1 Review	17
2122-0222	Dr Kate Weymouth-Crocker Jordan	UK Health Security Agency	A Surveillance Study of Congenital and Hospitalised Neonatal Varicella in the United Kingdom & Portugal (NEOPOX)	Approved	Tier 1 Review	27
2122-0214 SMR76	Dr Lisa Iversen	University of Aberdeen	The Royal College of General Practitioners' Oral Contraception Study	Approved with conditions	Tier 1 Panel Meeting	17
2122-0058	Dr Ceri Sellers	Glasgow Caledonian University	Prolong20+ Longitudinal study of pelvic floor dysfunction and relationship to childbirth: Access to current names, addresses and mortality statuses.	Approved	Tier 1 Panel Meeting	16
2122-0215	Laura Galletta	Murdoch Children's Research Institute	The Positive End-Expiratory Pressure Levels during Resuscitation of Preterm Infants at Birth Trial (The POLAR Trial)	Approved with conditions	Tier 1 Review	39
2122-0130	Professor Emma Thomson	University of Glasgow / NHS GGC	Evaluation of Variants Affecting Deployed COVID-19 Vaccines (EVADE)	Approved with conditions	Tier 1 Review	28
2021-0300	Professor Mike Reed	Northumbria Healthcare NHS Trust	Application for 7 Scottish orthopaedic departments to join the Bone and Joint Infection Registry	Approved with conditions	Tier 1 Review	36
2122-0197	Dr Ly-Mee Yu	University of Oxford	Platform Adaptive trial of NOvel antiVIRals for eARly treatMent of covid-19 In the Community (PANORAMIC)	Approved with conditions	Tier 1 Review	51
2122-0225	Dr Holly Tibble	University of Edinburgh	Short-Term Adult Asthma Attack Prediction using Electronic Health Record Data in the Primary Care Setting	Approved	Tier 1 Review	20
2021-0212	Caroline Fairhurst	University of York	BRIGHT Trial: Brushing RemInder 4 Good oral HealTh	Approved	Tier 1 Review	26
2122-0082	Dr Scott Ogletree	University of Edinburgh	Using secondary data to examine whether a programme of physical and social interventions in urban forests enhances	Approved	Tier 1 Panel Meeting	24

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			community health and wellbeing: the impact of WIAT interventions on mental health			
2021-0265	Professor Colin McCowan	University of St. Andrews	Multimorbid Pregnancy: Determinants, Clusters, Consequences and Trajectories (MuM-PreDiCT)	Approved with conditions	Tier 1 Review	25
2122-0212	Professor Sharon Cameron	NHS Lothian	Early medical abortion at home: national evaluation	Approved with conditions	Tier 1 Review	24
2122-0221	Farah Francis	University of Edinburgh	Detecting Fetal Hypoxia Using Machine Learning Based on Cardiotocography: A Pilot Study	Approved with conditions	Tier 1 Review	34
2021-0226	Dr Grant Mair	University of Edinburgh	Development and validation of the CT Clock Tool method for estimating time of ischaemic stroke onset	Approved	Tier 1 Panel Meeting	14
1920-0060 SR187	Dr Tom Russ	NHS Lothian	Lothian Birth Cohort 1936 (LBC1936) study: Linking longitudinal birth cohort data with health and prescriptions records	Approved with conditions	Tier 1 Review	55
1920-0284	Dr Obaid Kousha	University of St Andrews	Scottish Preschool Orthoptic Vision Screening Study	Approved	Tier 1 Panel Meeting	9
2021-0145	Dr Catriona Connell	University of Stirling	Mental health and substance use service utilisation by people released from prison	Approved with conditions	Tier 1 Review	32
2122-0254	Rachel Winch	Royal College of Paediatrics and Child Health	National Neonatal Audit Programme (NNAP)	Approved with conditions	Tier 1 Review	37
1920-0123	Professor Malcolm Sim	NHS Greater Glasgow & Clyde	Standard versus Accelerated Initiation of Renal Replacement Therapy in Acute Kidney Injury (STARTR-AKI) trial. Scottish data linkage to assess cost utility.	Approved	Tier 1 Review	25
1920-0047	Luisa Parkinson	University of Edinburgh	Modelling Environmental Risk for Dementia in the Scottish Mental Survey 1947 sample	Approved	Tier 1 Panel Meeting	7
2122-0116 SR240	Gretchen Meddaugh	University of Oxford	UK Biobank prospective cohort – longitudinal follow-up through linkage to health-related records in Scotland	Approved	Tier 1 Review	24
2122-0216	Cheryl Rees	The State Hospital	Progression through services: data linkage and analysis of transitions and overall pathway of the 2013 Scottish forensic inpatient population	Approved with conditions	Tier 1 Review	33
2122-0220	Professor Pam Sonnenberg	University College London (UCL)	National Survey of Sexual Attitudes and Lifestyles (Natsal) Named Sample	Approved with conditions	Tier 2 OOC	40
2122-0172	Professor Steve Cunningham	University of Edinburgh	Near Fatal Asthma in Children and Young People	Approved with conditions	Tier 1 Review	37

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2122-0102 SR221	Jan Mackenzie	University of Edinburgh	Transfusion Medicine Epidemiology Review (TMER)	Approved with conditions	Tier 1 Review	37
2122-0257	Dr Etimbuk Umana	Queen's University Belfast	Validating clinical decision aids for the assessment and management of febrile infants presenting to emergency care in the UK and Ireland	Approved	Tier 1 Review	27
2122-0123	Dr Mirjam Allik	University of Glasgow	Children's Health in Care Scotland 2 (CHiCS2)	Approved with conditions	Tier 2 OOC	69
2223-0033	Dr Nathalia Matveyev	University of Edinburgh	Characteristics and outcomes of high-risk COVID-19 patients treated with Sotrovimab, oral anti-virals, or no treatment in Scotland	Approved with conditions	Tier 1 Review	32
2223-0075	Bethanie Fenney	National Records of Scotland	National Records of Scotland (NRS) – Scotland's Census 2022 Administrative Data Contingencies for Population Estimation	Approved with conditions	Full Committee	19
2223-0095	Sharon Kennedy	PHS	EAVE II – Temporary extension to use of linked GP data to support PHS statutory public health remit	Approved with conditions	Tier 1 Review	17
2223-0101	Professor Jennifer Kurinczuk	University of Oxford	MBRRACE-UK – Delivering the UK Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP)	Approved	Tier 1 Review	23
2223-0019	Professor Harry Campbell	University of Edinburgh	PRomISE (Preparing for RSV Immunisation and Surveillance in Europe) Data Linkage	Approved with conditions	Tier 1 Panel Meeting	14
2122-0167	Dr Tiberiu A Pana	University of Aberdeen	Importance of Gender Differences in Secondary Prevention and Long-term Outcomes of Cardiovascular Diseases in Scotland	Approved	Tier 1 Panel Meeting	13
2021-0269	Paolo Mazzone	University of Edinburgh	Outcomes in pregnant women and children with epilepsy: A retrospective cohort study of Scottish national data.	Approved with conditions	Tier 1 Review	22
2122-0125	Kinga Kazanowska	AstraZeneca Pharma Poland Sp. z o.o.	DAPA MI Trial Scotland	Approved with conditions	Tier 1 Review	25
2223-0070	Hannah Edwards	University of Bristol	National PRECePT (Prevention of cerebral palsy in pre-term labour) Programme Evaluation: Devolved Nations extension study	Approved	Tier 1 Panel Meeting	7
2122-0258	Dr Cara Hughes	NHS GGC	WoSTRAQ 3: Pre-operative services and assessment in the West of Scotland	Approved	Tier 1 Review	26
2021-0208	Nicholas Webster	Welsh Government	AD ARC (Administrative Data Agri-Research Collection) Scotland: Linking Individual and Farm Level Data for Agricultural Research	Approved with conditions	Tier 1 Panel Meeting	9
2021-0178	Dr Bonnie Auyeung	University of Edinburgh	The COVID-19 Health Impact on Long-term Child Development in Scotland (CHILDS) study	Approved with conditions	Tier 1 Review	25

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2223-0006	Dr Ryan McHenry	ScotSTAR (Scottish Ambulance Service)	Association between socioeconomic status and geographic isolation, and use and outcomes in pre-hospital, retrieval and critical care medicine	Approved	Tier 1 Panel Meeting	27
2122-0261	Judith Tait	Public Health Scotland	NIPT evaluation and Down's syndrome project	Approved	Tier 1 Panel Meeting	33
1920-0266	Dr Glenn Nielsen	St George's, University of London	Physio4FMD	Approved	Tier 1 Panel Meeting	31
2223-0055	Dr William Whiteley	University of Oxford	UKPDS trial legacy study: long-term follow-up of participants using electronic health records	Approved	Tier 1 Panel Meeting	30
2223-0086 SR181	Dr Carl Counsell	University of Aberdeen	Parkinsonism Incidence in North-East Scotland (PINE) study: access to death certificates in participants who have died	Approved	Tier 1 Panel Meeting	21
2223-0065	Professor Rowland Kao	University of Edinburgh	Spatial and Network Analysis of SARS-Cov-2 Sequences to Inform COVID-19 Control in Scotland	Approved	Tier 1 Review	24
2223-0122	Dr Samira Bell	PHS	Cancer Incidence and Outcomes in Patients undergoing Kidney Replacement Therapy in Scotland	Approved with conditions	Tier 1 Review	41
2223-0100	Professor Calum Semple	University of Liverpool	ISARIC Comprehensive Clinical Characterisation Collaboration (ISARIC4C)	Approved with conditions	Tier 1 Review	27
2223-0040 SR244	Professor Amanda Cross	Imperial College London	Frequency of follow-up for patients with low-, intermediate- and high-risk colorectal adenomas. Short title: the All Adenomas study	Approved	Tier 1 Panel Meeting	9
2122-0244	Dr Peter Hall	University of Edinburgh	Children with Cancer Survivorship (CwCS): Tracking the health of people treated for cancer as a child or adolescent in the UK	Approved	Tier 1 Review	48

Lay summaries for approved applications

1718-0218 SR164 **Dr Michael Jones** **Institute of Cancer Research**
A cohort study of morbidity and mortality in people with cytogenetic abnormalities in Great Britain

This is a large-scale follow-up study into the long-term consequences of cytogenetic disorders and their treatment to discover risks of mortality and cancer incidence, and life expectancy. It is far larger than any published study of its type in the world, and indeed for most of the conditions investigated there appear to be no previous studies investigating these questions. There is a great desire on the part of parents of children born with cytogenetic (chromosome) disorders to know about their child's prognosis and risks of serious disease. It is also important to clinicians deciding about treatment of diseases and the balance of benefit vs. side-effects and complications, and to the Health Service, because of the costs accruing for continued follow-up and care of these patients and the planning required to take account of long-term consequences and to plan strategies, where possible, for the prevention and early detection of long-term adverse effects. The conditions are ones where there is reason to be concerned about long-term mortality and cancer risks, and a deficiency of large-scale cohort information about this.

1819-0094 SR267 **Professor Eve Roman** **University of York**
United Kingdom Childhood Cancer Study

Survival of children diagnosed with cancer has improved dramatically in recent decades, exceeding 80% in the UK and other economically developed countries. Indeed, it is estimated that there are half a million childhood cancer survivors in Europe alone; and this will increase as therapy improves and populations age. However, whilst the majority of cancers that occur in children are more responsive to chemotherapy than those occurring in adults, treatments are often more aggressive, and it is well known that this can lead to adverse health problems (e.g. second cancers, cardiac conditions, and bone problems) several years later. Building on one of the largest and most comprehensive childhood cancer case-control studies ever undertaken (the United Kingdom Childhood Cancer Study, UKCCS), this proposal aims to link to national datasets to investigate a range of questions relating to the long-term health and healthcare needs of childhood cancer survivors. Overall, around 72% (n=3221) of UKCCS children with cancer (diagnosed 1991-1996) survived for 5 years or more and, with UKCCS subjects currently 25-44 years of age, these maturing data now provide a valuable resource with which to begin to examine the health of childhood cancer survivors across their life course. Building on existing infrastructure, the present application's principal aim is to examine the long-term health and healthcare needs of childhood cancer survivors by incorporating linkages of cases and controls to additional national datasets, including cancer registrations and the Scottish Morbidity Records (SMR, inpatient, outpatient and emergency).

1920-0266 **Dr Glenn Nielsen** **St George's, University of London**
Physio4FMD

Functional Motor Disorder (FMD) is a common disorder affecting movement. People with FMD can experience a range of symptoms including weakness, shaking of the limbs, spasms, and difficulty walking. The problem is caused by functioning of the nervous system rather than damage to the

structure to the nervous system. People with FMD suffer disability and distress equivalent to neurological diseases such as Parkinson's disease.

We have designed a specialist physiotherapist treatment for patients with FMD, which we are comparing to treatment as usual (TAU) in this trial. We want to understand how effective this treatment is in terms of clinical change (e.g. improved mobility) and cost effectiveness (e.g. reduced health care costs). We have recruited 83 participants in Scotland and we are following them up for 12 months.

The cost-effectiveness of the trial will be assessed in a comprehensive analysis done by health economists. We will use health data from NHS Scotland to find out whether the specialist treatment helps reduce health care use compared to TAU. We will do this by examining the type and number of hospital contacts in outpatient, inpatient and Accident & Emergency (A&E) settings for all study participants over a 24-months period; comparing the 12 months before they joined the study to the 12 months thereafter.

1920-0047 Luisa Parkinson University of Edinburgh Modelling Environmental Risk for Dementia in the Scottish Mental Survey 1947 sample

Although dementia is a condition of later life, evidence shows that experiences and exposures across your lifetime can affect your risk of developing dementia. Where you live has also been shown to affect your risk of developing dementia. This study aims to investigate factors influenced by where you live, such as air pollution and drinking water quality, to see how they affect your risk of developing dementia.

To do this we will use a Scottish sample of people born in 1936 who have had information about them collected both in childhood (1939 and 1947) and in later life (1991, 2001 and 2011 Census information). This includes information on the areas where people have lived, their intelligence at age eleven, education, occupation, features about the household they lived in and information they reported about their health. We will use information from medical records to identify who has developed dementia. This data and access to it is controlled to ensure that no individual could be identified by the research team.

We will explore how the environment people have been exposed to affects their risk of developing dementia. This will allow us to understand whether particular aspects of your environment affect your risk of developing dementia. It will also allow us to look at whether an exposure is most important at a certain time in your life. The findings of this study may enable changes to be made to our environment that could reduce the number of people developing dementia in the future.

1920-0060 SR187 Dr Tom Russ NHS Lothian Lothian Birth Cohort 1936 (LBC1936) study: Linking longitudinal birth cohort data with health and prescriptions records

This proposal aims to take advantage of a rare opportunity to add information on important health outcomes to a study of cognitive and brain ageing, and health and ageing more generally, known as the Lothian Birth Cohort 1936 (LBC1936). We request linkage to NHS health information from: 1) routinely collected hospital admissions and discharge data from Scottish Morbidity Records (SMR); 2) medical prescriptions data from the Prescribing Information System (PIS), and; 3) health data from

paper and digital medical records. This crucial NHS health data will add to our already rich dataset which includes cognitive, brain imaging, psychosocial, lifestyle, self-reported health, physical fitness, biomarker, and genetic data, collected over five waves of assessments since 2004, making the LBC1936 dataset an unmatched resource for studying ageing. Our aim is to link requested data with the life-course data already collected in LBC1936 participants, for the purpose of research into health and ageing outcomes. Specifically, the proposal would facilitate indepth examination of cognitive-health associations, including (but not limited to): the role of illness episodes and medications on cognitive ageing and general health; the influence of early-life cognitive ability and social background on later health and survival; risk and protective factors with the potential to inform interventions to reduce the risk of later life cognitive decline. SMR, PIS and health records data will also supplement information obtained from deaths and other records to assist in the ascertainment of dementia and other geriatric syndromes (e.g. falls, incontinence, and frailty) in LBC1936 participants.

1920-0123 Professor Malcolm Sim NHS Greater Glasgow & Clyde
Standard versus Accelerated Initiation of Renal Replacement Therapy in Acute
Kidney Injury (STARRT-AKI) trial. Scottish data linkage to assess cost utility.

STARRT-AKI (Standard versus Accelerated Initiation of Renal Replacement Therapy in Acute Kidney Injury) is a multi-centred randomised trial investigating the best time to start Renal Replacement Therapy (kidney dialysis) in Intensive Care patients with acute kidney failure. Patients randomised to receive early dialysis or standard initiation of dialysis. Worldwide, over 3,000 patients were recruited. This trial showed that starting kidney dialysis early in critically ill patients was no better than standard initiation.

In addition to the main trial, funding is also available in the UK to look at a cost-utility analysis of the implications of early initiation of dialysis compared with standard initiation. This will use data from the trial over 1 year and longer term analysis through data linkage with routine NHS databases and registries. In the UK we finished recruiting patients to this additional part of the study in May 2022. In total approximately 600 patients were recruited in the UK. In Scotland, we recruited 40 patients. Of these, 23 survived to be discharged and also gave their consent to data linkage. The data linkage will be to several datasets held within Public Health Scotland. These include SMR00, which relates to data generated when a patient receives outpatient care and SMR01 which relates to data generated when a patient receives inpatient care in general or acute settings. We will also link with the Accident and Emergency database.

While the main study has already reported its findings, this data linkage will enable the estimation of costs for trial participants and allow us to determine the impact of early renal replacement therapy on NHS resources. The data will enable us to determine if early or standard renal replacement therapy is the most cost-effective treatment strategy.

1920-0284 Dr Obaid Kousha University of St Andrews
Scottish Preschool Orthoptic Vision Screening Study

The United Kingdom's national screening committee recommends assessing for vision defects in preschool children aged four to five years old. A common cause of poor vision in this age group is amblyopia. Amblyopia (also called 'lazy eye') is a condition where the connection between the eye and the brain has not developed properly. Early diagnosis and treatment of amblyopia can prevent

permanent visual impairment. However, amblyopia in one eye often goes undetected by the child and carers.

In Scotland, every child between the age of four and five years old is invited to vision screening. What separates the Scottish programme from the rest of the UK is the scope of the collected data (nationwide); the number of children involved (over half a million), the time period over which the data are collected (ten years), and the range and quality of data points for each child.

This study aims to understand both normal and abnormal vision in childhood. We will assess the uptake of the programme and the rate of subsequent referral to hospital eye services. Differences in vision, uptake and referrals by socio-economic status (the Scottish Index of Multiple Deprivation) and geographic location will be examined. All of this will be achieved by using pseudonymised/de-identified data from the screening programme.

Our findings could be used to help policy makers target areas in need. Our work will be a starting point for future work to understand the relationship between childhood visual function and educational achievements later in life.

See4School is a Scottish government programme where every child between the ages of four and five in Scotland is offered to have their vision checked by a trained healthcare professional before starting school.

Children with signs of poor vision in one or both eyes are identified and referred to hospital eye services as appropriate. The commonest cause of poor vision in one eye among the children is amblyopia or a 'lazy eye', which is usually caused by a squint or when a child needs to wear prescription spectacles but does not. Fortunately, timely treatment of amblyopia prevents permanent poor vision.

Over the past ten years, more than half a million children have been assessed. We will use this information to understand both normal and abnormal vision in childhood. Inequalities in vision and uptake of the screening programme related to socioeconomic, urban/rural status and health board will also be examined. Anecdotally we know that children from poorer backgrounds are more likely to have poorer vision and they are more likely to miss the opportunity to have their vision checked, leaving them at risk of permanent poor vision. By answering these questions we will be able to inform policy makers to direct resources to areas of need. Future work may correlate childhood vision with future educational achievements.

While carrying out this work, the security of individuals' personal information will be our priority. We will ensure this by following all the relevant regulations and implementing local safety checks.

2021-0046 **Dr Tom Clemens** **University of Edinburgh**
Change in alcohol and tobacco availability, population health and the lived experience

This research project will measure change in the availability of alcohol and tobacco in Scottish neighbourhoods over time (2008 through 2020) and explore how this change relates to behavioural and health outcomes among residents. The findings will be important because smoking and alcohol consumption are leading causes of illness and death.

In order to explore the relationship between supply, behaviour and harm we are examining data on the location of every outlet in Scotland selling tobacco and/or alcohol. Ideally, to be able to say something about whether the relationship may be causal, we need this data over time. We have already collected data on the specific location of every outlet selling tobacco and licensed to sell alcohol over multiple time periods (2012, 2016 and 2020 (for nationwide alcohol and tobacco) and

2008 (for alcohol in four cities: Aberdeen, Dundee, Edinburgh, and Glasgow)). Collectively, these data will allow us to measure and model change over time.

To measure the relationship between changing neighbourhood-level availability we will link modelled profiles of availability over time to alcohol and tobacco health-related behaviours and outcomes. Formally, we will use statistical models to see whether neighbourhoods experiencing an increase or decrease in outlets have seen a corresponding increase or decrease in the health outcomes. This will allow us to get a better understanding of whether an over-supply of alcohol and tobacco is related to smoking and alcohol consumption and harm. These findings will provide important evidence related to the provision of such commodities in our neighbourhoods.

2021-0145 Dr Catriona Connell University of Stirling Mental health and substance use service utilisation by people released from prison

In Scotland about 15,000 people are released from prison each year. They are more likely than other people to die by suicide, drug overdose, and illnesses linked to mental health and substance use (drugs/alcohol). This suggests they are not getting the right help in the community, including from NHS services.

Before changes can be made, we need to understand if and how people released from prison in Scotland use NHS services for mental health and substance use.

We will find out how much people released from prison in Scotland are using NHS services for mental health and substance use needs. To do this we will use data, with personal details removed, to match people released from prison to their use of NHS services for mental health and substance use.

We will compare use of services between people released from prison and people who have not been in prison. We will look at differences based on sex, age, and local area. For people released from prison, we will explore differences based on other characteristics too (e.g. ethnicity), and look at differences between people released in different ways (e.g. parole).

People with prison experience are involved in all stages, including on the project team and in the Lived Experience Advisory Panel (LEAP).

2021-0178 Dr Bonnie Auyeung University of Edinburgh The COVID-19 Health Impact on Long-term Child Development in Scotland (CHILDS) study

The COVID-19 (COV) pandemic has exposed populations world-wide to potential infection with a new, highly infectious coronavirus. Little is yet known about the long-term effects of COV and a major concern is the potential impact on pregnant women and their newborn children. This includes not only the potential effects of the virus itself, but also the direct and indirect effects of accompanying Public Health & Social Measures (PHSM) on the long-term wellbeing of both mother and child. Early evidence from studies relating to both direct and indirect effects of the pandemic also point towards the influence of social inequality on outcomes for both mother and child.

The COVID-19 Health Impact on Long-term Child Development in Scotland (CHILDS) study will use the population-based COVID-19 in Pregnancy in Scotland (COPS) dataset. The COPS dataset will be used to examine the effects of COV and the related PHSM (including changes to healthcare

provision) on all women who had ongoing pregnancies on or after March 1, 2020, up until 31 August 2022, and their children across Scotland, to the age of 5.

COPS also includes all completed and ongoing pregnancies in Scotland from January 1, 2015, to compare effects from the pandemic to a pre-pandemic historic cohort. The pre-pandemic data included in the COPS cohort will be used to establish baseline rates of adverse outcomes. This will allow the team to build a detailed understanding of pregnancy, maternal and child health and development for all children born during the pandemic.

Our data extraction end date will be November 30, 2028, which allows for the youngest children to reach the age of 5 and includes additional time (6 months) needed to finalise analyses, publish reports, and respond to reviewers' comments. Our final study end date will be November 30, 2029.

COPS is a sub-study of the EAVE II cohort (Early Pandemic Evaluation and Enhanced Surveillance of COVID-19), an observational study using linked Scottish national data. As this is a COPS follow up study, we will be using the same EAVE ID numbers. This is for processing purposes only and to ensure consistency across datasets.

The CHILDS study will provide a unique reference point for healthcare providers and policymakers in Scotland and globally about the needs of those born in the pandemic, allowing improved targeting of resources and a better understanding of how policy can improve outcomes at these crucial early stages of life.

2021-0187

Dr Nathaniel Quail

NHS GG&C

How does advance care planning and palliative care input affect the place of death of motor neurone disease patients in the West of Scotland?

Advance care planning involves patients discussing their expected future care with a healthcare professional, noting their expressed wishes on issues such as resuscitation status, preferred place of death, and in what circumstances hospital admission would be appropriate (NICE 2020). This is often performed by the relevant speciality team or palliative care team. Generally, terminally ill patients' preferred place of death is outside of hospital - this can help prevent futile, invasive, and expensive treatment, as well as decreasing the anxiety of patients and those close to them (Murray and Butow, 2015).

Motor neurone disease (MND) is the common name for a group of similar progressive neurological diseases. Advance care planning can be especially useful in MND as ability to express treatment wishes may decrease over time, due to decreasing cognitive and muscular capability. The National Institute for Health and Clinical Excellence guidelines on assessment and management of MND suggest that advance care planning should form an essential part of routine care for MND patients (NICE 2016).

Our study uses data from patients registered on the Scottish Clinical Audit Research and Evaluation for MND (CARE-MND) audit and research tool between 2015-2017, who are now deceased, in conjunction with data from Clinical Portal, an electronic notes database used in Scotland, and local hospices to examine the factors that impact place of death and hospital attendances in the last year of life in patients with MND in the West of Scotland. This research could help improve MND care in both the West of Scotland and further afield.

Murray, L. and Butow, P. (2015). Advance care planning in motor neuron disease: A systematic review. *Palliative and Supportive Care*, 14(4), pp.411-432.

NICE (2016). Motor neurone disease: assessment and management. [online] Available at: <https://www.nice.org.uk/guidance/ng42/resources/motor-neurone-disease-assessment-and-management-pdf-1837449470149> [Accessed 14 Jan. 2020].

NICE. (2020). Advance care planning. [online] Available at: <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/advance-care-planning> [Accessed 14 Jan. 2020].

2021-0205 Claire Lawrie NHS NSS
Admission to Psychiatric In-Patient care of Women within one year of child's
birth Approved with conditions

Under Scottish mental health legislation, women who require inpatient psychiatric care, and who have infants under 12 months old, should be admitted jointly with their infant to appropriate facilities (that is, a mental health mother and baby unit), unless it is not in the clinical interests of mother or baby to do so. Existing research shows that in up to a third of cases this does not happen, and women may be separated from their babies unnecessarily. This proposal aims to provide ongoing monitoring of psychiatric admissions of women within one year of childbirth across Scotland to report the proportion of women not admitted with their babies, and to identify barriers to joint admission. This will assist the Perinatal Mental Health National Managed Clinical Network to identify gaps in service provision and to improve standards of care for women with the most severe forms of perinatal mental illness, and their babies.

2021-0208 Nicholas Webster Welsh Government
AD|ARC (Administrative Data Agri-Research Collection) Scotland: Linking
Individual and Farm Level Data for Agricultural Research

Agriculture is facing a range of challenges. There is concern about the potential impact of economic and environmental change on farm households. Furthermore, the Scottish Government has declared a climate emergency which will require the agricultural sector to change significantly over the next few years. These changes may require many farm households and communities to adapt significantly from the ways they have done previously.

This project developed following the 2019 Public Health Wales Report: Supporting farming communities at times of uncertainty. This report outlined concerns from public health authorities about the capacity for farming communities to adapt for the challenges listed above and a lack of robust evidence-based studies about farmers to inform future policies.

This project will generate much needed evidence to support farmers.

Farms are not only places of work but are residences for farmers and their households, there is a close relationship between the farm business and family life. The aim of the project is to create an anonymised agricultural data resource bring together datasets on both the farm household and the farm business to answer questions for all farms in Scotland. This will generate new evidence to support the development, implementation and evaluation of future policies; improve general understanding of help policy makers understand farmers and farm families and the issues that they face; and assist in improving the health, resilience and prosperity of farming communities and support their transition to a greener future.

Our research will focus on describing the composition and characteristics of farm households and investigating farming household health and well-being, prosperity and resilience and farmer engagement with agri-environmental issues.

2021-0212 Caroline Fairhurst University of York
BRIGHT Trial: Brushing RemInder 4 Good oral HealTh

BRIGHT (Brushing RemInder 4 Good oral HealTh) is a randomised controlled trial of the clinical and cost-effectiveness of an intervention for young people of secondary-school age delivered through a classroom-based session embedded in the school curriculum and twice-daily SMS (text message) reminders to brush your teeth, compared to usual education and no SMS messages, on tooth decay. To conduct the cost-effectiveness analysis, in addition to various costs of the intervention, we need to compare the resource use of health care services in the intervention and control groups. Resource use for this study include the number and location of dental visits, any specific treatments at the visits, etc. For a subset of BRIGHT trial participants from Scotland only, we have obtained consent from parents/carers to link data collected in the trial to data on the dental visits and specific treatment received by young people from Scotland for the duration of the trial. This will provide us with accurate costs to calculate the cost-effectiveness of the intervention for the participants from schools in Scotland. In England and Wales, we will obtain the resource use data only from questionnaires that parents or carers have completed. The response rate for these questionnaires have been low and the information provided will be subject to how much people can recall. Therefore, the more accurate estimates from the linked data in Scotland may provide us useful information that we can use for the participants in England and Wales.

2021-0226 Dr Grant Mair University of Edinburgh
Development and validation of the CT Clock Tool method for estimating time of ischaemic stroke onset

Stroke commonly causes disability and death. Most strokes occur when a blood vessel supplying the brain becomes blocked. Two treatments are available to unblock the vessel and reduce harm from stroke, one uses a medicine (thrombolysis), the other a surgical procedure (thrombectomy). Both treatments must usually be given within a time limit after stroke begins: 4.5 hours for thrombolysis and 6 hours for thrombectomy. Unfortunately, 1 in 5 patients wake up with stroke or are found collapsed. If we do not know when the stroke began, it is usually not safe to offer treatment. Imaging methods have been developed that can identify patients for treatment without knowing when their stroke began. However, such methods are complicated to deliver and not widely available, especially for patients who live remote from big cities.

We have therefore developed a new method for estimating how much time has passed since a patient's stroke began using data from patients where the time of stroke onset is known, the CT Clock Tool. Our method uses only the plain CT imaging that most patients get when they arrive at any hospital with stroke.

We now wish to use historical CT scans from patients in Scotland with stroke to improve our CT Clock Tool. We aim to increase the number of patients whose data are used to make time estimates and then to test whether this increased data reduces error in our method. These are the final steps before testing our CT Clock Tool in the real world.

2021-0259 Christine Menzies NIHR
Removal of deceased Scottish residents from JDR Registry

The Join Dementia Research (JDR) register is a national service funded and owned by the Department of Health and Social Care; it enables members of the public to register to be contacted about potential research studies. In registering they consent for their information to be available to the dementia research community.

The link requested to PHS information will ensure people who are deceased are removed from the Department of Health and Social Care (DHSC) Join Dementia Research System. By removing deceased volunteers it will ensure potential research volunteers are not harmed or distressed by attempting to contact people who have died.

The intention is to send PHS information on all volunteers from the register every 6 months. PHS will simply confirm if any of the volunteers have died by supplying the fact of death. No updated demographics will be provided to us.

2021-0265 Professor Colin McCowan University of St. Andrews
Multimorbid Pregnancy: Determinants, Clusters, Consequences and Trajectories
(MuM-PreDiCT)

What is the problem?

One in five pregnant women have two or more active long-term health conditions. These can be both physical conditions (like diabetes or raised blood pressure), and mental health conditions (such as depression or anxiety). Often women also have to take several medications to manage their different health needs. Having two or more health conditions is also becoming increasingly common in pregnant women as women are increasingly older when they start having a family. We don't really understand what the consequences are of multiple health conditions or medications for mothers and babies. This can make pregnancy, healthcare and managing medications more complicated.

Our research is divided into five work packages. The first work package will examine how health conditions accumulate over time and identify what makes a woman more at risk of developing two or more long-term health conditions before pregnancy. The second work package will explore women's experiences of care during pregnancy, birth and after birth. In the third work package we will examine how often women experience pregnancy complications and we will explore how frequently women and their children develop additional long-term ill health. In the fourth work package we will describe how medications are prescribed and investigate how taking combinations of medication may affect pregnant women and their babies. In our fifth work package, we will build a prediction model to help identify how likely a previously healthy pregnant woman will develop multiple long-term conditions after pregnancy.

2021-0269 Paolo Mazzone University of Edinburgh
Outcomes in pregnant women and children with epilepsy: A retrospective cohort
study of Scottish national data.

Patients, carers, and clinicians have outlined some important questions in epilepsy; including prescribing anti-seizure medications (ASMs) in pregnancy, in-utero effects in epilepsy, cognitive

effects of ASMs in childhood, and public awareness to reduce stigma and improve schooling for children.

We know already that women with epilepsy (WWE) are at increased risk of negative pregnancy outcomes such as spontaneous abortion, ante/post-partum haemorrhage, hypertensive disorders, caesarean section, preterm birth, and maternal death. However, we still do not know how much of this is associated with epilepsy compared to other factors including ASMs, deprivation, obesity, smoking, alcohol consumption, and maternal age.

This is also true for outcomes in offspring of WWE such as congenital anomalies, learning difficulties, childhood epilepsy (CE), and neurodevelopmental disorders. Learning difficulties, CE, and neurodevelopmental disorders often coexist, with multi-morbidity associated with worse educational and employment outcomes; yet, understanding the role of socioeconomic deprivation in this context is also important.

Scotland has extensive routinely collected health and educational data that will allow us to account for more factors and potentially identify causal pathways. To do this, we will identify WWE and CE, and compare outcomes to those without epilepsy. The results of this project will help to inform health and education policy, and will answer some of the important questions raised by those affected.

2021-0297 Dr Fabien Puglia Royal College of Surgeons of England Quality and Outcomes in Oral and Maxillofacial Surgery (QOMS) Approved

Oral and Maxillofacial Surgery (OMFS) is a surgical specialty, which treats conditions of the head and neck. The 1st Getting It Right First Time report for OMFS in England highlighted that fact that, unlike some surgical specialties, OMFS does not have a national clinical effectiveness programme to assess the quality of care provided. This observation can be extrapolated to Scotland and the other UK nations.

In response, the British Association of Oral and Maxillofacial Surgeons initiated a specialty-wide quality improvement and clinical effectiveness programme called the Quality and Outcomes in Oral and Maxillofacial Surgery (QOMS) project.

QOMS collects information on several conditions, operations, and their associated outcomes that can be analysed to assess the quality of surgical care, for audit/service evaluation purposes. Procedures and quality indicators were selected based on the cumulative evidence derived from the published literature with clinical sense checking by UK clinicians to ensure relevance to current NHS practice. Data collection is prospective and performed directly in hospitals by health care professionals or dedicated data entry personnel. First, QOMS will establish benchmarks then produce yearly comparative results for each participating hospital to see how they are performing relative to their peers. Finally, QOMS will also identify and describe the care practices associated with the best performing hospitals with the aim of helping to improve the quality of patient care in all. Where hospitals are performing significantly less well than their peers, BAOMS will offer to provide mentorship for change.

2021-0300 **Professor Mike Reed** **Northumbria Healthcare NHS Trust**
Application for 7 Scottish orthopaedic departments to join the Bone and Joint Infection Registry

We seek to be able to add information from Scottish patients who patients who have suffered a bone or joint infection, including those that occur around existing implants such as hip and knee replacements, to the UK Bone & Joint Infection Registry (BAJIR).

Bone and joint infections are particularly important as they often have a significant impact on a person's health and wellbeing. They are typically difficult to treat, and are very costly to healthcare providers like the NHS. In the future an ageing population, associated with more joint replacement operations, will likely lead to even higher numbers of people who suffer bone and joint infections. This registry is currently already established in England and Wales, and provides the best way of gathering a large amount of information about such problems in order to help improve patient care.

The registry works by collecting initial information on those people presenting to participating hospitals with bone and joint infection. Once patients have recovered from their illness they will be contacted see if they wish to continue to be included in the registry. If a patient does not want their information included, or does not respond within 18 months, then their information is removed.

2122-0023 SR311 **Karen Dennison** **University College London**
The Early Life Cohort Feasibility Study (ELC-FS)

The primary aim of the Early Life Cohort Feasibility Study (ELC-FS) study is aims to provide evidence on the potential for successful recruitment into a new national birth cohort study, and the best approach to design and measurement. The Early Life Cohort Feasibility Study (ELC-FS) will test proof of concept for a new national birth cohort study. It will also collect rich data on babies, and their families, born across the UK in the year 2021, capturing their economic and social environments into which these babies are born, and their health, well-being and development in their babies' first 6-9 months. The study will provide data of substantive value in itself, providing vital evidence on new lives across the UK at a critical time, particularly with regards to the shock to health and the economy induced by the impact of the Covid-19 pandemic, as well as and the impacts of Brexit on our economy and society. It will highlight identify major sources of early developmental inequalities and family stressors factors, and identify potential foci areas at policy level for early intervention and support.

In Scotland, the sample several hundred mothers of new-borns will be selected using maternity records linked to birth registrations, with up-to-date addresses and deaths and embarkations notifications from central databases. Other parents who live at a different address will also be selected where possible via joint birth registrations or the mother. Parents will be invited by letter to take part in a voluntary interview in their own home. With consent, the study will collect saliva samples from some parents and babies for DNA extraction to help understand how environmental and genetic influences interact to shape infant development. The study will use additional fields (such as social factors, ethnicity, occupation) to tailor invitation letters/leaflets to typically under-represented groups (such as ethnic minorities) and to compare the characteristics of those chosen to take part with those of the general population.

2122-0058 Dr Ceri Sellers Glasgow Caledonian University
Prolong20+ Longitudinal study of pelvic floor dysfunction and relationship to
childbirth: Access to current names, addresses and mortality statuses.

The Prolong longitudinal study looks at the pelvic floor dysfunction issues women experience during their lives after childbirth. Women were originally recruited in 1993-94 from maternity units in Aberdeen, Birmingham and Dunedin (New Zealand), and have been invited to take part in 3 further postal surveys since that time.

The most recent survey, ProLong20+, was carried out between 2019-21. When interpreting the results of that survey, it is important to understand whether there were any differences between the women who responded to the survey (responders) and those that did not (non-responders). For example, it is possible that women who have experienced issues with incontinence or prolapse were more likely to respond to our survey, in which case, our survey would report a higher level of issues than actually occur in the wider cohort. It also important to understand if those women who were part of the original cohort but were not sent study invitation letters (not invited) are different – these women were not invited to take part because we have lost contact with them, or they have withdrawn or died.

We are applying to access selected medical records information for cohort members originally recruited in Aberdeen. This will allow us to compare whether the number of women who have reported pelvic floor issues to the NHS is similar in each response group (responders, non-responders, not invited). e.g. we will be able to calculate and compare the numbers of women who have been diagnosed with urinary incontinence in each group.

We will also be able to compare the numbers of women from different ethnic backgrounds in each group to see if they are similar.

Access to this information will allow us to assess whether the survey results could reasonably be applied to the whole study cohort (and therefore a much larger number of women), rather than just those that responded.

The medical records information will be held securely in the National Safe Haven for a limited time period. A single researcher will be given access in order to carry out the analysis. While the medical records information will not include any identifiers (e.g. names, date of birth, CHI number, address), it might be possible for the researcher to identify a small number of individuals if they have a unique combination of clinical factors, although it would be very difficult. Information cannot be removed from the National Safe Haven without meeting rigorous Public Health Scotland disclosure checks to ensure anonymity of any individuals. The data will be deleted at the end of the agreed time period.

2122-0068 Dr Robert Porter University of Strathclyde
Growing up in Kinship Care

Nearly 1/3 of all children and young people who are looked after and accommodated in Scotland live with members of their extended family or friends – kinship care. At present, we do not have a full understanding of their experiences of health, social care and protection, and education services, or the outcomes that are achieved through these.

Through creating a dataset that links individual child records across these areas, this project will explore the characteristics, pathways, and outcomes where a child has been living with relatives or friends as part of a response to concerns for the safety and wellbeing of that child. This analysis will allow us to identify the numbers, pathways, and outcomes for children living in formal kinship care.

More widely, the project will allow us to explore the value of reporting on particular populations in such a manner to improve understanding and policy development.

2122-0082 Dr Scott Ogletree University of Edinburgh
Using secondary data to examine whether a programme of physical and social interventions in urban forests enhances community health and wellbeing: the impact of WIAT interventions on mental health

Our innovative research plan will make use of the Scottish Longitudinal Study which provides individual census records which can be linked to individual health service records. We will link these to Scottish Forestry data which capture the location, nature, costs and timing of all “Woodlands In and Around Town” (WIAT) interventions delivered in three phases between 2005 and 2018. Together, these data will allow us to assess the impacts of WIAT interventions on mental health, using both ‘within subjects’ (i.e. comparing people’s health before and after the WIAT intervention) and ‘between subjects’ (i.e. comparing trajectories of health between those exposed and not exposed to the WIAT intervention).

Our over-arching aim is to provide better evidence on the contribution urban forestry can make to human wellbeing. Our study responds to growing policy and practitioner demand for research evidence about the potential for green space, and urban woodlands in particular, to benefit population health and reduce inequalities. Outputs will include peer-reviewed papers and further accessible publications with Scottish Forestry. Findings will be presented to inform policy and practice that can benefit peoples’ health, reduce health inequalities and enhance quality of life for urban residents.

2122-0102 SR221 Jan Mackenzie University of Edinburgh
Transfusion Medicine Epidemiology Review (TMER)

The Transfusion Medicine Epidemiology Review (TMER) is a collaborative project between the UK National CJD Research & Surveillance Unit (NCJDRSU), which is part of the University of Edinburgh, and the UK Blood Services (UKBS), which incorporates NHS Blood and Transplant (NHSBT), the Welsh Blood Service (WBS), the Scottish National Blood Transfusion Service (SNBTS) and Northern Ireland Blood Transfusion Service (NIBTS). The TMER project was set up in 1997 with the aim of investigating whether Creutzfeldt Jakob Disease (CJD) and its variant form (vCJD) is transmissible through blood transfusion, an issue of great importance for public health following the advent of vCJD. To date, 3 cases of vCJD and one sub-clinical infection have been linked to transfusion transmission through this study and it is essential to identify any further infections through this mechanism.

2122-0116 SR240 Gretchen Meddaugh University of Oxford
UK Biobank prospective cohort – longitudinal follow-up through linkage to health-related records in Scotland

UK Biobank, a registered charity, is one of the world’s largest medical research resources. Established in 2003 and largely funded by the Wellcome Trust, the Department of Health and Social Care, and the Medical Research Council, recruitment of its 500,000 participants, aged between 40

and 69, took place between 2006 and 2010, including in Scotland (7% participants, ~36,000 participants). All participants gave consent for their health to be followed-up through linkage to their health related data. Participants receive an annual newsletter updating them on UK Biobank's current activities and use of their data.

Access is available to bona fide researchers anywhere in the world to perform health-related research in the public interest. UK Biobank has transparent access procedures and since access opened in 2012, over 27,000 researchers have been enabled to use the resource with 3,000 applications approved and over 5,200 publications using data from the resource.

UK Biobank is a unique resource, due to its very large size and the range and detail of data that it contains, including extensive phenotype and genotype information on each participant. It is a prospective population-based resource supporting research into a wide range of diseases affecting people in middle and older age.

2122-0120 Dr Amy Chandler University of Edinburgh
Suicide Cultures WP1

Suicide is a complex and important issue – current understandings of suicide focus on mental health, psychology and psychiatry and tend to use statistical, quantitative approaches. In contrast, this project is being carried out by a multi-disciplinary team of social scientists (including anthropology, sociology and geography) who will use qualitative methods, focusing on meaning and interpretation. The project aims to develop a deeper understanding of the social and cultural contexts in which suicides take place, and how they are explained by a range of individuals and organisations. This proposal focuses on how suicides are made sense of by NHS and multiagency suicide review groups. The project is conducting a qualitative analysis of completed reviews of deaths by suicide held by four NHS Health Boards. This involves reading pseudonymised reviews and looking for patterns and features of how the reviews understand suicides, and what details and explanations for suicide deaths are put forward.

2122-0130 Professor Emma Thomson University of Glasgow / NHS GGC
Evaluation of Variants Affecting Deployed COVID-19 Vaccines (EVADE)

The SARS-CoV-2 virus is evolving over time, changing genetic composition over time to form “new variants” that may require updates to the vaccine schedule (like influenza which is updated on a yearly basis). The applicants have been involved in tracking the genomic evolution of SARS-CoV-2 since March 2020, initially with funding from the COVID-19 Genomics UK (COG-UK) consortium and more recently from the Scottish Government via National Services Scotland in partnership with the NHS and PHS. While vaccination has resulted in a stepchange in reduction in risk of developing COVID-19 in the population, it is likely that vaccine updates will be required and that these will be based on variants that show the strongest evidence of escape from vaccine-induced immunity.

2122-0123 Dr Mirjam Allik University of Glasgow
Children's Health in Care Scotland 2 (CHiCS2)

Our initial work has shown that care experienced children and young people – those who have been “looked after” by the state (e.g. in kinship, foster or residential care, or under the supervision of social workers) – have higher rates of ill health compared to children and young people who have not been in care. The inequalities are especially large for mortality, sexual, reproductive and mental health, and are not explained by the deprivation levels of their immediate neighbourhoods. With this project we aim to explore these inequalities in greater detail.

First, we will include health outcomes from birth until 2022 to investigate how health outcomes change over the course of childhood and between care settings. We will compare health outcomes for the care experienced and not care experienced children at birth (before entering care), during and/or between care episodes, and after leaving care. This can indicate whether inequalities in health are already present at birth or whether they increase/decrease during or after leaving care.

Second, we will investigate differences in health service use, such as in completing vaccinations, emergency admissions, missed appointments, and length of stay in hospital. Here our aim is to determine if care experienced children and young people are less likely to engage in preventive health care and adhere to treatment, both of which could lead to worse health and greater health service use later on.

Our study will also cover the period of the national lock-downs due to Covid-19, allowing us to assess if and how this affected health service use and health outcomes among the care experienced and not care experienced children and young people.

2122-0125 Kinga Kazanowska AstraZeneca Pharma Poland Sp. z o.o.
DAPA MI Trial Scotland

Globally at least 7 million individuals suffer a heart attack (myocardial infarction) annually. Development of heart failure following a myocardial infarction is associated with incapacitating symptoms, reduced quality of life and an unfavourable long-term prognosis. Therefore, myocardial infarction therapies that could prevent the development of heart failure represent a large and unmet medical need.

This study will evaluate the effect of Dapagliflozin 10 mg versus placebo, given in addition to Standard of Care therapies for patients with myocardial infarction. The aim of the study is to find out if treatment with Dapagliflozin can prevent events of hospitalisation for heart failure or cardiovascular death. The study is conducted in Sweden and in the United Kingdom and will randomize approximately 6400 patients. The study will utilize 2 high-quality national, population-based clinical registries to include patients into the study. The study started in Q4 2020 and enrolment is expected to end in Q3/4 2023. The anticipated overall duration of the study is at least 30 months together with the estimated median follow-up period of 21 months but this is dependent on the observed event rate.

Dapagliflozin treatment has proven to prevent events of heart failure hospitalisations and cardiovascular death in patients with type 2 diabetes mellitus with cardiovascular disease and also in patients with established heart failure with reduced pumping function of the heart muscle.

This study hopes to confirm that treatment with Dapagliflozin reduces the risk for development of heart failure after a myocardial infarction, and if so this treatment can be offered as a standard treatment to patients suffering myocardial infarction in the future to improve their prognosis and quality of life.

2122-0132 Michelle Oliver NHS Forth Valley
An exploration of the experiences of identity and resilience in adolescents assigned female at birth (AFAB) with Autism Spectrum Disorder (ASD) and Gender Dysphoria (GD) who have not surgically transitioned: An Interpretative phenomenological analysis (IPA) study

This study was developed to help to understand the experiences of adolescents born female with Autism and Gender Dysphoria (the distress caused by feeling that you are the wrong gender). This group has had little opportunity to voice their views in research. We hope to look at their experiences of identifying (or not) with a social group, coping and how they feel about their own identity.

The study is for 12–18-year-olds who were born female, have Autism and feel that their physical gender does not fit with their gender identity to participate. Each person will be invited to attend one online interview with the main researcher. There will be an opportunity to use audio or text chat to communicate.

Interviews will be audio recorded so that they can be written down and pseudo-anonymised. The researcher will try to interpret the interviewees experience and look for common themes that come up. The participants may be contacted by the main researcher to query interpretation of their findings, as the researcher would like to make sure that the interviewees views are accurately portrayed.

The results of this study will be submitted as part of the researcher’s doctoral thesis. After this, the researcher intends to publish the paper in a journal that can be accessed freely by everyone.

By opening this information up to all people, anyone can become aware of the difficulties the group face and the resilience they have, increasing the potential for greater understanding and empathy.

2122-0158 Professor Ewan Pearson University of Dundee
GoDARTS Scotland

The purpose of the GoDARTS Scotland (Genetics of Diabetes Audit and Research in Tayside and Scotland) study is to discover biological indicators (so called “biomarkers”) that will help clinicians better care for patients with diabetes, in particular by enabling them to assess if a patient’s disease is getting worse, how well they are responding to treatment and whether they are likely to develop other conditions associated with diabetes. A key aim of the study is to try and better understand how Metformin (the most common drug used to treat type 2 diabetes) works and how different patients respond to the drug. GoDARTS Scotland specifically focusses on patients who have been diagnosed with diabetes in the previous 2 years. In order to investigate how these patients’ disease progresses, and how they respond to treatment, researchers need to be able to view and link specific data from the patients’ electronic health records - such as blood test results - but without knowing the identity of the patients involved.

GoDARTS Scotland study has enrolled ~1250 patients who have consented to researchers to analyse their medical record data and link this to biomarkers measured in their blood. This specific application is to seek approval to link electronic medical record data for each study participant in line with their consent to allow us to address the approved research questions. In line with each

participant's consent, only authorised researchers can access the data and even then on a limited basis and without knowing the identity of any patient.

2122-0167 **Dr Tiberiu A Pana** **University of Aberdeen**
Importance of Gender Differences in Secondary Prevention and Long-term Outcomes of Cardiovascular Diseases in Scotland²

Heart attacks and strokes are the leading causes of illness and death in Scotland. Women are less likely than men to suffer these conditions. However, we do not know whether men and women fare differently in terms of dying in the long-term or having further heart attacks or strokes. Several studies from other parts of the world suggest that women have a higher risk of death and repeated heart attack/stroke than men. Such differences may at least partly be driven by differences in prescription of medications proven to reduce the risk of further disease, such as lipid-lowering drugs or blood thinners.

In this study, we aim to describe for the first time the differences between men and women in appropriate prescription of these medications after heart attack/stroke in Scotland. We also aim to understand factors which may explain these differences using a pseudonymised, linked national dataset. Importantly, we will also determine if such differences in prescribed medications also translate into differences in death and subsequent heart attack/stroke. Knowledge of such differences is an essential step in Scotland's ambition of reducing health inequalities for women, highlighted by the recent launch of the Women's Health Plan by the Scottish Government.

2122-0172 **Professor Steve Cunningham** **University of Edinburgh**
Near Fatal Asthma in Children and Young People

We are seeking approval for a new British Paediatric Surveillance Unit (BPSU) 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 near fatal asthma. Near fatal asthma in patients is rare. Presently, we have insufficient information about the number of children and young people with near fatal asthma, which patients are most at risk and what problems they will likely face. There is also no agreed guidance on how we should investigate and treat children and young people with near fatal asthma. The study aims to answer these questions and raise awareness of near fatal asthma amongst clinicians, as it is often under-reported.

A monthly e-reporting card is sent to paediatricians in the UK and Ireland. Clinicians will notify the research team, through the BPSU, if they care for a patient with near fatal asthma. 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.

2122-0197 Dr Ly-Mee Yu University of Oxford
Platform Adaptive trial of NOvel antivirals for eArly treatment of covid-19 In the
Community (PANORAMIC)

Despite high uptake of COVID-19 vaccines, the disease remains prevalent around the world, with many patients experiencing considerable morbidity and requiring hospital admission. There is therefore an urgent need to identify treatments for COVID-19 for use in the community early on in the illness that speeds recovery and prevents the need for hospital admission.

We propose to use a platform randomised trial in primary care and the community to investigate the effectiveness of novel antivirals in preventing hospitalisations and/ or death in patients with confirmed COVID-19, who have a higher risk of an adverse outcome. A “platform trial” is a trial in which multiple treatments for the same disease can be tested simultaneously, and in which new interventions can be added or replace existing ones during the course of the trial in accordance with pre-specified criteria. Each new anti-viral treatment for investigation will be specified The Antivirals Taskforce.

Participants will be recruited in the community via different pathways, including signposting from clinicians and social media and national media outlets as well as from PANORAMIC Hubs. Alternatively, patients can self-refer to the trial by completing registration and screening questions either on our web-based platform or with a member of the trial team. Participants will require to provide consent of taking part in the study, complete a daily symptom diary for 28 days, and then be followed up at 3, 6 and 12-months by a trial team member. We will also follow-up patients long-term for up to 10 years by collecting data from routine clinical records. We will also perform linkage of data obtained from other sources in order to better capture the primary outcome and also enable us to carry out health economics evaluation.

2122-0212 Professor Sharon Cameron NHS Lothian
Early medical abortion at home: national evaluation

In Scotland, the majority of abortions that take place are medical abortions that involve taking two medications called mifepristone and misoprostol to end the pregnancy. Most abortions are conducted at an early stage of pregnancy and most patients choose to pass the pregnancy at home rather than in a hospital or clinic (early medical abortion at home).

At the start of the coronavirus pandemic the government issued an approval so that those having an early medical abortion at home could access this care without having to attend an in-person appointment. Changes that took place included consultations taking place by telephone or video call, medication could be delivered and taken at home and an ultrasound scan was only performed if required. Evidence collected from one region of Scotland indicated that this way of delivering care was safe, effective and appreciated by patients. We now plan to examine the experience of delivering and using abortion care across the whole of Scotland. Specifically, we will examine the safety and effectiveness of this way of delivering abortion care by comparing the rates of success of treatment and complications before and after the changes were introduced. We will also survey women having medical abortion across Scotland to determine their experience and seek the views of staff who deliver this care. The findings will inform future policy in this area.

2122-0214 SMR76 Dr Lisa Iversen University of Aberdeen
The Royal College of General Practitioners' Oral Contraception Study

The Oral Contraception Study aims to determine the health effects of oral contraceptives (“the pill”). It is one of the world’s largest studies of oral contraception and women’s health. Now in year 54, over 13,000 deaths and over 22,000 incident cancers have occurred. The collection of comprehensive medical information allows the study to significantly contribute to the evidence about the safety of combined oral contraceptives and other women’s health issues. The study continues to assess the very long-term safety of oral contraceptives in the first generation of pill users. This final five years of study follow-up will allow examination of overall lifetime risks and benefits associated with pill use in terms of cancer and cause of death.

In 1968, 1400 general practitioners (GPs) across the United Kingdom recruited 23,000 women who were using oral contraceptives and a similar number who had never used. To maintain confidentiality each participant had a unique study number, the key to which only the GPs knew. Using the unique study numbers, every six months until 1996, the GPs updated the study with details of hormone prescriptions and health events occurring in the women.

To avoid loss of important information because a woman changed general practice or a GP left the study, in the 1970s those remaining in the study (approximately 36,000) were “flagged” at the NHS Central Registries for cancers and deaths notification. On behalf of the study, the GPs gave identifying information for each woman with her unique study number, directly to the registries. The registries noted (“flagged”) on each woman’s registry entry her unique study number. When a cancer or death occurs in a flagged woman, the NHS Central Registry removes any identifying details informing the study using the unique study number.

2122-0215 Laura Galletta Murdoch Children’s Research Institute
The Positive End-Expiratory Pressure Levels during Resuscitation of Preterm
Infants at Birth Trial (The POLAR Trial)

Very premature babies almost always need help to breathe immediately after birth. The lungs of preterm babies will often collapse between each breath. Applying gentle pressure, often by using a mask over their nose and mouth, helps to open their lungs with air and oxygen so that they can start to breath for themselves. This also makes it more comfortable for them to breathe.

To help with this nearly all preterm babies receive a treatment called Positive End-Expiratory Pressure, or PEEP. PEEP applies a gentle pressure to a baby’s lungs between breaths that makes it easier for the baby to breath and prevents the lungs from collapsing after each breath.

Currently we do not have enough evidence on the right amount of PEEP to give at birth. As a result, doctors around the world give different amounts (or levels) of PEEP to premature babies at birth. In this clinical trial, our aim is to compare 2 different approaches to PEEP treatment. At the moment we do not know if one approach is better than the other.

Very premature babies have a greater risk of needing long-term breathing support whilst in hospital and this is called chronic lung disease of prematurity. The longer a premature baby needs breathing support in the Neonatal Intensive Care Unit (NICU), the more likely they are to develop this chronic lung disease. We want to find out whether one approach of opening the baby’s lungs at birth results in them needing less breathing support in the NICU and developing less lung disease.

This research is being coordinated by the Murdoch Children’s Research Institute (MCRI) and will be conducted in up to 25 hospitals that deliver premature babies in Australia, Europe, the United Kingdom (UK), and the USA. This clinical trial will enrol 906 babies from these 25 hospitals involved

internationally. The overall lead study doctor for the trial is Associate Professor David Tingay, Murdoch Children's Research Institute, Melbourne Australia.

We are working closely with other researchers and doctors that look after premature babies in the other hospitals as part of a collaboration. For babies who are a part of the POLAR trial, the PEEP groups and treatments are exactly the same in all hospitals.

2122-0216 Cheryl Rees The State Hospital Progression through services: data linkage and analysis of transitions and overall pathway of the 2013 Scottish forensic inpatient population

Forensic mental health services specialise in the assessment, treatment and risk management of people with a mental disorder who are/were involved with legal or court proceedings. Some people are managed by forensic mental health services because of a high risk of harming others or themselves. All forensic patients are detained under the Mental Health (Care and Treatment)(Scotland) Act2003.

This service evaluation has been prompted by findings from the 'Independent Review into the Delivery of Forensic Mental Health Services' (The Scottish Government, 2021)

<https://www.gov.scot/publications/independent-forensic-mental-health-review-final-report/>

This review raised issues with the pathways patients navigate around and within forensic mental health inpatient services. A lack of transparency about time spent moving through levels of security (from high secure care to medium/low then the community) and the impact of transfer/discharge delays were raised, with possible inequity for vulnerable groups a concern. To explore pathway issues we are proposing to link data from a range of sources to allow the pathway through forensic mental health services of N=522 individuals, every inpatient within Scottish forensic hospitals on a census date in 2013, to be mapped. We will also examine how individuals were managed in prison before being transferred for forensic mental health care and how they progressed if they were transferred back.

The management of patients on The State Hospital transfer list (2017-2019) will also be explored. Findings will inform pathway planning, ensure transfer processes and decision making are evidence based, and reduce the burden on the public purse by alleviating system delays.

2122-0220 Professor Pam Sonnenberg University College London (UCL) National Survey of Sexual Attitudes and Lifestyles (Natsal) Named Sample

The National Survey of Sexual Attitudes and Lifestyles (Natsal) has taken place every 10 years since 1990 and is used to guide sexual and reproductive policy and deliver health services.

In previous Natsals, potential participants were identified solely using the Postcode Address File (PAF), with doorstep screening to establish participant eligibility. For the fourth Natsal survey, the team would like to use administrative health records (e.g. records created when someone visits a hospital or GP) to "enhance" an address-based sample selected from

Addresses will be selected from the PAF and a small amount of information from patient records (date of birth and gender) will be matched to these addresses in order to establish whether any of the residents are within the eligible age range for the study (16-59 years at core addresses, 16-29

years at young person addresses). Using this approach, interviewers will visit all sampled addresses where patient records indicate that one or more residents is eligible, or where no information is available from the patient records.

This approach ensures Natsal participants are broadly representative of the British population. For previous Natsal surveys, we only used addresses to get in touch with a household and did not know any information about residents beforehand, meaning that only 6 in 10 addresses contained an eligible study participant. This new approach is more efficient and also enables us to include a boost sample of young people.

No additional data (e.g. patient names or health data) will be required. Survey data will only be collected from people invited to participate in Natsal who agree to do so. People will have the opportunity to tell us that they don't want to be contacted again by the Natsal team. All data transferred by PHS will be stored securely and destroyed once people have been contacted.

Similar work is underway with NHS Digital and Digital Health and Care Wales to facilitate the English and Welsh components of the Natsal sample.

2122-0221 Farah Francis University of Edinburgh
Detecting Fetal Hypoxia Using Machine Learning Based on Cardiotocography: A Pilot Study

Fetal hypoxia occurs when there is a lack of oxygen supply in the womb. Active womb contractions disrupt constant oxygen flow during labour, damaging the baby's cells. This leads to developmental disorders such as cerebral palsy. Cardiotocography (CTG) helps to monitor fetal wellbeing in the womb during labour, where it can detect hypoxic fetuses. However, visual CTG suffers inconsistent interpretations and is insensitive in detecting fetal hypoxia. This contributes to over-diagnosed and missed cases, resulting in poor birth outcomes. We plan to use machine learning (artificial intelligence) to increase the sensitivity and specificity of CTG to detect fetal hypoxia.

This study uses previously collected maternity data. Electronic CTG data (in digital binary format) during labour and associated babies Apgar scores (a surrogate measure of hypoxia) will be extracted and pseudonymised from BadgerNet by Clevermed staff who is not involved with this research. Data will be stored in the University of Edinburgh's computer secure location. Results from this study will increase the sensitivity and specificity of CTG. From here, fetal hypoxia cases will decrease while reducing the rate of unnecessary caesarean section, thus, improving maternity care.

2122-0222 Dr Kate Weymouth-Crocker Jordan UK Health Security Agency
A Surveillance Study of Congenital and Hospitalised Neonatal Varicella in the United Kingdom & Portugal (NEOPOX)

Chickenpox (varicella) is a common childhood infection, which most individuals in the UK contract before they are teenagers. Although often mild, severe chickenpox is more likely in young babies, pregnant women and those with poorly functioning immune-systems. Chickenpox can be particularly devastating if contracted during pregnancy. Infection can be passed to the developing baby, increasing the likelihood of stillbirth, premature birth, and affecting fetal development. Chickenpox acquired in this way is known as fetal varicella syndrome (FVS).

FVS can cause problems with the way an infant learns and develops. Many children with FVS have lifelong health consequences, including limb problems, learning disabilities and visual impairment.

Babies who contract chickenpox in the first month of life, known as neonatal varicella, are also vulnerable to severe consequences. These can include breathing difficulties and brain infection, as their immune systems are still developing.

A safe and effective chickenpox vaccine has been developed, but has not been implemented as part of routine UK immunisation programmes. Currently data about infection rates of fetal and neonatal varicella is not collected, meaning information is lacking regarding the burden and treatment of chickenpox in these extremely vulnerable groups, which is crucial for directing future public health policy. The proposed study through the British Paediatric Surveillance Unit (BPSU) aims to collect data for 13-months from paediatricians across the UK on the number of cases, severity, and treatment of FVS and babies hospitalised with neonatal varicella. This crucial information will help inform public health interventions, guide decisions about the benefits and cost effectiveness of introducing the vaccine to the routine immunisation schedule, and describe short term outcomes and treatments for these conditions in the UK.

2122-0225 Dr Holly Tibble University of Edinburgh
Short-Term Adult Asthma Attack Prediction using Electronic Health Record Data in the Primary Care Setting

Asthma can be incredibly unpredictable, and it can be very hard to foretell when an attack is likely to occur. Persistent symptoms don't always equate to a lot of asthma attacks – some people are more prone to attacks than others. We also know that inconsistent use of an inhaler (or other treatment), smoking, obesity, history of respiratory infections, and more, are associated with higher risk of attacks. Despite knowing so many risk factors, identifying who is actually going to have an attack has proven a challenging task.

Our risk prediction uses machine learning algorithms, applied to routine health data, like a GPs record of a consultation, to estimate asthma attacks. Machine learning models are able to account for interactions – specific combinations of risk factors which are treated as more than the sum of their parts. These methods often estimate outcomes very accurately, but they require a lot of data and a lot of computing power. This makes them highly suitable for analysis of routine data, which is collected every day on a large scale.

Being able to predict attacks accurately means both that preventative care can be provided to stop the attack happening, and that unnecessary additional treatments can be avoided if an attack is unlikely. This could reduce the amount of steroids that someone with a high recurring risk of attacks might need over a lifetime, which could reduce the likelihood of steroid related side effects.

2122-0238 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. From 1 October 2021, 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.

1 National Records of Scotland. Vital Events Reference Tables 2018. Viewed 16 June 2020.

www.nrscotland.gov.uk/statistics-and-data/vital-events-reference-tables/2018/

2 National Records of Scotland. Avoidable Mortality. 2018. Viewed 16 June 2020.

www.nrscotland.gov.uk/statistics-and-data/vital-events/deaths/avoidable-mortality

2122-0244 Dr Peter Hall University of Edinburgh
Children with Cancer Survivorship (CwCS): Tracking the health of people treated
for cancer as a child or adolescent in the UK

The aim of this project is to identify people in Scotland treated for cancer as children or young adults (defined here as adults under the age of 40 years) and to assess their survivorship and healthcare use over time. This application seeks to create a comprehensive Scottish cohort using Scottish administrative data to describe a wide spectrum of outcomes, including mental health and community prescribing, compared with a similar general population without cancer. In doing so, we aim to identify groups of cancer survivors with a higher risk of developing specific illnesses or conditions, and estimate the associated costs. Data will be analysed within the CRUK Trusted Research Environment (TRE).

2122-0254 Rachel Winch Royal College of Paediatrics and Child
Health
National Neonatal Audit Programme (NNAP)

The National Neonatal Audit Programme (NNAP) is run by the Royal College of Paediatrics and Child Health (RCPCH). We are commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England, the Scottish Government and the Welsh Government.

The National Neonatal Audit Programme helps neonatal units to improve the care they provide to babies who need specialist treatment. We use information about your baby's care to help neonatal units in England, Scotland and Wales to improve the care and outcomes for other babies.

We look at whether babies receive consistent, high quality care, whether babies have recommended health checks to reduce the risk of complications and monitor how well babies are doing following this care.

Neonatal unit staff enter your baby's information onto a secure electronic record system named BadgerNet. All neonatal units share information from these electronic records with the National Neonatal Audit Programme (NNAP) project team within the RCPCH, via another processor,

Clevermed Ltd, who manage the BadgerNet system used by neonatal units to record clinical data. This includes sensitive personal data. The NNAP project team only uses the information for the purpose of the National Neonatal Audit Programme to monitor and try to improve standards of patient care.

When we have analysed the data collected for the NNAP we report on any key findings and make recommendations on which areas of care should be improved. We publish our reports openly online and we also publish a short summary booklet each year named “Your Baby’s Care” which highlights what we focus on and their key findings and recommendations that we have made for that year.

2122-0257 Dr Etimbuk Umana Queen’s University Belfast Validating clinical decision aids for the assessment and management of febrile infants presenting to emergency care in the UK and Ireland

We are considering new ways to help detect serious infections in young children who have a fever. Young infants under three months of age with a fever are at higher risk of serious infections than older children. Serious infections such as urinary tract infections, meningitis and bacteraemia are uncommon in young infants but potentially life threatening. In the early stages many serious infections, in this age group, are difficult to distinguish from common viral infections, such as those which cause head colds. The ideal approach to the assessment and management of infants with fever is cautious and not clear, as exemplified by the contrasting approaches advocated by the National Institute for Health and Care Excellence (NICE). The NICE guideline NG51 “Sepsis: recognition, diagnosis and early management” Overview | Sepsis: recognition, diagnosis and early management | Guidance | NICE advises that all febrile infants (under 3 months of age) receive parenteral antibiotics immediately whereas NICE guideline NG143 “Fever in under 5s: assessment and initial management” Overview | Fever in under 5s: assessment and initial management | Guidance | NICE suggests a tailored approach based on clinical assessment and laboratory testing. Most infants are given antibiotics and admitted to hospital, even though most will turn out to have a common viral infection that would get better without treatment. To avoid the over-use of antibiotics and prevent unnecessary hospital stays for infants we wish to define new ways to diagnose what sort of germs (viruses and bacteria) are making the child sick. We will collect data on young infants who come to hospitals throughout the UK, with fever. We will also collect some blood from these children to identify which blood tests are best to perform on this vulnerable group. The treatment of any infants enrolled in this study will not be altered, so there will be no direct harm or benefit to the infant. However, we hope that the data they provide will be of great benefit to the diagnosis other infants in the future.

Young infants with a fever (under 3 months of age) represent a high-risk group for serious bacterial infection (urinary tract infection, bacteraemia, and meningitis). These young infants will undergo procedures such as blood and urine testing. They may also undergo invasive testing such as a lumbar puncture to identify those with serious bacterial infection. Most young infants usually are admitted to hospital and treated with intravenous antibiotics. However, only a few will end up having a serious bacterial infection. The ideal approach to managing and treating these young infants with a fever isn’t clear as some of these infants will be at low risk obviating the need for invasive testing, antibiotics, and admission.

The FIDO (Febrile Infant Diagnostic assessment and Outcome) study aims to look at different diagnostic approaches and see which is best at identifying infants with a fever low and high-risk of serious bacterial infection. In addition, we intend to explore how new blood test called procalcitonin which could be used to enhance current clinical practice.

We plan to recruit infants under 3 months of age presenting with a fever and suspected serious bacterial infection to the emergency department. All infants will get emergency clinical care as usual without delays.

As the management of this young infants with a fever is time critical, we will use a method of delayed consent from the parents/guardians which is nationally accepted. During routine care and blood testing, some infants will have 1 ml of blood taken that will be saved for evaluating new blood tests. We will follow up these infants for seven days to see which of them develops serious bacterial infection. In some hospitals parents and doctors will be interviewed about how the communication of the risk and benefits of different approaches is undertaken. We will also look at the cost of various approaches and which would be most cost-effective for our population in UK and beyond. Our results will be published in scientific journals, presented at conferences, and used to inform future guidelines. This will shape how we manage infants 3 months and younger with a fever.

2122-0258 Dr Cara Hughes NHS GGC
WoSTRAQ 3: Pre-operative services and assessment in the West of Scotland

The Covid-19 pandemic has resulted in a large backlog of patients waiting for non-urgent surgery.

Safely meeting demand from so many patients requires effective pre-assessment. This is where nurses and doctors assess how fit a patient is for surgery, the risk of complications and how to communicate and reduce this risk by ensuring necessary tests are performed and that the appropriate level of care is available.

This audit will be conducted by the West of Scotland Trainee Research Network, a network of doctors in anaesthetic training within NHS boards in the West of Scotland. The main aim of this audit is to evaluate what pre-assessment processes these patients have been through, and does this meet national guidelines produced by a UK-wide organisation, the Centre for Peri-operative Care?

The audit will include all adults presenting for elective surgery at any hospital in the West of Scotland during one week in March 2023. No additional information will be taken from patients beyond that recorded during their routine hospital care. Patients' notes will be accessed to gather information about the operation performed and pre-operative assessments carried out. No identifiable data will be collected. This information will be stored securely on an encrypted database, and analysed to answer the questions above. The findings of this study could help direct resources and training to ensure all patients are being appropriately pre-assessed, and that the health service can safely provide surgery for the patients that need it.

2122-0261 Judith Tait Public Health Scotland NIPT evaluation and Down's syndrome project

Most people have 23 pairs of chromosomes in the cells in their body. A trisomy is a genetic condition caused by the presence of a full or partial third copy of one of the chromosomes in the body's cells. Down's syndrome is the commonest trisomy condition: it is caused by an additional copy of chromosome 21 in some or all of the cells in the body (trisomy 21, T21). The next commonest trisomy conditions seen are Edwards' syndrome (T18) and Patau's syndrome (T13).

Approximately one in every 1,000 babies in the UK is born with Down's syndrome. Individuals with Down's syndrome can lead active, healthy, and independent lives. Most will have mild to moderate

learning disabilities, and some may have more complex needs. Edwards' Syndrome and Patau's syndrome are rare but serious conditions which affect a small number of babies every year. Most babies with Edwards' syndrome or Patau's syndrome have complex medical needs. Some babies with these conditions may survive to adulthood, but this is rare.

Antenatal screening for Down's syndrome (has been offered in Scotland for many years. In September 2020, the antenatal screening programme for fetal trisomy was extended to, include screening for Edwards' syndrome and Patau's syndrome, and the screening offered to women with twin pregnancies was extended. In addition, the screening pathway was extended to offer non-invasive prenatal testing (NIPT) as a second line screen to women who receive a higher chance result from the first screening test. These changes were set out in the Chief Medical Officer letter on the implementation of NIPT in Scotland.

Public Health Scotland has been asked to evaluate the impact of the changes through analysis of national data.

At the first midwife appointment, also known as the (antenatal) booking appointment, pregnant women are offered the first fetal trisomy screening test (first line screening). Blood test results and ultrasound scan measurements are combined with maternal age to assess the chance that the baby has one of the trisomy conditions. From September 2020, women with a higher chance result from the first line screening test are offered NIPT as a second line screening test. NIPT is a blood test that is more accurate than the first screening test. Women with a high chance NIPT result are then offered an invasive prenatal diagnostic test (amniocentesis or chorionic villus sampling) to confirm whether the baby has one of the trisomy conditions. One of the key objectives of the implementation of NIPT was improving the safety of the antenatal screening programme by minimising the requirement for invasive prenatal diagnosis, which carries a small risk of miscarriage.

This programme of work headed by Public Health Scotland (PHS) will evaluate the 2020 change by linking and analysing datasets routinely held Public Health Scotland, including recently established data returns from laboratories providing results of antenatal trisomy screening and antenatal/infant genetic diagnostic testing. It will describe the choices made by women in the screening and diagnostic pathway for fetal trisomies, before and after the change made, and examine the performance of the NIPT test. An interlinked Medical Research Scotland (MRS) funded PhD project will support the evaluation and also look at the impact to longer term trends in outcomes of singleton pregnancies and babies with Down's syndrome. The PhD is hosted by University of Aberdeen and PHS is the external partner organisation.

New annual official statistics on the uptake and delivery of antenatal trisomy screening in Scotland will be developed and published by Public Health Scotland and overall findings will be submitted for academic publication. Results will inform the ongoing policy and service development of the antenatal screening programme in Scotland.

2223-0006 Dr Ryan McHenry ScotSTAR (Scottish Ambulance Service) Association between socioeconomic status and geographic isolation, and use and outcomes in pre-hospital, retrieval and critical care medicine

There are differences in healthcare use and results between people according to where they live and how deprived they are. Scottish Ambulance Service ScotSTAR responds to emergencies; treating

people outside of hospital and transporting them to hospital. It covers the whole of Scotland including remote, rural and island areas. This study will find out whether ScotSTAR treatment and results also depend on where people live and how deprived they are. The study will also assess all those admitted to critical care in Scotland and how these same factors influence their outcomes.

The study will link data collected by ScotSTAR with data on people admitted to hospital, the national audit projects for critical care and trauma, and death certificates to find out how patients were managed and their outcomes. From the Scottish Data Zone of residence we will know the Scottish Index of Multiple Deprivation (a measure of the level of deprivation in the area where people live) and geographic location to determine their isolation from critical care provision. Management and outcomes will be compared between Scottish Index of Multiple Deprivation sub-groups and mapped by geographical location to see if deprivation-based and geographic inequalities exist and whether these differ between patients who were managed by ScotSTAR and those who were not.

The published outcomes will not identify individuals, but be grouped according to degrees of socioeconomic status, and geographic isolation.

2223-0019 Professor Harry Campbell University of Edinburgh PRomISE (Preparing for RSV Immunisation and Surveillance in Europe) Data Linkage

Respiratory syncytial virus (RSV) causes severe disease in the very young, elderly and in high risk groups. A recent study found that globally, RSV caused 33.0 million acute lower respiratory infections (ALRI), 3.6 million admissions, 26 300 in-hospital deaths, and 101 400 overall deaths in children aged 0-60 months. For high risk groups such as children with congenital heart disease and bronchopulmonary dysplasia, RSV infection is associated with higher risks of hospitalisation, admission to intensive care unit (ICU), oxygen supplementation, mechanical ventilation and death compared to non-high risk children. In older adults, severe RSV infections needing hospitalisations may occur in adults with chronic medical conditions such as chronic obstructive pulmonary disease (COPD), diabetes, chronic kidney disease (CKD), ischemic heart disease, stroke, and asthma. This study will use linked routine health data to estimate the healthcare burden (such as illnesses, deaths, hospital admissions, and financial costs) of RSV and coronavirus disease 2019 (COVID-19), and the impact of COVID-19 and COVID-19 population-based non-pharmaceutical interventions on RSV epidemiology in all age groups. The study population will include individuals with hospital admission for a range of respiratory diseases (including cardio-respiratory disease in adults), or deaths due to respiratory infections including bronchiolitis for children. Data will be collected from 2017 to 2024 or the latest date with complete data. The study will provide additional estimates of RSV disease burden (the sum of RSV-related morbidity/illness) in Scotland and may contribute to the knowledge base and evidence-based decision making for the prevention and management of RSV.

2223-0033 Dr Nathalia Matveyev University of Edinburgh Characteristics and outcomes of high-risk COVID-19 patients treated with Sotrovimab, oral anti-virals, or no treatment in Scotland

Since the start of the pandemic, new vaccines and treatments have been developed to reduce the risk of people becoming very unwell with COVID-19. People who are particularly at risk include those who are:

- Older (65 years of age or above)

- Living with impairment of the immune system
- Living with liver disease or long-term kidney disease
- Living with other high risk conditions or treatments, including transplants and some cancers.
- These new treatments include neutralising **monoclonal antibodies** and **antiviral** medications.

Antibodies are part of the body's immune response to viruses, like the SARS-CoV-2 virus which causes COVID-19. Monoclonal antibody treatments, like **sotrovimab**, are given to people who need extra support for their immune system to protect them from severe disease.

Antiviral medications stop viruses from spreading in the body. They include:

- **Nirmatrelvir/Ritonavir**
- **Molnupiravir**

These treatments have all been shown, in clinical trials, to reduce severe disease in high-risk patients. However, we need more information about how well the treatments work in routine clinical care. By monitoring this at a national population level, we can look at patterns of treatment benefit that might not be obvious in smaller clinical trials. For example, we could see if treatment reduced symptoms better in older women than older men. We can also investigate whether people with certain variants (like Omicron and Delta) responded better to the treatment than others, so we can see what the best treatment is for new variants.

In this study, we are going to describe groups of high-risk COVID-19 patients who had these treatments after they were diagnosed, and whether they became unwell. We will compare these patients to people who were eligible, but did not receive treatment (or were only treated when they started to become even more unwell). We will also look at whether people treated with **sotrovimab** get better at the same rate when they have a newer version of the Omicron variant (BA.2).

2223-0040 SR244 Professor Amanda Cross Imperial College London Frequency of follow-up for patients with low-, intermediate- and high-risk colorectal adenomas. Short title: the All Adenomas study

In our 2017 application and subsequent amended versions (Ref: 1718-0048, see SD1) we proposed to extend the remit of the original Intermediate Adenomas study which evaluated the 'frequency of follow-up for patients with intermediate-risk adenomas'. Using the same retrospective cohort database, we proposed to update the study to the 'All Adenomas study' to review the frequency of follow-up for the low- and high-risk adenoma groups in addition to the intermediate-risk group.

Among individuals classed as having intermediate-risk adenomas, we found that adequate colorectal cancer (CRC) protection can be achieved with less than the recommended surveillance^{1, 2}. We identified a subgroup in which CRC risk was so low that surveillance after adenoma removal was not warranted. The study also justified using CRC risk as a more valid measure than advanced adenomas of the need for regular colonoscopy surveillance. Among low-risk patients, CRC risk without surveillance following adenoma removal was no higher than in the general population, indicating that surveillance is not required. Finally, surveillance was shown to be necessary and effective for high-risk patients, who remained at increased CRC risk following adenoma removal³.

We have now completed the analyses associated with the primary aims of this study (see below). We request an extension to continue our ongoing secondary statistical analyses of study evidence.

1. Atkin WS, Wooldrage K, Brenner A, Martin J, Shah U, Perera S, Lucas F, Brown JP, Kralj-Hans I, Greljak P, Pack K, Wood J, Thomson A, Veitch A, Duffy SW, Cross AJ. Adenoma surveillance

- and colorectal cancer incidence: a retrospective, multicentre, cohort study. *Lancet Oncol* 2017. Published Online April 27, 2017 [http://dx.doi.org/10.1016/S1470-2045\(17\)30187-0](http://dx.doi.org/10.1016/S1470-2045(17)30187-0)
2. Atkin WS, Brenner A, Martin J, Wooldrage K, Shah U, Lucas F, et al. The clinical effectiveness of different surveillance strategies to prevent colorectal cancer in people with intermediate-grade colorectal adenomas: a retrospective cohort analysis, and psychological and economic evaluations. *Health Technology Assessment*, 2017 volume 21, number 25.
 3. Cross, A.J., Robbins, E.C., Pack, K., Stenson, I., Kirby, P.L., Patel, B., Rutter, M.D., Veitch, A.M., Saunders, B.P., Duffy, S.W., Wooldrage, K. (2020). Long-term colorectal cancer incidence after adenoma removal and the effects of surveillance on incidence: A multicentre, retrospective, cohort study. *Gut*. 2020 Sep;69(9):1645-1658.

2223-0055 **Dr William Whiteley** **University of Oxford**
UKPDS trial legacy study: long-term follow-up of participants using electronic health records

We wish to follow-up the participants in the UK prospective diabetes study (UKPDS) who first took part in the study about 40 years ago. The UKPDS study randomly allocated people with diabetes to more or less intensive blood pressure lowering, and more or less intensive glucose lowering. The long-term follow-up of the UKPDS has two main aims:

- (1) To assess the effect of blood pressure lowering on dementia, major vascular diseases (such as heart attack and stroke) and death in people with diabetes; and
- (2) To assess the effect of better glucose control on dementia, major vascular diseases (such as heart attack and stroke) and death in people with diabetes.

The reason for very long-term follow-up is because diabetes is a life-long condition, the up to 40 years benefit of these treatments is likely to have been underestimated in the shorter trial follow-up.

People with higher blood pressure or diabetes have an increased risk of developing dementia, but there is no evidence that lowering either blood pressure or glucose reduces the risk of developing this debilitating condition. A randomised trial like UKPDS with very long follow-up which is necessary since dementia is an insidious condition which takes many years to develop represents a unique opportunity to directly assess the effect of these treatments on dementia risk. This question is highly relevant. If we demonstrate that blood pressure lowering or glucose lowering prevents dementia, many more patients will be considered for blood pressure lowering thereby reducing the burden of disease posed by dementia.

2223-0065 **Professor Rowland Kao** **University of Edinburgh**
Spatial and Network Analysis of SARS-Cov-2 Sequences to Inform COVID-19 Control in Scotland

It is now possible to genetically 'fingerprint' viruses including SARS-CoV-2, the causal agent of COVID-19. When this is done for two samples of virus from two different infected individuals, then if the samples contain viruses that are very closely related to each other, the probability that one of the two infected the other is relatively high. With large numbers of fingerprinted viruses we can learn a great deal about not just what the risk factors are for becoming infected, but also what the

risks are for the circulation of the virus by geographically defined risk factors throughout all of Scotland (e.g. levels of deprivation, or age distributions). Understanding and being able to quantify what drives circulation is a critical step for improving disease control, both because it allows us to assess with greater accuracy how good past controls have been, but also it provides bench marks against the interpretation of future fingerprinting data.

In this project, we shall develop computer simulations and “machine learning” tools that exploit these data in order to assess the value of past control measures in Scotland. In turn, this understanding will help us to develop tools for interpreting fingerprint data in the future when there is expected to be substantially less testing and therefore information data available. These approaches could also be adapted for combatting other infectious diseases in the future including for example epidemics of seasonal influenza or any emergent viral pandemics as they will likely be interpretable via the same methods.

We shall therefore be providing insights into understanding the burden of premature death and severe or hospital associated outcomes for COVID-19 in areas of high deprivation, generate, analyse and disseminate secondary data that would be invaluable for other epidemiological investigations, and provide outputs that would support PHS and SG in developing and improve the appropriateness of future COVID-19 controls, therefore protecting public health and especially those severely infected by infection.

**2223-0070 Hannah Edwards University of Bristol
National PReCePT (Prevention of cerebral palsy in pre-term labour) Programme
Evaluation: Devolved Nations extension study**

Babies born preterm are at risk of brain damage including Cerebral Palsy (CP). Giving Magnesium Sulphate (MgSO₄) to mothers in preterm labour helps reduce the risk of CP. Since 2015 the UK National Institute for Health and Care Excellence (NICE) has recommended use of MgSO₄ in preterm deliveries. However, it was not consistently being used.

In 2018, the National PReCePT (Preventing Cerebral Palsy in Pre-Term labour) Programme (NPP) was run in England to increase maternity units’ use of MgSO₄. We conducted an evaluation which concluded the NPP was effective and cost-effective in the 12 months after its start. Scotland and Wales do not have similar programmes.

The current study builds on the previous one, and will:

- (a) Evaluate the longer-term effectiveness and cost-effectiveness of the NPP in England, including a comparison with the devolved nations.
- (b) Determine whether a similar national programme might be effective and cost-effective in Scotland and Wales.
- (c) Explore the experiences of implementing NICE guidance on MgSO₄ in Scotland and Wales via qualitative interviews with perinatal clinical/managerial leads.

We will use unidentifiable data of mothers and babies from the National Neonatal Research Database (NNRD), which has all data on admissions to NHS neonatal units in England, Wales, Scotland and the Isle of Man.

Results will help identify whether the English NPP could be a useful blueprint for similar perinatal services in Scotland and Wales to deliver the best possible care for mothers and babies across the UK.

2223-0075 Bethanie Fenney National Records of Scotland
National Records of Scotland (NRS) – Scotland’s Census 2022 Administrative
Data Contingencies for Population Estimation

National Records of Scotland (NRS) is responsible for Scotland’s Census. It happens every decade, providing information on all people and households in Scotland.

The census is of national strategic importance, being fundamental to resource allocation between UK countries, and across Scotland. Government, councils, the NHS, and public, private and third-sector users rely on census outputs. Accurate census outputs support the planning of many vital public services across Scotland, aiming to improve the lives of Scotland’s people.

International best practice complements census collection with “post-collection work”. This includes the census coverage survey (CCS) and other statistical methodological and assurance work, which ensures high-quality census outputs.

Scotland’s Census 2022 faced unexpected challenges, leading to a lower-than-expected return rate. The scale of this means it is essential to consider new methods including using administrative sources to count those missed by the census field collection.

NRS propose:

1. using administrative data alongside census and CCS records when calculating the high-level population estimates, improving their accuracy and ensuring they are representative of all groups of society
2. using demographic information from administrative data to guide the imputation of records to the census dataset to represent the non-responding population, improving the accuracy of lower community-level census estimates.

The proposal is vital to NRS’ objective to provide accurate basic information on population size, age, sex and location. It draws on international best practice, for example in New Zealand on using administrative data in a trustworthy way to enhance the public benefit of the Census.

2223-0086 SR181 Dr Carl Counsell University of Aberdeen
Parkinsonism Incidence in North-East Scotland (PINE) study: access to death
certificates in participants who have died

Between 2002-2004 and 2006-2009, the PINE research team recruited all patients in Aberdeen with a newly diagnosed neurological disease called Parkinson’s as well as age-sex matched controls who did not have Parkinson’s. These groups are being followed up lifelong to establish how this disease evolves over time and what impact it has on people’s lives compared to the controls. One important measure is how long people survive and so participants have consented to be linked to the death register so we know when they die (see consent forms: SD 9, SD 10).

2223-0095 Sharon Kennedy PHS
EAVE II – Temporary extension to use of linked GP data to support PHS statutory public health remit

The GP data and linked NHS records utilised by EAVE II are required for the ongoing surveillance of COVID-19 and other infectious respiratory diseases in Scotland. In the absence of any pre-existing mechanism for PHS to request access to GP data from each GP practice in Scotland, endorsement for the use of GP data to support the Covid-19 pandemic response was sought via representation from the two main GP governing bodies in the UK, the Royal College of General Practitioners (RCGP) and the BMA Scottish General Practitioners Committee (SGPC). As NHS Boards are joint controllers of GP data, GP representatives agreed together with the Scottish Government (SG), to grant PBPP temporary powers to authorise the use of GP data for EAVE II linkage and analysis during the Covid-19 pandemic. This remains the only mechanism for requesting access to GP data and current PBPP approvals run out on 30th September 2022. This is a request for permission to continue using EAVE II linked GP data to support statutory PHS public health activities, including surveillance and/or usual public health practice, to March 2023. PHS are working on an alternative mechanism for requesting continued access to GP data for this purpose post March 2023 that is hoped will be agreeable to GPs.

2223-0100 Professor Calum Semple University of Liverpool
ISARIC Comprehensive Clinical Characterisation Collaboration (ISARIC4C)

The International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) Comprehensive Clinical Characterisation Collaboration, or ISARIC4C, is the UK-wide group of ISARIC members who developed the ISARIC Clinical Characterisation Protocol (CCP-UK).

This protocol is a “sleeping protocol” – designed to be activated in the event of a new infection or outbreak. At the start of the COVID-19 pandemic, this protocol was used to collect data on COVID-19 patients in NHS trusts and boards across the UK. On 13 February 2020, ISARIC4C recruited the first COVID-19 patient admitted to hospital in UK. By 28 February 2022, ISARIC4C has recruited over 300,000 COVID-19 patients across the UK.

ISARIC4C work closely with public health agencies to respond to new outbreaks of infections and other threats to public health. Making data available for the benefit of all, is at the core of how ISARIC4C works. We quickly shared COVID-19 data. This meant our data was able to inform government policies, and was helpful in guiding a UK-wide pandemic response. ISARIC4C identified patients most at risk of getting very sick, very early in the pandemic and our data was also key to finding new treatment options to COVID-19.

With HSC-PBPP approval, we were able to link ISARIC4C data to routinely collected health data in Scotland. This include primary care, hospital data, and data from death registries. This made it possible for us to find out more about COVID-19, specific to Scottish people. This included finding groups most at risk and the impact of the vaccine roll-out on severe disease, amongst many other discoveries. This also allowed ISARIC4C to create an accessible dataset that others could use to find out more about this new disease.

We would like to continue this data linkage to allow ISARIC4C researchers, access to the data to allow quicker discoveries for the benefit of all.

2223-0101 Professor Jennifer Kurinczuk University of Oxford
MBRRACE-UK – Delivering the UK Maternal, Newborn and Infant Clinical
Outcome Review Programme (MNI-CORP)

MBRRACE-UK is the group appointed to run the national Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP). This involves collecting information to monitor the rates of deaths of mothers and babies across the UK, including Scotland; this is called surveillance. MBRRACE-UK also carries out expert reviews of the care provided for individual mothers and babies using their medical records; these are called confidential enquiries. MBRRACE-UK also reviews the care provided to samples of mothers and babies where the mother and/or baby experiences very serious illness but have not died. These are called confidential enquiries of serious morbidity.

MBRRACE-UK collects information across the UK about:

- all mothers who die during pregnancy or up to 12 months after giving birth (surveillance and confidential enquiries);
- some mothers who experience very serious illness in pregnancy (confidential enquiries);
- all mothers whose pregnancy results in late miscarriage or the baby being stillborn (surveillance);
- all mothers and babies when the baby dies in the first few weeks after birth (surveillance);
- samples of mothers and babies where the baby is stillborn, dies in the first few weeks or is very seriously ill in the period after birth (confidential enquiries).

Information about all mothers giving birth is used to calculate the rates of death. Based on the deaths rates and the confidential enquiries, MBRRACE-UK publishes recommendations about how care can be improved to ensure that services provided for mothers and babies are safe and are of high quality, with the goal of preventing future mother and baby deaths.

2223-0122 Dr Samira Bell PHS
Cancer Incidence and Outcomes in Patients undergoing Kidney Replacement
Therapy in Scotland

Patients with who have kidney failure requiring a transplant or dialysis are known to have a higher risk of cancer than the general population with rates of specific cancer including colorectal, lung, prostate, stomach, oesophagus, pancreas, ovarian, breast, skin and kidney) rising in these patient groups. This may be due to changes in immunosuppressive treatments used for transplant patients, but it remains unclear why this is the case for dialysis patients rising in these patient groups. Patients with kidney failure are often excluded from clinical trials and so are relatively understudied compared with the general population. The use of real-world data is therefore an important means of generating important evidence which can influence care for these patients. Scotland is one of the few countries globally where this work can be carried out due to the ability to link high quality national datasets. Understanding the pattern of cancer risk and factors associated with development of cancer in these patients will provide vital information which can inform national screening and prevention strategies. We will link the Scottish Renal Registry to the Scottish Cancer Registry to understand patterns of how cancers develop and whether this has changed over time as medicines that suppress the immune system have improved. This will allow for implementation of tailored screening strategies for patients with kidney failure with the aim of reducing cancer risk and improving survival in these vulnerable patient groups.