Applications approved by HSC-PBPP in 2018/2019

Click on application reference to access the lay summary for this application.

Application Reference	Applicant	Title of Study	Level of Approval	Decision
1617-0152	Dr Anna Pearce	Improving life chances & reducing child health inequalities: harnessing the potential of existing data	Tier 1 Panel	Approved
1718-0380	Dr James Wilson	Harmonisation of Record Linkage in Two Northern Isles Cohorts – “Viking"	Tier 1 Panel	Approved
1718-0151	Alexandra Hellyer	OASI Care Bundle Quality Improvement Project	Tier 1 Panel Meeting	Approved
1718-0241	Professor Martin Scott Dennis	Fluoxetine or Control under supervision for stroke (FOCUS) trial	Tier 1 Panel Meeting	Approved with conditions
1718-0252	Dr Michael Lockhart	Electronic Communication of Surveillance in Scotland (ECOSS) – Reference Laboratory Data content and quality review	Tier 1 Review	Approved with conditions
1718-0156	Dr Michael Lockhart	Electronic Communication of Surveillance in Scotland (ECOSS) – Diagnostic Laboratory Data content and quality review	Tier 1 Review	Approved with conditions
1718-0274	Professor Patrick Doherty	National Audit for Cardiac Rehabilitation	Tier 1 Review	Approved
1718-0246	Dr Aditya Sharma	Surveillance of Incidence of first time diagnosis of Early Onset Depression in children aged 3-13 years across the United Kingdom and Republic of Ireland	Tier 1 Review	Approved with conditions
1718-0305	Dr Devesh Dhasmana	Non-Tuberculous Mycobacteria infection in Scotland; the burden of M.abscessus and M.avium complex in Fife and Tayside (MAAFT)	Tier 1 Review	Approved with conditions
1718-0181	Hazel Dodds	Collection of Patient Reported Outcome Measures (PROMs) data as part of the Scottish Trauma Audit Group (STAG).	Tier 1 Panel meeting	Approved with conditions
1718-0152	Dr Richard Haylock	National Registry for Radiation Workers epidemiological cohort study	Tier 1 Panel meeting	Approved with conditions
1617-0253	Graham Kirkwood	Patient choice and equality of access in Scotland: an analysis of NHS funded treatments in the NHS and private sector	Tier 1 Review	Approved
1718-0354	Dr Riinu Ots	Quality and outcomes in global cancer surgery	Tier 1 Review	Approved

1819-0015	Dr Richard Haylock	British Nuclear Fuels Ltd. workers epidemiological cohort study	Tier 1 Panel meeting	Approved with conditions
1718-0263	Dr Catherine Hanna	Assessing the "impact" of clinical trial results: Proposal to assess chemotherapy prescribing practices in Scotland prior to and following the publication of the Short Course Oncology Trial (SCOT).	Tier 1 Review	Approved
1718-0358	Koen Rietdijk	Multimorbidity in Scottish ICUs	Tier 1 Panel meeting	Approved with conditions
1617-0371	Professor Marion Bennie	Cancer Medicines Outcomes Programme (CMOP)	Tier 1 Panel meeting	Approved with conditions
1718-0370	Stephen Riddell	NHS Information Services Division/Alan Turing Institute Collaboration – SPARRA Algorithm Development	Tier 1 Panel meeting	Approved with conditions
1617-0142	Dr Kevin Pollock	Scottish Penile Cancer Epidemiology: SPICE	Tier 1 Panel Meeting	Approved
1819-0041	Professor Austyn Snowden	A comparison of wider health service usage in two matched cohorts	Tier 1 Review	Approved
1718-0280	Louise Cuthbertson	Scottish Cancer Patient Experience Survey	Tier 2 OOC	Approved
1718-0324	Dr Colin Tilley	The retention of dentists in NHSScotland	Tier 1 Review	Approved with conditions
1718-0328	Dr Marisa Mason	Medical and Surgical Clinical Outcome Review Programme	Tier 2 OOC	Approved with conditions
1718-0001	Prof Adrian Stanley	Scottish audit on upper gastrointestinal bleeding	Tier 1 Review	Approved
1718-0356	Dr Will Atkinson	MR110 UKAEA Mortality and Morbidity Study	Tier 1 Review	Approved
1718-0357	Dr Will Atkinson	MR183 Atomic Weapons Research Establishment Worker Study	Tier 1 Review	Approved
1718-0299	Dr Elizabeth Starkey	A Prospective Study of Acute Severe Poisonings in Children Listed under the BPSU Surveillance of rare disease approved application (1516-0292)	Tier 1 Review	Approved
1718-0342	Dr Jonathan Mayes	End of Life Care in Critical Care Units	Tier 1 Panel Meeting	Approved
1617-0224	Dr Pia Hardelid	Long-term health outcomes following childhood hospital admissions	Tier 2 OOC	Approved with conditions

1718-0313	Dr Adriana Duta	Disentangling the importance of individual and family factors on educational outcomes using a sibling design	Tier 1 Review	Approved
1617-0100	Dr Holly Ennis	Allocation of resource in end-of-life care: health care use and cost trajectories of people in the last year of life	Tier 1 Review	Approved
1617-0380	Dr Elizabeth Richardson	Regeneration, health, and health inequalities: a longitudinal data linkage study	Tier 2 OOC	Approved with conditions
1718-0364	Karen Smith	Improving the Cancer Journey (ICJ) Invite letter service	Tier 1 Review	Approved with conditions
1718-0240	Dr Daniel Mackay	The association between differential pricing of tobacco products and perinatal and infant health outcomes in the United Kingdom	Tier 1 Review	Approved
1819-0057	Dr Richard Haylock	Nuclear Weapons Test Participants Study (NWTPS)	Tier 1 review	Approved
1819-0005	Amelia Rudd	Establishing the incidence of Tako-tsubo Cardiomyopathy in Scotland – the STARR study (Scottish Tako-tsubo Network/Registry) – Phase 1	Tier 1 review	Approved
1819-0092	Caroll Brown	Linkage of patients using Home and Mobile Health Monitoring technologies for Respiratory diseases (COPD and Asthma) in NHS Greater Glasgow and Clyde, NHS Ayrshire & Arran and NHS Highland	Tier 1 review	Approved
1718-0266	Inna Thalmann	Trends and determinants of cardiovascular medication use for the secondary prevention of cardiovascular disease in Scotland	Tier 1 review	Approved
1718-0197	Dr Holly Ennis	Post-adoption audit of eribulin for metastatic breast cancer	Tier 1 review	Approved
1718-0325	Dr Zhiqiang Feng	Does commuting affect health?	Tier 1 review	Approved
1819-0077	Dr Tamsin Newlove-Delgado	Modern illness or a thing of the past? Surveillance study of childhood/adolescent Sydenham's chorea in the UK and the Republic of Ireland	Tier 1 review	Approved
1819-0011	Dr Libby Morris	NHS Scotland Managed Services Network for Children and Young People with Cancer (NHS Scotland MSN CYPC)	Tier 1 review	Approved with conditions
1617-0359	Dr Alice Jackson	The epidemiology of peripartum cardiomyopathy in a Western European country: An analysis of the Scottish population from 1986-2017	Tier 1 review	Approved with conditions
1617-0228	Nadine Dougall	CHildhood Adversities and their impact on Suicidality (CHASe)	Tier 1 panel Meeting	Approved

1718-0134	Viktoria McMillan	National Asthma and COPD Audit Programme (NACAP)	Tier 1 review	Approved
1718-0327	Professor Ian Deary	Lothian Birth Cohort 1936 (LBC1936) Study	Tier 1 Panel Meeting	Approved
1718-0359	Dr Martin McCoy	Distress Brief Interventions (DBI) Programme Data Collection	Tier 2 OOC	Approved with conditions
1718-0334	Aghimien Iyayi-Igbinovia	Hospice at Home data pilot	Tier 1 Review	Approved with conditions
1718-0213	Jill Barton	ASCEND (A Study of Cardiovascular Events iN Diabetes)	Tier 1 Review	Approved with conditions
1718-0227	Professor Rustam Al-Shahi Salman	REstart or STop Antithrombotics Randomised Trial (RESTART)	Tier 1 Panel Meeting	Approved
1516-0163	Dr Christopher Burgess	The PIES (Paediatric-onset Inflammatory Bowel Disease Epidemiology in Scotland) study: data linkage exploration of perinatal risk factors and long-term adverse consequences	Tier 1 Review	Approved
1718-0257	Dr Heather Whalley	Scottish Bipolar Family Study	Full Committee	Approved with conditions
1718-0330	Dr Shamez Ladhani	Severe complications of Enterovirus and human Parechovirus infections in children in UK and Republic of Ireland	Tier 1 Panel Meeting	Approved with conditions
1718-0026	Dr Holly Ennis	Creating a UK Colorectal Cancer Intelligence Hub (CORECT-R)	Tier 2 OOC	Approved with conditions
1819-0099	Professor Colin McCowan	Population-Based Research on the Incidence, Prevalence, Patient Characteristics Treatment patterns & Outcomes in Patients with Coronary Artery Disease, Peripheral Artery Disease & Heart Failure in Scotland	Tier 1 Review	Approved
1819-0073	Professor Ian Deary	Mental health within the family and between generations – Phase 1: Linking the Scottish Mental Survey 1947 cohort to mental health outcomes	Tier 1 Review	Approved
1819-0125	Dr Stephen Pavis	Exemplar project for Scottish Medical Imaging (SMI)	Tier 1 Review	Approved
1819-0066	Dr Shadrach Dare	Social Inequalities in Educational Attainment: An Investigation into the Mediating Role of School Absenteeism	Tier 1 Panel Meeting	Approved with conditions

1617-0302	Professor David Conway	Dental Health of Children with Additional Support Needs in Scotland	Tier 1 Review	Approved with conditions
1819-0031	Professor Daniel Rea	aTTom-Extended: Extended follow-up of patients enrolled in the Adjuvant Tamoxifen - To Offer More? (aTTom) trial	Tier 2 OOC	Approved
1819-0052	Dr Abigail Short	Liberation from Mechanical Ventilation Audit	Tier 1 Review	Approved
1718-0133	Dr Beverly P Bergman	Trends in Scottish Veterans' Health	Tier 1 Panel Meeting	Approved with conditions
1718-0326	Professor Ian J Deary	Lothian Birth Cohort 1921(LBC1921) Study	Tier 1 Panel Meeting	Approved
1516-0030	Professor Frank Sullivan	Detection in blood of autoantibodies to tumour antigens as a case-finding method in lung cancer using the Early CDT-Lung test	Tier 1 Panel Meeting	Approved
1718-0113	Professor Anne Ellaway	SR72 - West of Scotland Twenty-07 Study: Health in the Community	Tier 1 Review	Approved with conditions
1819-0098	Dr Fozia Roked	Surveillance of Congenital Ichthyosis in UK and Ireland in neonates. Listed under the BPSU Surveillance of rare disease approved application	Tier 1 Review	Approved
1819-0007	Kenny Haining	Socioeconomic outcomes measurement in survivors of major illness	Tier 1 Panel Meeting	Approved with conditions
1718-0365	Dr David Carslake	SR152 Glasgow Students Study	Tier 1 Review	Approved with conditions
1819-0019	Hima Daby	Analysis on childhood cancer incidence around nuclear installations in England, Wales and Scotland	Tier 1 Review	Approved
1718-0329	Professor Lesley Colvin	Data and Measurement for Chronic Pain Services. A Project to Inform National Pain Service improvement	Tier 1 Review	Approved
1819-0172	Dr Marisa Mason	Child Health Clinical Outcome Review Programme	Tier 1 Panel Meeting	Approved
1819-0026	Dr William Whiteley	Long term follow-up of ASCOT trial into Electronic Health Records (LATER)	Tier 1 Review	Approved with conditions
1819-0108	Dr Christopher Verity	Progressive Intellectual and Neurological Deterioration - PIND Study	Tier 1 Review	Approved

1718-0183	Professor Steve Turner	Slowing the flow of zero day admissions to hospital: data linkage to inform priorities for future intervention along paediatric referral pathways	Tier 1 Review	Approved
1718-0232	Dr Ceri Sellers	Prolong20+ Longitudinal study of pelvic floor dysfunction and relationship to childbirth: Access to current names, addresses and mortality statuses	Tier 1 Panel Meeting	Approved
1819-0079	Professor Jennifer Kurinczuk	A confidential enquiry of intrapartum-related perinatal deaths in births planned in midwifery-led settings in Great Britain (ESMiE)	Tier 1 Panel Meeting	Approved
1819-0089	Dr Lynne Warrander	Determining incidence and survival rates in extreme early onset fetal growth restriction	Tier 1 Panel Meeting	Approved
1819-0150	Dr Peter Murchie	National Cancer Diagnosis Audit (NCDA) Scotland - Analyses	Tier 1 Panel Meeting	Approved
1718-0379	Professor Tom McMillan	The relationship between recorded hospitalisation and self-report of head injury in male and female prisoners in Scotland	Tier 1 Review	Approved
1718-0368	Pallavi Tyagi	Incidence of retinal dialysis in United Kingdom	Tier 1 Review	Approved
1718-0333	Dr Artaban Jeldi	Investigation of outcomes of navigated TKA after 5 years	Tier 1 Review	Approved
1819-0105	Dr Norah Palmateer	Record linkage initiative to monitor hepatitis C testing, diagnosis and treatment of children born to hepatitis C infected mothers in Scotland	Tier 1 panel meeting	Approved with conditions
1819-0102	Dr Claudia Geue	Estimating the value of Precision Medicine Technologies: Developing a Scottish Toolkit	Tier 1 panel meeting	Approved
1819-0048	Dr Clare Frobisher	Cohort study of mortality and cancer incidence in UK oil refinery and petroleum distribution workers (1951-2016).	Tier 1 review	Approved
1819-0153	Dr Alastair Ross	FACTORS- (Fluoride Application: a Co-designed Toolkit of ORganisational Strategies)	Tier 1 panel meeting	Approved
1819-0189	Michael Blayney	Multimorbidity in Scottish ICUs	Tier 1 review	Approved
1819-0229	Viktoria McMillan	National Asthma and COPD Audit Programme (NACAP) – pulmonary rehabilitation audit	Tier 1 panel meeting	Approved
1819-0123	Dr Gary Stiefel	Surveillance of Food Protein Induced Enterocolitis Syndrome (FPIES) presenting to paediatricians in UK and Ireland.	Tier 1 review	Approved with conditions

1819-0055	Professor Marion Bennie	Cancer Medicines Outcomes Programme (CMOP)	Tier 1 review	Approved with conditions
1819-0232	Emily Petch	Each Baby Counts ascertainment using NNRD data	Tier 1 Panel Meeting	Approved
1819-0186	Professor Richard Anderson	Reproductive outcomes in survivors of childhood, adolescent and young adult cancer in Scotland: a population based cohort study	Tier 1 review	Approved
1718-0341	Professor Esther Crawley	BPSU survey of severe Chronic Fatigue Syndrome/Myalgic Encephalopathy	Tier 1 Review	Approved
1718-0075	Dr Laura Forsyth	Duration of Dual Anti-Platelet Therapy in Acute Coronary Syndrome in Scotland (The DUAL-ACS2 Trial)	Tier 1 Panel Meeting	Approved
1819-0256	Professor Gerald Humphris	A pilot trial of the Mini-AFTERc intervention to manage Fear of Cancer Recurrence in breast cancer patients	Tier 1 Review	Approved
1819-0147	Dr Yvonne Bramma	WoSTRAQ: Post-operative Cognitive Impairment and Delirium in the West of Scotland	Tier 1 Review	Approved
1819-0006	Amelia Rudd	Is there a genetic predisposition for acute stress-induced (Takotsubo) Cardiomyopathy?	Tier 1 Review	Approved
1819-0234	Dr Kenneth McLean	REspiratory COmplications after abdomiNal Surgery (RECON)	Tier 1 Review	Approved
1819-0080	Professor Joan Morris	Follow Up of Participants in the Randomised Trial of Helicobacter Pylori Screening (HPSS)	Tier 1 Panel Meeting	Approved
1617-0226	Professor Laura Goldstein	CODES	Tier 1 Review	Approved
1718-0248	Dr Richard McNally	Thyroid Cancer study - Cumbrian Birth Cohort	Tier 1 Review	Approved

Lay summaries of approved applications

1516-0030 Professor Frank Sullivan
Detection in blood of autoantibodies to tumour antigens as a case-finding method in lung cancer using the Early CDT-Lung test

The ECLS trial will investigate the effectiveness of EarlyCDT-Lung test and subsequent CT scanning in potentially identifying those at high risk of lung cancer, and as a result reduce late-stage lung cancer (3&4) or unclassified diagnosis.

Lung cancer remains the fourth least likely cancer to be picked up early by GPs. Low dose computed tomography (CT) scanning of high risk individuals can reduce lung cancer mortality by 20% but it is expensive and, despite scanning, late stage diagnosis results in substantial morbidity.

The EarlyCDT-Lung Test is an early detection test designed to assist in lung cancer risk assessment and detection in the earliest stages of the disease. Survival rates are much higher when cancer is diagnosed early but because lung cancer is often diagnosed symptomatically, most cases are discovered after the disease has spread. In these cases, the 5-year survival rate is less than 10%. By testing patients who are at a high risk for developing lung cancer before symptoms appear, the EarlyCDT-Lung test could help diagnose lung cancer sooner, when treatment options are more likely to be successful. The EarlyCDT-Lung test detects autoantibodies, which are a patient's immune response to antigens produced by solid-tumor cells. Because these autoantibodies are produced by healthy individuals at lower levels, the EarlyCDT-Lung test enables physicians to identify those patients producing autoantibodies at higher levels and who are at an increased lung cancer risk or who are already in the early stages of lung cancer.

1516-0163 Dr Christopher Burgess
The PIES (Paediatric-onset Inflammatory Bowel Disease Epidemiology in Scotland) study: data linkage exploration of perinatal risk factors and long-term adverse consequences

Paediatric-onset inflammatory bowel disease (PIBD; IBD diagnosed <16 years of age) comprises Crohn's disease (CD), ulcerative colitis (UC) and IBD unclassified (IBDU). The incidence of PIBD in Scotland is the highest in the United Kingdom and one of the highest worldwide. Epidemiological data for greater than 4 decades confirms a 5-fold increase in CD incidence in Scottish children, with marked geographical differences and socio-economic associations. The latest Scottish paediatric incidence data on IBD from 1996 onwards has not been validated and does not include any children aged 13-16 years who may have been seen exclusively in adult IBD (medical and surgical) services. It is therefore likely to underestimate the actual numbers of affected children.

This current project aims to continue work by Dr Emma Armitage and Professor Anne Ferguson between the Western General Hospital and Royal Hospital for Sick Children, Edinburgh who previously validated the incidence of PIBD in Scotland from 1981-1995. The data to be collected now from 1996-2017 will be used to calculate robust and up-to-date incidence figures for children in Scotland with IBD and capture previously missed cases that were never managed in established

paediatric clinical services. This information will be used to further our knowledge on whether the true incidence rate of IBD in children is rising even faster than previously thought. Collection and validation of robust population-based epidemiological data will then allow data-linkage to investigate and explore potential environmental risk factors contributing to the increasing incidence of PIBD as well as the consequences of PIBD.

This is a retrospective study of routinely held administrative health care data and patients are not being asked to participate in any way. Identifiable data within NHS Lothian is required for phase 1 validation stage of the study to demonstrate the accuracy of ICD coding within our population. Phase 2 data-linkage and all data-analysis will be carried out using de-identified data.

1617-0100 Dr Holly Ennis

Allocation of resource in end-of-life care: health care use and cost trajectories of people in the last year of life

Every year more than half a million people die in the UK and the number of deaths per year is growing. The care we receive towards the end-of-life (EoL) can be very good, but sometimes it is neither the care we need nor the care we would choose. EoL is complex, expensive and will become difficult to finance in the NHS. The majority of deaths occur in hospitals where patients often undergo intensive treatments without any tangible benefits in terms of survival or quality of life. In addition, EoL care needs can be very different in different patient groups. These differences can be explained by clinical factors such as the type of disease but are also impacted by patient preferences.

This project aims to describe health care resource use and costs of patients who are in the last year of life. Its main objective is to inform a more efficient allocation of available resources in the provision of EoL care that meets patients' needs.

We will use linked patient-level datasets from Scotland (in parallel with colleagues at Imperial College London accessing similar datasets from England) to assess the trajectories of health and social care services use and costs in the last year of life by examining:

- Health care resource use and health care costs in the last 12 months of life
- Emergency hospitalisations
- Avoidable hospital admissions
- Use of palliative care
- Intensity of care
- Appropriateness of care

This evidence will inform a microsimulation model aimed at assessing the potential for allocative efficiency in the last year of life across the two countries. Finally, qualitative work will be conducted to assess potential barriers at the patient and system level for a more efficient use of resources in this area.

1617-0142 Dr Kevin Pollock
Scottish Penile Cancer Epidemiology: SPICE

The incidence of penile cancer has increased over the last three-decades in Scotland [1], such that it now has one of the highest global rates [2]. The increase in penile cancer may be linked to an increase in “high risk” human papillomavirus HPV infection (HR-HPV) although there is as yet no robust evidence for this [3]. We aim to deliver a comprehensive, longitudinal assessment of Scottish penile cancer to address this significant public health issue. Characterisation of risk factors in penile cancer will inform strategies for prevention and management of this cancer - including vaccination of boys - which will have international implications. Having a greater understanding of the impact of HPV on the aetiology of disease will provide preliminary but crucial insight as to whether HPV annotation of penile cancer may inform disease management strategies.

1. Information Service Division, Scotland. Cancer incidence and mortality in Scotland: 2002-2011. http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/ (Accessed on 4th March 2015).
2. World Cancer Report 2008. http://www.iarc.fr/en/publications/pdfs-online/wcr/2008/index.php(Accessed on 4th November 2014).
3. 3. Hernandez BY, et al. Burden of invasive squamous cell carcinoma of the penis in the United States, 1998-2003. Cancer 2008; 113:2883-91.

1617-0152 Dr Anna Pearce
Improving life chances & reducing child health inequalities: harnessing the potential of existing data

Children growing up in less socially advantaged families live shorter and less healthy lives than their more-advantaged peers. Parents are more likely to experience barriers to achieving healthy lifestyles for them and their children (e.g. breastfeeding, smoking, immunisation). These health inequalities (HIs) are particularly high in Scotland. They persist into adulthood, fuel inequalities in life chances (e.g. education, employment), are passed from one generation to the next, and have grave societal and economic consequences.

The early years are a crucial time to intervene to prevent HIs, because impacts may be life long and a range of intervention entry points already exist (ante-natal classes, health visiting, children’s centres, schools). However, despite concerted efforts by researchers and policymakers for several decades, child HIs have persisted, and in some cases widened. This is because there remains a lack of understanding around why children from less advantaged backgrounds have poorer health, and what policies and interventions should seek to change in order to alleviate these health differences. A number of practical questions remain unanswered, including how interventions should be rolled out to the population - should they be offered to all families (which will minimise stigma, but potentially lead to greater uptake and benefit in more advantaged groups), or only to those thought to be at greater risk? If the latter, then can we use information already collected on families to better identify who is most likely to benefit from additional support?

Administrative records, when confidentially linked, hold the scale and breadth of information required to further our understanding of HIs for all children (and not just those included in health surveys, which inevitably under-represent the least advantaged and healthy), at the individual-level

(since two-thirds of low income individuals do not live in deprived areas), and throughout early childhood (including before birth). This potential has yet been fully realised.

We will use linked administrative data to investigate several important early life health outcomes (physical and socio-emotional development; mental health; thinness/overweight/obesity, unintentional injuries), and three parental health-related behaviours crucial to child health (smoking in pregnancy/early years, breastfeeding, timing of immunisation). Health inequalities will be estimated using a range of socio-economic measures, including the non-health related domains of the Scottish Index of Multiple Deprivation (SIMD) and individual-level characteristics (e.g. parental occupation status, maternal age at first live birth, lone parenthood). We will consider the extent to which health inequalities change when area and individual-level measures of socio-economic circumstances are used. We will use mediation analysis to understand the pathways through which child health inequalities develop, including via the parental health behaviours previously mentioned. Additionally, we will examine a common but under-researched and potentially amenable factor which is likely to lie on the pathway between socio-economic circumstances and child health / parental health behaviours: poor maternal mental health.

This work will be carried out by a multidisciplinary team, which collectively possesses expertise in public health, child health, health inequalities, analysis of linked data, statistics and advanced epidemiological analysis.

1617-0224 Dr Pia Hardelid
Long-term health outcomes following childhood hospital admissions

Our research team focusses on the provision of health services for children, health outcomes for children with chronic conditions, the impact of respiratory infections on use of secondary care services, and the health of vulnerable children and adolescents. We currently hold an extract of NRS birth records linked to SMR11, Scottish birth records, SMR02, ACaDMe, Scottish Immunisation Recall Service (SIRS) and laboratory surveillance data. We have used these data for research into risk factors for hospital admissions and mortality in relation to respiratory infection (influenza and respiratory syncytial virus),[1-3] and to investigate markers of adversity and distress (self-harm, drug/alcohol and violent injuries)[4] This work has been funded by the National Institute for Health Research (NIHR, through a postdoctoral fellowship to PH) and the Department of Health through the Children's Policy Research Unit (https://www.ucl.ac.uk/cpru). CPRU was funded in order to provide evidence for policy and practice for the heath of children, young people and families. We also use similar datasets in England, and have carried out international comparative projects of childhood mortality and trends in childhood hospital admissions in England, Scotland and Canada and Australia[4,5].

We are now planning to extend these analyses to incorporate linkage to mothers' longitudinal health records and community dispensing data. We have already developed a birth cohort in England where we have linked mothers' and babies' longitudinal hospital records,[6] and we hope to extend these analyses to also include Scotland to examine the effect of differences in health policy in the two countries on the health of mothers and children. Health of mothers and children is closely linked, and government policy supports 'whole family' or 'think family' approaches. We aim to generate evidence that can help services understand associations between mother and child health care needs.

We plan to carry out three projects for which we are seeking permissions to use NSS data. Because of this, we plan a tiered access strategy for accessing the data on our Data Safe Haven. Only the

applicant (PH) and named a named data manager (LW) will have access to all of the data. When a researcher within the research team led by Dr Hardelid and Professor Gilbert needs access to data for their project, the data manager will extract the data they need for the project. This prevents researchers from accessing data that is not relevant for their research. In addition, although we will ask eDRIS to provide us with a study ID number which will allow us to identify individual children and their mothers, these will also only be available to the data manager. When an extract is requested for each of the projects below, the data manager will generate a study specific ID for each child and mother, to ensure that data cannot be linked between the three substudies. Please note that we will only use the data for the three projects provided. Apart from the data manager, only the three researchers named in the application will have access to the data, and they will only have access to data relevant for their project. We are not going to release data to anyone outside of the project team, and not to anyone outside of UCL. We outline below how we will let PBPP know of any changes to the project team or possible amendments to the project.

The three projects are summarised below.

Vulnerable children and families (lead researcher: RB):
We will investigate long-term outcomes (death, hospital admission, pregnancy) in relation to multiple adversity, as indicated by hospital attendance with injuries relating to drug and alcohol use, maltreatment or assault, and self-harm (collectively termed "adversity-related injury") in adolescents (aged under 25 years) and their families..

Our previous work in England showed that 4% of all 10 to 19 years old are admitted to hospital with an adversity-related injury. These adolescents are more frequently re-admitted to hospital and are more likely to die within 10 years than adolescents admitted with an accidental injury[7,8]

We are also examining family trajectories in relation to multiple indicators of adversity by considering parent and child outcomes together. In England, we identified a tenfold higher rate of death for women who used opioids during pregnancy (indicated by symptoms of drug withdrawal in the new-born) compared to mothers in the general population. These women also had larger family sizes and became mothers at an earlier age than mothers in the general population (paper in preparation).

We will now investigate whether similar patterns are found in Scotland and examine how these risks change in relation to age and time, geographic area and underlying health status, such as mental health.

Influence of birth and infant risk factors on respiratory health in later childhood (lead researcher KL):
Our second proposed research programme, building on our previous work to quantify the burden or respiratory infections in childhood, we will examine the association between risk factors at birth or during infancy, including severe respiratory infections, and respiratory health in later childhood. We will examine the extent to which interventions to improve maternal health during pregnancy and early infancy can improve long-term outcomes in children, and reduce socio-economic disparities in childhood health.

As a first step we will focus on examining the association between early life risk factors and the development of asthma. Asthma is the most common chronic illness among children in the UK; however the precise factors that lead to the development of this disease are not fully known. We will examine various early life factors, such as respiratory infections, prematurity, delivery method, and how these relate to the development of asthma. Examination of these risk factors for asthma is

particularly important amongst children who are known to be socially disadvantaged, and are placed at a greater risk for respiratory illness and other chronic conditions.

Socio-economic variation in health outcomes for children with chronic conditions, their mothers and siblings (lead researcher: PH)

Advances in neonatal care and healthcare for children with chronic conditions means that around 13-27% of children are currently living with a long-term condition or disability.[9] We have previously shown, using data from England, that children with chronic conditions are more likely to experience emergency hospital readmissions than previously healthy children,[10,11] and increasing rates of emergency hospital admissions among young people transitioning to adult care.10 We are now proposing to develop cohorts of children with specific chronic conditions and examine more detailed risk factors for emergency hospital admissions and mortality among these children, including maternal age, deprivation, and comorbidities. Initially, we will develop cohorts of children with the following chronic conditions: children born extremely prematurely (<28 weeks' gestation); epilepsy or cancer. We will also examine use of primary health care services, including vaccination and common drug dispensing (such as for antibiotics) among these children.

The main care burden for a child with chronic conditions or learning disabilities falls on the child's family. Caring for a child with chronic conditions, particularly complex conditions and learning disabilities, can be challenging and a major source of stress leading to health problems for parents and siblings.[12-14] We will therefore also examine rates of emergency hospital use, and use of prescription drugs (including antidepressants) among mothers and siblings of children with chronic conditions.

Potential changes to study team/projects within the programme

If further researchers in the Professor Gilbert's or Dr Hardelid's team request to access data for any of the three projects listed below, their requests will need to be sent in writing (email) to the PI and the data manager for initial review. If access is deemed relevant to any of the three projects, a PBPP amendment request form will be sent to the PBPP for consideration by the panel. The researcher to be added will need to complete appropriate information governance training; documentation will be forwarded to PBPP. Similarly, if a research objective related to any of these three projects is to be added, the same procedure will be followed. In either case, we will also submit an amended PBPP application form with changes clearly highlighted. As a result of our research, further research projects for which these data would be suitable may arise. In this case, we would liaise with the eDRIS team and take their advice regarding whether an amendment form or new application would be appropriate.

References

1. Hardelid P, Verfuerden M, McMenamin J, et al. Risk factors for admission to hospital with laboratory-confirmed influenza in young children: birth cohort study. European Respiratory Journal 2017; 50.
2. Hardelid PV, M.; McMenamin, J.; Gilbert, R.;. The contribution of child, family and health service factors to respiratory syncytial virus-associated hospital admissions in the first three years of life: birth cohort study (under review in Pediatric Infectious Disease Journal). 2018.
3. Verfuerden MS, NJ; Gilbert, R; Hardelid, P;. Avoidable mortality from respiratory tract infection and sudden unexplained death in children with chronic conditions: a data linkage study (under review in Archives of Disease in Childhood). 2018.
4. Herbert A, Gonzalez-Izquierdo A, McGhee J, et al. Time-trends in rates of hospital admission of adolescents for violent, self-inflicted or drug/alcohol-related injury in England and Scotland, 2005-11: population-based analysis. J Public Health (Oxf) 2017; 39: 65-73.

5. Gonzalez-Izquierdo A, Cortina-Borja M, Woodman J, et al. Maltreatment or violence-related injury in children and adolescents admitted to the NHS: comparison of trends in England and Scotland between 2005 and 2011. BMJ Open 2014; 4: e004474.
6. Harron K, Gilbert R, Cromwell D, et al. Linking Data for Mothers and Babies in De-Identified Electronic Health Data. PLoS One 2016; 11: e0164667.
7. Herbert A, Gilbert R, Cottrell D, et al. Causes of death up to 10 years after admissions to hospitals for self-inflicted, drug-related or alcohol-related, or violent injury during adolescence: a retrospective, nationwide, cohort study. Lancet 2017; 390: 577-87.
8. Herbert A, Gilbert R, Gonzalez-Izquierdo A, et al. 10-y Risks of Death and Emergency Re-admission in Adolescents Hospitalised with Violent, Drug- or Alcohol-Related, or Self-Inflicted Injury: A Population-Based Cohort Study. PLoS Med 2015; 12: e1001931.
9. Wijlaars LP, Gilbert R, Hardelid P. Chronic conditions in children and young people: learning from administrative data. Arch Dis Child 2016; 101: 881-5.
10. Wijlaars LH, P; Guttmann, A; Gilbert, R; . Emergency admissions and long-term conditions during transition from paediatric to adult care: a cross-sectional study using Hospital Episode Statistics data. Under review in BMJ Open. 2018.
11. Wijlaars LP, Hardelid P, Woodman J, et al. Who comes back with what: a retrospective database study on reasons for emergency readmission to hospital in children and young people in England. Arch Dis Child 2016; 101: 714-8.
12. Brekke I, Früh EA, Kvarme LG, et al. Long-time sickness absence among parents of pre-school children with cerebral palsy, spina bifida and down syndrome: a longitudinal study. BMC Pediatrics 2017; 17: 26.
13. Raina P, O'Donnell M, Rosenbaum P, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics 2005; 115: e626-36.
14. Edelstein H, Schippke J, Sheffe S, et al. Children with medical complexity: a scoping review of interventions to support caregiver stress. Child Care Health Dev 2017; 43: 323-33.

1617-0226 Professor Laura Goldstein CODES

The COgnitive behavioural therapy for Dissociative non-Epileptic Seizures (CODES) study is a large multi-site study examining the treatment for a condition called Dissociative Seizures. They resemble epilepsy in nature, but are not caused by the same mechanisms. This study is the first in the world to examine this condition and to seek an evidence base for treatment and for health care costs to the NHS of the condition. People who suffer from dissociative seizures tend to have costly and inappropriate medical use, especially before a diagnosis is made. There are a few estimates of the costs to those who are diagnosed, and to the health care systems but no extensive research has been undertaken. It has been suggested that it takes nearly 5 years to diagnose and in Ireland, the average annual cost for undiagnosed DS was €5429.30.

Participants in the CODES study were randomised to either standard medical care with a neuropsychiatrist or this plus additional Cognitive Behavioural Therapy. They consented to provide data about their health use in the six months prior to baseline and in the six months before their final follow-up point to allow for their health care use and lost work time to be costed. The centralised data requested will provide further evidence of this use across health care services. This will ultimately be beneficial to the patients and public by creating an evidence base of the cost to services when the condition remains undiagnosed and the cost following treatment.

1617-0228 Nadine Dougall
CHildhood Adversities and their impact on Suicidality (CHASe)

Deaths by suicide among young people are too common and have devastating consequences for everyone involved. In 2015 the leading cause of death in the UK for both genders aged 10-34 was suicide, with more than 3,500 people taking their own life. In Scotland those dying aged 10-34 between 2015 and 2016, rose from 163 to 194. The biggest threat to young men's lives are themselves.

Despite the seriousness of this problem we have no definitively effective interventions, and still fewer that are easily implementable. At the core of this problem is difficulty in knowing who to deliver interventions to. Known risk factors for suicidal behaviour are mental health problems and self-harm, and there is now widely-accepted evidence that adverse childhood events (ACEs) are a frequent precursor to many mental health problems and suicidal behaviour.

In Scotland there has not been a study quantifying the types of ACEs, and the pattern of ACEs that are recorded in hospital records. Summarising hospital records for ACEs such as abuse and neglect, provides an opportunity to understand what number and combination of recorded ACEs that are mostly likely to lead to mental health problems and suicidal behaviour. Having this understanding will help identify those in contact with services who will be most at risk later on in life, and offers opportunities to intervene and target trauma-informed care earlier on.

We propose to use anonymised hospital records to find this out, by comparing lifetime hospital records for people who died by suicide with a control group of people who are alive. Throughout this project we will be advised by people with lived experience of ACEs.

1617-0253 Graham Kirkwood
Patient choice and equality of access in Scotland: an analysis of NHS funded treatments in the NHS and private sector

In February 2003 'Partnership for Care – Scotland's Health White Paper' invoked spare capacity in the private sector as a means of treating NHS patients whose waiting times exceeded the national guaranteed limits. No evidence was given in support of the policy of giving patients a choice of provider. Choice took the form of a patient's own NHS board, another territorial NHS Boards, the NHS Golden Jubilee National Hospital (GJNH) or the private sector with the intention that this would 'complement and not detract from NHS Boards' corporate responsibility to develop sustainable local solutions to long waits'.

Using data on elective hip arthroplasty we found evidence that the use of the private sector to provide NHS funded treatment in the form of elective hip arthroplasty disadvantaged older patients and patients from the most socio-economically deprived areas of Scotland; use of the Golden Jubilee Hospital also may have disadvantaged older patients.

We propose to extend this research by examining the effect different provider types (NHS boards [home and other], national NHS resources [such as the Golden Jubilee] and private providers) have on inequalities in access by age, gender and deprivation across a range of high volume elective procedures across medicine and surgery. Analysis by the different types of private providers will be carried out and comorbidity included as a potential confounder.

This analysis will provide opportunities to make comparisons with the experience of NHS patients in England where similar work to this is being conducted in which the researchers in this application are collaborators.

Findings from the study will be published in a peer reviewed journal and provide evidence on inequalities in access to help inform politicians, policy makers and commissioners of NHS care to help reduce inequities in access to effective treatments.

1617-0302 Professor David Conway
Dental Health of Children with Additional Support Needs in Scotland

The dental health of children with additional support needs in Scotland is unknown. We will link NHS Scotland dental-records with School pupil-records to investigate differences in dental health and access to dental services between children with additional support needs and the general child population. We will explore whether differences relate to pre-existing other conditions or medications

1617-0359 Dr Alice Jackson
The epidemiology of peripartum cardiomyopathy in a Western European country: An analysis of the Scottish population from 1986-2017

Peripartum cardiomyopathy (PPCM) is a pregnancy-related heart condition in which the heart's ability to pump blood is reduced (heart failure). The number of women affected by PPCM in the UK is unknown. While some women make a full recovery, in others heart function worsens and may lead to the need for a heart transplant, or even death. Women who develop PPCM are at risk of other life-threatening complications, such as development of blood clots, heart attacks or strokes. The cause of PPCM is poorly understood and no specific treatments are available. A difficulty for doctors and patients is the lack of information to guide decisions. Many PPCM studies are small and only from certain parts of the world. To improve the care of women with PPCM and their children, we must first understand the condition better.

We have identified four important research questions:

1. What is the pattern of PPCM in the UK?
2. What are the long-term outcomes (after 5 years) for women with PPCM?
3. What happens to women who have a further pregnancy?
4. What happens to babies of women with PPCM? (Although we will briefly describe infant outcomes in this study, this will be the focus of a second part of our study for which a separate, future application will be submitted.)

Using the unique resource available in Scotland – the Information Services Division of the NHS – we will collect data on all women in Scotland with PPCM from 1986 onwards, which will allow us to answer these questions.

1617-0371 Professor Marion Bennie
Cancer Medicines Outcomes Programme (CMOP)

It is important to monitor the benefits and adverse effects of cancer medicines in real life to enable patients and clinicians to make more informed decisions about their treatment plan.

This study is part of a larger project – the Cancer Medicines Outcomes Programme (CMOP), as described in section 3.1.07 and PAPER 14 – aimed at exploring the availability of electronic health records (EHR), and how they can be used to monitor medicines used in cancer patients; one of the main objectives of this project is to compare the quality and scope of the information in EHR with that collected by cancer specialist teams manually for a series of cancers. This study provides the opportunity to improve the quality of data routinely captured to understand the benefits and side effects of cancer treatment in Scotland.

A pilot project, focusing on patients with melanoma within NHS Greater Glasgow & Clyde (PAPER 15), is already under way; the study presented here will expand this pilot to melanoma patients throughout the West of Scotland (WoS), providing proof of concept and scalability of the methodology.

1617-0380 Dr Elizabeth Richardson
Regeneration, health, and health inequalities: a longitudinal data linkage study

The proposed research aims to provide policy-relevant evidence of the impact of urban regeneration projects on health and health inequalities. 'Regeneration' is a term often used to describe place-based activities designed to reverse the impacts of economic, social and physical 'degeneration'. Regeneration activities target aspects of communities' physical and socioeconomic environments that are important determinants of health and health inequalities. These include housing, transport, employment, public services, and the social and physical fabric of communities.

As a result, regeneration activities could be potentially important ways to improve health and reduce health inequalities. Indeed, their potential for health benefits has been used to justify large-scale public investment in such activities. However, evidence about whether regeneration activities can improve health and reduce health inequalities is currently weak. Reviews of relevant literature have found some evidence of health benefits, but also evidence that regeneration can sometimes be detrimental for health.

To strengthen the evidence base, studies into the health impacts of regeneration must address flaws that affect much of the existing work. These include lack of follow up over time, small sample sizes, low response rates, drop-out of sample members, and inadequate comparison populations. In particular, selective migration of people of lower socioeconomic status from regeneration areas, and of those of higher socioeconomic status into the areas (also known as 'gentrification'), must be assessed.

Our proposed study aims to evaluate the impacts of the Clyde Gateway urban regeneration scheme (which began in 2008) on health, health inequalities and population composition. The health outcomes of interest are all-cause and cause-specific deaths and hospital admissions. By using routinely-collected health and demographic data for the entire populations of the regeneration and comparison areas, rather than relying on survey data, we will reduce recruitment and follow-up biases. Anonymised address data will allow us to assess selective migration, routine data sources will allow longitudinal follow-up, and improved methods of selecting comparison populations will be

used. Hence we aim to contribute to and strengthen the evidence base, by addressing many of the flaws that affected previous work.

1718-0001 Prof Adrian Stanley
Scottish audit on upper gastrointestinal bleeding

Bleeding from the upper gastrointestinal tract (UGIB) remains a common cause of admission to hospital in the UK, with the incidence in Scotland one of the highest in the world. There appears to have been a gradual reduction in death rates from this condition over the past few decades in the UK and other countries, although there is some evidence of a "weekend effect" from Scottish and other international studies, with worse outcome if patients are admitted at weekends.

However, over the past 10 years there have been several interventions which may have improved management and outcome of patients with UGIB in Scotland. These include a UK audit of this condition (2007) with subsequent major publications and recommendations, a SIGN guideline on UGIB (2008), a Healthcare Improvement Scotland UGIB improvement project (2010-11), a British Society of Gastroenterology "UGIB toolkit" for units to improve services (2011), a NICE guideline on UGIB (2012) and various published international guidelines.

Due to the rising incidence of patients with cirrhosis due to alcohol, hepatitis C and non-alcoholic liver disease in the UK, there is some evidence that the number of patients with serious variceal bleeding (high pressure blood vessels in the upper gastrointestinal tract due to liver cirrhosis) is increasing. In addition, a strong relationship between the incidence of UGIB and deprivation has been reported, especially for variceal bleeding, with studies unclear as to whether deprivation is related to outcomes after UGIB.

Aims
We aim to investigate any change in the numbers of patients admitted to Scottish hospitals with UGIB between 2000-2015 and clarify if there is any evidence of higher death rates or other evidence of worse outcome if patients are admitted at weekends.

We will also investigate whether there is a geographical variation across Scotland regarding the frequency of presentation with this condition and outcomes. We will also assess whether there has been any change in frequency of presentation of patients with variceal bleeding in Scotland over this time period and also assess any relationship between deprivation, presentation and outcomes of patients with UGIB

Methods
We will identify patients presenting to Scottish hospitals with UGIB during the study time period from existing Scottish data which is collected routinely. Using this (anonymised) data we can assess any other known underlying significant health problems, how many patients were readmitted of died from this condition, the relationship between day or presentation with this condition (weekday versus weekend), deprivation and any change in the number of patients presenting each year with bleeding from varices. We will also assess any change in overall numbers presenting with UGIB and death rates across Scotland during this 15 year time period.

Data extract
The extract is to include everyone admitted with or dying from the relevant disease code over the study period, irrespective of whether they have previously been admitted with this code. Therefore, some patients may be included more than once in the extract. They should be identifiable from a

unique study code. The SMR01/death events should be linked retrospectively (5yrs) to previous SMR01 records to provide Charlson scores and prospectively (30 days from admission date) to provide readmission/death within 30 days of admission.

1718-0026 Dr Holly Ennis
Creating a UK Colorectal Cancer Intelligence Hub (CORECT-R)

Colorectal cancer (CRC) is a major public health problem. Every year in the UK around 41,000 people are diagnosed with the disease and 16,000 die from it. Overall, survival rates are poor. It is estimated that detecting and managing the illness costs the NHS in excess of £1.1 billion annually. Despite this outlay, there remain major variations in diagnosis, treatment and outcomes. The research community, in parallel, invests significant resource and effort into understanding the cause of the disease and developing more effective methods of detecting and managing it. At present, there are many different datasets covering all aspects of care but access for researchers to link and exploit these data are limited.

The overall aim of the CORECT-R project is to quantify the characteristics of, and any variation in, colorectal cancer and its management. The purpose is to identify the opportunities to impact on care to improve outcomes across the UK and provide evidence to guide interventions that will minimise inequalities and improve survival.

The programme consists of four overlapping workstreams. Workstream 1 will establish a Programme Advisory Group. They will provide direction and oversight to the programme as a whole. Workstream 2 will deliver CORECT-R by creating a single colorectal research data system enable analysis all data collected across all four UK nations relating to colorectal cancer. Workstream 3 will focus on development, evaluation and application of the optimal methods to exploit the data collected and Workstream 4 will undertake or promote exemplar projects illustrating what the data will enable.

Building a colorectal cancer intelligence hub to ensure the data are used to their full potential, that capacity is built in this area and that outputs are used to maximum effect to drive up standards of care and ultimately improve outcomes from this common disease.

The objective of this initial application ("CORECT-R Stage I Scotland") will be as part of workstream 3, but first defining the quality and availability of data from the point of colorectal cancer diagnosis and the ability to measure patient pathways, outcomes and healthcare costs at an individual patient level.

1718-0075 Dr Laura Forsyth
Duration of Dual Anti-Platelet Therapy in Acute Coronary Syndrome in Scotland (The DUAL-ACS2 Trial)

We hope this study will show the best way of treating patients after a heart attack.

Coronary heart disease causes the most deaths worldwide and happens when small fatty lumps (plaques) build up, narrowing the blood vessels supplying the heart. If the plaques become disrupted a small blood clot can form reducing the flow of blood and oxygen to part of the heart muscle - and this sometimes leads to a heart attack or chest pains (acute coronary syndrome).

The standard treatment after an acute coronary syndrome is to give two blood thinning drugs. This dual anti-platelet therapy helps the fatty lumps heal in order to stop the heart attacks happening again but thinning the blood can also raise the risk of bleeding. Several trials have shown that taking dual anti-platelet therapy does help stop heart attacks, but it's not clear how long dual anti-platelet therapy should last to maximise this benefit but minimise the risk of serious bleeding. Recent evidence suggests that giving dual anti-platelet therapy for a shorter time is better because the risk of serious bleeding, or even death, is higher the longer it is given.

1718-0113 Professor Anne Ellaway
SR72 - West of Scotland Twenty-07 Study: Health in the Community

We are requesting the continuation of notification of deaths of our Twenty-07 study members.

The Twenty-07 Study was set up in 1986 in order to investigate the reasons for differences in health by socio-economic circumstances, gender, area of residence, age, ethnic group, and family type.

4510 people were followed for 20 years. The initial wave of data collection took place in 1987/8, when respondents were aged 15, 35 and 55. The final wave of data collection took place in 2007/08 when respondents were aged 35, 55 and 75.

The Twenty-07 Study provides us with unique opportunities to investigate both the changes in people's lives over 20 years and how they affect their health, and the differences in people's experiences at the same ages 20 years apart, and how these have different effects on their health.

The data we receive on the deaths of our study members are used to explore the health and social factors associated with age and cause of death.

The cohort is based in the West of Scotland and the information has been used by researchers investigating social factors and health and life-course epidemiology. The continued collection of deaths data would enhance the research value of the dataset.

1718-0133 Dr Beverly P Bergman
Trends in Scottish Veterans' Health

Trends in Scottish Veterans' Health will follow on from the Scottish Veterans Health Study and will, similarly, compare the health of military veterans in Scotland with a matched group of people with no record of service, in order to examine the long-term health outcomes in veterans in comparison with people who have never served, and whether trends observed in the first study have changed. The study will use demographic data from the NHSCR database which is probability matched to CHI data and linked to Scottish Morbidity Record (SMR) and death certificate data to provide information on long-term health outcomes. The data will be pseudo-anonymised to protect privacy, and the results will be presented in statistical format (predominantly hazard ratios and graphically). The original study has been in progress since 2012, initially as a PhD study (thesis available at http://theses.gla.ac.uk/7144), and it is proposed to obtain a new download of both demographic and SMR data to the end of 2017, in order to capture emerging health issues in both the ageing older veteran population and new young veterans, many of the latter having experienced recent combat, and to observe health trends following the implementation of a number of initiatives aimed

at protecting these potentially high-risk groups through the Armed Forces Covenant and the Defence Health Promotion Strategy.

1718-0134 Viktoria McMillan
National Asthma and COPD Audit Programme (NACAP)

The RCP is commissioned to deliver the National Asthma and COPD Audit Programme (NACAP). This programme, which launched in March 2018, is funded by HQIP.

NACAP is a continuation of the National COPD Audit Programme. This three year 'extension' involves the addition of audits of adult and paediatric asthma to form a combined airways audit, which will also be delivered in Scotland.

This proposal requests permissions for NACAP to deliver the following audits of secondary care in Scotland:

a. COPD
This audit collects data on the care of people admitted to hospital with COPD exacerbation, and has been running continuously in England and Wales since February 2017.

Patient Identifiable Data (PID) is collected to enable linkage to external sources for outcome data. The collection of these data in England and Wales is covered by Section 251 (reference: CAG 8-06 (b) 2013).

The audit will be launched in Scotland in November 2018. We request permission to collect PID without explicit patient consent. We would use this to link our data to the 'Inpatient and Day Case Activity' dataset (for case ascertainment purposes and readmission rates) and mortality data.

b. Asthma
A continuous audit of adults admitted to hospital with asthma exacerbations will be launched in all nations in November 2018. An equivalent paediatric audit will be launched in June 2019.

As per the COPD audit, these audits will collect PID to enable linkage to external sources for information regarding medium and long-term clinical outcomes for patients in the audit cohort.

1718-0151 Alexandra Hellyer
OASI Care Bundle Quality Improvement Project

It is common for the perineum to tear to some extent during childbirth. Up to 9 in every 10 women will experience some sort of tear or graze.

First and second degree tears are the most common and are very unlikely to cause long term problems. These may or may not require stitches. For some women the tear may be deeper. Third or fourth degree tears, also called obstetric anal sphincter injuries (OASI) occur in up to 6% of births for first time mothers and in 5% of subsequent births. These extend to the muscle that controls the anus (the anal sphincter) and will require stitches.

For many women there is no clear reason for experiencing a third or fourth degree tear and it is not possible to predict. However, there are some things which make them more likely, for example if it is their first vaginal birth or if they have an assisted birth (amongst others).

Most women who have a third or fourth degree tear heal completely. However, some women find they are not able to control their bowels or the passing of wind. Some women who have a third or fourth degree tear may be concerned about having sex and may also be apprehensive about giving birth again.

This project aims to standardise the care that women receive during vaginal births in 16 hospitals and ensure that clinicians are using consistent and best evidenced care. The project involves a training programme as well as providing more information to women and clinicians about tears. These actions are incorporated into the OASI Care Bundle and has been developed by an expert team of midwives and doctors.

The care bundle will not affect the choices that women make about their babies' birth and they can still give birth in the position that they find most comfortable.

We will evaluate the OASI Care Bundle to provide evidence on how effective it is by analysing clinical data which is already routinely collected by hospitals. For those units we are working with in England and Wales, this data will be collected from their Maternity Information Systems and approval has been sought from their Caldicott Guardians. For St John's Hospital, NHS Lothian, we have sought Caldicott Guardian approval locally and will receive their data from their electronic data system directly (see supporting document (DPA between RCOG and NHS Lothian). The second unit we are working with in Scotland, Queen Elizabeth University Hospital, has not had an electronic data system over the full project period and therefore we are requesting this data via SMR-02 and SBR (see supporting document Caldicott Approval – NHS GGC). We will assess changes in OASI rates over the project period (1st October 2016-31st March 2018) in line with other risk variables for OASI. We will also look at changes to other clinical indicators over this period.

The rates OASI in each of the hospitals we are working with will be continually monitored. Midwives and doctors will be asked to provide their views on the Care Bundle and some women will be asked to talk about their birth experiences in these hospitals through focus groups and interviews. This data will not be linked directly to the quantitative data and will be used as an evaluation of the implementation of the care bundle.

1718-0152 Dr Richard Haylock
National Registry for Radiation Workers epidemiological cohort study

The National Registry for Radiation Workers (NRRW) is a long term follow up cohort study. Its goal is to examine the health effects of occupational exposure to radiation in workers in the UK and thereby provide high quality direct evidence to help protect radiation workers and the public from harm through excessive radiation exposure. The cohort now exceeds 300,000 individuals first employed from the 1950's to the present day.

More specifically the study aims to identify if relationships exist between the frequency of diseases in the workers and the amount of radiation they were exposed to during their employment with participating employers.

The information on workers and their external radiation exposure is provided by participating employers or the approved dosimetry service that they use while information on deaths and cancer incidences come from NHS Digital for England and Wales and for Scotland from NHS Scotland.

The purpose of this application is to support the continued supply of death and cancer incidence information from NHS Scotland to the study.

Current occupational and environmental exposure limits for ionising radiation are based mainly on scientific evidence arising from the study of the long term health of the populations exposed to the atomic bombings in Japan (Hiroshima and Nagasaki).

Analysis of the health of the NRRW cohort can provide reassurance that the UK protection standards, derived largely from the Japanese cohort studies are transferrable to occupational exposure scenarios (i.e a protracted low-dose occupational exposure compared with a high dose exposure in the bombings) experienced by UK workers and the public.

1718-0156 Dr Michael Lockhart
Electronic Communication of Surveillance in Scotland (ECOSS) – Diagnostic Laboratory Data content and quality review

The ECOSS (Electronic Communication of Surveillance in Scotland) system has been in use by Public Health Intelligence (PHI) and restricted health board users since 2008. Initially the aim was for ECOSS to provide an electronic system for Scottish laboratories to communicate the identification of Notifiable Organisms as required in the Public Health etc. (Scotland) Act 2008. However, since its launch laboratory results captured by ECOSS have expanded in an uncoordinated way across Scotland. Recent quality improvement work led by HPS has confirmed significant variation in data submission which is impacting on the quality and content of the data in ECOSS. It also highlighted a need to standardise these variations and provide consistency in future laboratory data capture.

Furthermore, HPS has a sponsored Public Health Microbiology programme of work whose vision is to deliver high quality, standardised, and timely data for public health purposes from wherever that data may be generated. This will be aligned with the ECDC public health microbiology strategy, which identifies the need to capture data of public health importance from all potential sources, not exclusively laboratories analysing human clinical samples.

Therefore, HPS requests approval for 6 key developments that will greatly improve the quality and content of data captured within ECOSS:

- Expansion of Data currently collected from human diagnostic laboratories to include all positive sample results;
- To seek permission to receive identifiable negative results where these are outputs from a combined analysis where there is at least one positive result and where the negative result cannot be excluded for technical reasons and will not be available for further analysis (see appendix B Example Reports – Report 1)
- To update and reconfirm governance approvals for Negative results currently collected. These are Hepatitis B, Hepatitis C, Influenza A and Blood Culture negative samples. The Public Health Microbiology Team have reviewed justification for holding these negative results at an identifiable level. In all four cases the team has confirmed and are satisfied that the purpose is to inform public health action.
- To seek permission to receive and retain free text clinical comments, which are received as part of the ECOSS report, without the need for modification. (See appendix B

Example reports – Report 2). These comments can include information that relates to the current condition being treated (i.e. strain information). However, comments may also contain details of pre-existing conditions that do not relate to current condition being treated. For example, patients who are diagnosed with TB will have their HIV status checked. This will appear in the clinical comments, stating either their current HIV status or that a HIV test is required. Currently these comments are manually removed however this has become labour and resource intensive due to the volume of data received and is therefore unsustainable. Furthermore clinical comments are used by HPS staff for two particular reasons – one to pull out risk factors and the other is for strengthening validation processes.

- To collect data from other Non-NHS laboratories (i.e. Food Standards Scotland, Scottish Water, Scottish Agricultural College, Scottish Environmental Protection Agency) where possible. This data would apply to food, water and environmental samples but would not relate to a person but may relate to a business or premise.

The data capture of all positive and selected negative human microbiology laboratory data will be simplified and hence ensure consistency in data submissions to ECOSS, improving data quality and potential public benefit from use of the national data resource. The resulting data will enable robust public health surveillance and reporting to be conducted in the future, independent of any changes in the public health environment. This will also benefit planning and policy making by informing key health protection interventions e.g. through improving the knowledge base for vaccine preventable infections; highlighting issues with drug resistant organisms etc. It will ensure that Scotland can expand their current contribution to epidemiological research and the capture of non-human laboratory data will further develop opportunities for epidemic intelligence and early identification of emerging threats to public health identified by non-human microbiology laboratories.

For clarity the purpose of Reference Laboratories is to accurately determine whether a particular organism is present within a sample or a particular resistance genotype or virulence mechanism as well as to provide additional typing data on relatedness of organisms with similar organisms isolated from other patients or sites. Reference laboratories work on samples or organisms previously isolated by partner Scottish diagnostic laboratories. Diagnostic laboratories are front line testing facilities, where all samples are initially submitted by clinicians, and are identified as negative samples; positive samples where Reference laboratory review is not required; Positive samples where reference laboratory review is required.

1718-0181 Hazel Dodds
Collection of Patient Reported Outcome Measures (PROMs) data as part of the Scottish Trauma Audit Group (STAG).

Injuries due to trauma remain a major cause of illness, disability and death in the United Kingdom (UK) and throughout the world. It is the leading cause of death in the 15-44 age group worldwide and a major cause of disability and loss of economic ability.

Within the spectrum of injury, major trauma describes serious and/ or multiple injuries where there is a high likelihood of death or permanent disability. The internationally accepted definition of major trauma is based on the Injury Severity Score (ISS) where an ISS score of greater than 15 defines major trauma. Annually within Scotland, there are approximately 800 adults (age 16 and over) with an injury leading to an ISS score of greater than 15 with a further 2300 with an ISS score of 1-15 who require hospitalisation for more than 72 hours or who die from their injury. The Scottish Trauma Audit Group (STAG) have collected data on adults who have sustained trauma for a number of years.

STAG commenced collection of paediatric data with the launch of their new electronic data collection system (eSTAG) in November 2017.

It is planned at a later stage to include paediatric patients in the PROMs. It is estimated that there are around 50 children per year with an ISS score of greater than 15 and a further 100-150 with an ISS score of 9-15. A revision to this PBPP or a further PBPP application will be made when the plans are in place to include paediatric patients.

1718-0183 Professor Steve Turner
Slowing the flow of zero day admissions to hospital: data linkage to inform priorities for future intervention along paediatric referral pathways

Zero day hospital admissions (i.e. being admitted and discharged on the same day) are becoming more common in children. Some zero day admissions may be safely avoided. We do not know how to 'slow the flow' of zero day admissions. For example we do not know whether doctors in emergency departments, general practice surgeries or out-of-hours facilities are sending children to hospital in equal proportions or whether the majority of zero day admissions come from one of these three 'stream'. Our research will answer the questions (1) "within the 'flow' of zero day admissions are there identifiable 'streams' of zero day admissions which could be slowed?", for example are there lots of zero day admissions with chest infections coming from the out-of-hours service in the evenings? (2) "what are the implications to general practice of slowing the flow of zero day admissions?", for example if we reduced the zero day admission with chest infections referred by the out-of-hours service would this increase GP workload the next day? To answer these questions we will link details of every hospital admission between 2015 and 2017 to other routinely collected NHS data. We will study patterns of admissions. We will identify "cases" (children with a zero day admission) and "controls" (this will be children with GP contacts but not admitted) and compare their GP attendance in the days after the "cases" were admitted. This study will give information which will be essential to developing interventions to safely reduce paediatric hospital admissions.

1718-0197 Dr Holly Ennis
Post-adoption audit of eribulin for metastatic breast cancer

Robust information about real-world clinical outcomes, cost-effectiveness and the budget impact of new medicines is required as a basis of national decisions on the adoption of new drugs. It is also vital to monitor the impact of drugs following uptake, in order to confirm value is as expected, to look for adverse safety signals and to monitor the implications for the NHS service provision and future patients. Scotland has a wealth of administrative datasets that offer a foundation for such data intelligence.

Eribulin is a new cytotoxic chemotherapy drug that was approved by the SMC in 2016 for the palliative treatment of advanced breast cancer in patients who have previously been treated with an anthracycline, a taxane and capecitabine.

Future NHS patients will benefit from more information on how eribulin has affected patients treated to date.

1718-0213 Jill Barton
ASCEND (A Study of Cardiovascular Events iN Diabetes)

Adults with diabetes are at increased risk of heart attacks and strokes. Aspirin use reduces the risk of heart attacks and stroke but also causes bleeding. In people with existing heart or circulatory problems aspirin use leads to clear benefits but, in people with diabetes who have no evident circulation problems, whether aspirin produces overall benefit is not clear. Similarly, omega-3 fatty acids, 'fish oils' are recommended for people with heart problems but it not clear if their use is worthwhile in people with diabetes who do not have heart or circulatory problems.

The ASCEND study is designed to help answer these questions.

15,480 people with diabetes, identified from NHS records, were randomly allocated to take a daily aspirin (100 mg) or matching dummy tablet and also a fish oil capsule (1 g) or matching dummy capsule for at least 7 years. They have been followed up by 6-monthly health questionnaires. Neither the study participants nor the study team are aware of the study treatment allocation (known as 'blinding').

All aspects of the study are coordinated by the Clinical Trial Service Unit (CTSU) at Oxford University, including storing the study data securely. An independent Data Monitoring Committee (DMC) ensures participant safety by regularly reviewing unblinded study data. The study is funded by a grant to the University of Oxford from the British Heart Foundation with study treatment provided by Bayer Pharma AG and Mylan EPD.

1718-0227 Professor Rustam Al-Shahi Salman
REstart or STop Antithrombotics Randomised Trial (RESTART)

RESTART is studying the potentially beneficial effects of starting antiplatelet drugs (one or more of aspirin, clopidogrel or dipyridamole, chosen by the patients physician), on the risks of a heart attack, stroke and other clotting problems as well as their effect on the risk of a brain haemorrhage happening again, for adults surviving a stroke due to bleeding in the brain and who were taking a prescribed antithrombotic (i.e. anticoagulant or antiplatelet) drug for the prevention of illnesses such as angina, heart attack or stroke before their bleed.

An MRI sub-study will also study whether the presence of brain microbleeds modify the effects of antiplatelet drugs.

537 consented participants were recruited from 103 recruiting sites in NHS hospitals throughout the UK and randomly allocated to take an antiplatelet or avoid. All participants are followed up for at least 6 months after randomisation either by postal or telephone questionnaire to check for the occurrence of any relevant events or outcomes and their medications. In addition, participants GPs, and the hospital which recruited them, provide information on any relevant adverse events which occur during the follow up period including hospital admissions and deaths. These events will be compared in those taking an antiplatelet and those avoiding it to compare the event rate.

Recruitment commenced on the 22nd May 2013 and closed at midday on the 31st May 2018 with 537 participants (this application only relates to the ~97 patients from Scotland). Follow-up will be completed for events that occur by the end of November 2018.

This proposal for NHS Scotland data will enable us to more accurately determine the number of outcome events which occur after the date of a patient's randomisation, until the time of this data extract or the last period of data available. We already know that our primary source of ascertainment of these outcome events (annual postal questionnaires to participants' general practitioners) miss some events that participants report to us. Therefore, we seek secondary data to improve the accuracy of our data on the occurrence of the trial's major outcomes, which will improve the scientific validity of the trial's findings. The data required include the dates of admission to NHS hospitals, and the primary diagnosis leading to these admissions; Date and cause of death.

We will supply NSS with patients' identifiers CHI No, and the RESTART study id to facilitate the linkage. We will provide NSS with the participant's date of randomisation to limit the data extraction from this date to the end of the available follow up period. We will not request data on any patient who has withdrawn consent to be followed-up remotely following recruitment. A similar application is being made to NHS Digital for data relating to patients recruited in the remainder of the UK.

1718-0232 Dr Ceri Sellers

Prolong20+ Longitudinal study of pelvic floor dysfunction and relationship to childbirth: Access to current names, addresses and mortality statuses

ProLong20+ is a longitudinal study looking at pelvic floor dysfunction in a group of women who have given birth. Pelvic floor dysfunction can involve urinary incontinence, faecal incontinence, pelvic organ prolapse or sexual dysfunction.

Women who gave birth during 1993-94 at one of three maternity units (Aberdeen or Birmingham in the UK, and Dunedin in New Zealand) were invited to take part in a survey about incontinence. Two further surveys were administered to the women who took part in the original survey, 6 and 12years later. The later surveys included questions about prolapse and sexual dysfunction in addition to incontinence.

The current study involves sending out a postal questionnaire and inviting the women to undertake an optional physical examination.

This application concerns women who gave birth in 1993-94 at the Aberdeen Royal Infirmary maternity unit. The study team already holds address details for these women from previous data collections. However, some of the women may have moved since the last data collection which was 12 years ago. Some women may have changed their names following marriage, divorce etc. In order to maximise the response rate, we would like to ensure that we are posting study invitation letters and questionnaires to the correct names and addresses. We would also like to ensure that we are not causing unnecessary distress to family/friends of cohort members by sending study correspondence to women who have died.

The data obtained would be held until study mailing is complete. The name and postcode would be retained securely for participants who opt into future contact from the study team.

Completed study questionnaires, physical examination results sheets and paper study correspondence will be stored in a locked filing cabinet located in the NMAHP research unit. Completed questionnaires from previous study data collections have been archived by the University of Aberdeen. Electronic data from the current and previous study data collections will be held on a secure network drive at Glasgow Caledonian University.

1718-0240 Dr Daniel Mackay
The association between differential pricing of tobacco products and perinatal and infant health outcomes in the United Kingdom

Increasing the price of tobacco products through raised taxation has been linked to a variety of positive health outcomes including reduced infant mortality. Evidence from the UK suggests that tobacco companies have adopted a strategy to load tax rises onto more expensive tobacco products so that economy brands maintain their relatively cheap prices. This allows tobacco users to trade down to cheaper products which may potentially undermine health benefits that would otherwise accrue through tax increases. The UK government has sought to reduce price differentials in tobacco products as announced in its Budget since 2011, by instituting additional tax increases on economy cigarettes and hand rolled tobacco. However, the associations between these tobacco price differentials and health outcomes are not yet known.

We hypothesise that the observed child health benefits associated with tax increases on tobacco products may have been attenuated by a large price differential within UK tobacco market. Therefore we aim to examine the associations between cigarette price differentials and a range of perinatal and infant health outcomes (preterm birth, low birth weight, perinatal and infant mortality) in the UK between years 2004 and 2017.

This study will require access to a previously supplied and fully anonymised SMR02 dataset (Project: XRB15064) that contains in-hospital birth of babies in Scotland and linked death certificates (as recorded in the Scottish Stillbirth and Infant Death Registrations data). The SMR02 supplies data on maternal smoking during pregnancy which will permit an examination of the extent to which any attenuation in health benefits is due to changes in active smoking among pregnant women. The Office for National Statistic's (ONS) data for England and Wales does not allow us to examine maternal smoking, but it does provide a larger sample size for sub-group analyses. Access to the birth and death registers for England and Wales has been granted by the ONS (Please see S1-ONS project approval letter attached separately).

1718-0241 Professor Martin Scott Dennis
Fluoxetine or Control under supervision for stroke (FOCUS) trial

The FOCUS trial is testing whether a 6 month course of a drug called fluoxetine, started within 15 days of a stroke, leads to better recovery over the following year. Consenting patients with stroke are recruited by one of the 105 participating UK NHS hospitals and randomly allocated to take the fluoxetine or a matching placebo and then followed up by a postal or telephone questionnaire at 6 and 12 months to establish how well they recover. In addition their GPs, and the hospital which recruited them, provide information on adverse events which occur during the follow up period including hospital admissions. The recovery, use of NHS resources including hospital admissions and outpatient attendances, will be compared in those taking fluoxetine and those taking placebo to establish the effect of the fluoxetine. The group coordinating the FOCUS trial are also collaborating with researchers in Australia and Sweden who are carrying out similar trials in their countries (AFFINITY and EFFECTS trials respectively). The FOCUS trial has completed recruitment of 3127 UK patients and will complete follow up in April 2018, but recruitment in the other trials is ongoing. Eventually the results of the three trials will be pooled to provide the most precise estimate of the effect of fluoxetine on stroke patients' recovery. This application for NHS Scotland data will provide data on NHS hospital use and longterm survival for the subgroup of 372 patients recruited in

Scotland. A similar application is being made to NHS Digital for data relating to patients recruited in the remainder of the UK.

1718-0246 Dr Aditya Sharma
Surveillance of Incidence of first time diagnosis of Early Onset Depression in children aged 3-13 years across the United Kingdom and Republic of Ireland

Depression is well recognised in adolescents and has been described widely in the literature. Early onset depression (EOD) defined as onset of depression which occurs in youth before the 13th birthday has been rarely investigated. Though still considered a rare event in childhood there is evidence that those that develop this condition are associated with a more than fourfold increased risk of suicide attempts compared with adult-onset disease. Increased knowledge regarding the number of cases and presentation of these children to the NHS is of importance in helping with recognition of the condition, planning of service provision and developing management approaches for children with this treatable illness. This study will aid in this by identifying all new cases of EOD in the UK and Republic of Ireland presenting to consultant child psychiatrists, allowing a review of the presentation, management and outcome at 1 and 2 years for the child.

1718-0248 Dr Richard McNally
Thyroid Cancer study - Cumbrian Birth Cohort

In October 1957, one of the nuclear reactors at Windscale Works at Sellafield, Cumbria, caught fire. The materials released into the air from the reactor chimney included radioactive iodine ("iodine-131"), which was found in milk from farms near Sellafield after the fire, so this milk had to be thrown away. Radioactive iodine concentrates in the thyroid gland and this can cause thyroid cancer, possibly many years later. Young children are particularly at risk. This study will look at thyroid cancer in people born in Cumbria from 1950 onwards, and will look at areas with different levels of contamination by radioactive iodine. Because thyroid cancer can develop many years after exposure to radioactive iodine, thyroid cancers will be looked for over as long a period as possible, wherever people may be living in Britain. People born in 1950-1958 will have been babies or young children (or in the womb) at the time of the fire, so if radioactive iodine is increasing their risk of thyroid cancer then this should be seen in the most contaminated area near Sellafield when compared to other areas. However, thyroid cancer has other causes, so other influences need to be accounted for. One way of doing this is to look at thyroid cancer in people born in Cumbria after 1958, who will not have been exposed to radioactive iodine from the accident, and this will be done in this study. The study offers the best practicable opportunity to determine whether any extra thyroid cancers can be detected.

1718-0252 Dr Michael Lockhart
Electronic Communication of Surveillance in Scotland (ECOSS) – Reference Laboratory Data content and quality review

The purpose of Reference Laboratories is to accurately determine whether a particular organism is present within a sample or a particular resistance genotype or virulence mechanism as well as to provide additional typing data on relatedness of organisms with similar organisms isolated from

other patients or sites. Reference laboratories work on samples or organisms previously isolated by partner Scottish diagnostic laboratories.

This proposal is linked to the PBPP application 1718-0156 (Electronic Communication of Surveillance in Scotland (ECOSS) – Diagnostic Laboratory Data content and quality review). The most significant difference between the 2 applications is that we seek approval for all reference laboratory results to be submitted and captured by ECOSS, whether positive or negative. This is because the role of a reference laboratory is to support national epidemic intelligence as well as to provide a diagnostic confirmatory service. Related to this is a change in diagnostic laboratory practice in increasingly not transcribing reference laboratory results and therefore unless we ensure that Reference laboratory results are also shared with ECOSS directly, then epidemic intelligence will be lost nationally.

1718-0257 Dr Heather Whalley
Scottish Bipolar Family Study

Bipolar disorder is a highly heritable psychiatric disorder characterized by extreme fluctuations in mood. The Scottish Bipolar Family Study (SBFS, initiated in 2007), is an existing longitudinal study of young (16-25 years) unaffected close relatives of patients with established bipolar disorder (1,2). The original aim of this existing project in 2007 was to recruit these young individuals at familial risk whilst they were unaffected, before any psychiatric illnesses had developed, and follow them over the period where they were most likely to develop a psychiatric disorder. These individuals have been compared to a group of matched controls with no family history of major psychiatric disorder (see 1,2). The ultimate aim was to see if it is possible to predict those who are most likely to develop a future illness from our existing baseline and follow up data, and to examine changes over this critical period in those on the trajectory to a mood disorder.

We now have a substantial amount of research data on these unaffected relatives and control individuals. Study participants have taken part in neuroimaging assessments, and provided detailed psychological, clinical and genetic data as part of the SBFS. Face to face assessments were undertaken at recruitment, along with consent for data linkage, and approximately every 2.5 years subsequently. However, it has not been possible to obtain eventual full clinical outcome details for all the baseline participants. Now that the original study has concluded, 10 years from its initiation, we seek in the current proposal to maximise the clinical outcome data for all study participants by requesting data linkage in order to leverage our existing wealth of research data. Consent for access to health records has been obtained, though we are applying to access and process health data under the legal framework of public benefit.

(1) The neural basis of familial risk and temperamental variation in individuals at high risk of bipolar disorder. Whalley HC, Sussmann JE, Chakirova G, Mukerjee P, Peel A, McKirdy J, Hall J, Johnstone EC, Lawrie SM, McIntosh AM. Biol Psychiatry. 2011 Aug 15;70(4):343-9

(2) White matter integrity in individuals at high genetic risk of bipolar disorder. Sprooten E, Sussmann JE, Clugston A, Peel A, McKirdy J, Moorhead TW, Anderson S, Shand AJ, Giles S, Bastin ME, Hall J, Johnstone EC, Lawrie SM, McIntosh AM. Biol Psychiatry. 2011 Aug 15;70(4):350-6

1718-0263 Dr Catherine Hanna

Assessing the "impact" of clinical trial results: Proposal to assess chemotherapy prescribing practices in Scotland prior to and following the publication of the Short Course Oncology Trial (SCOT).

Background:
Cancer treatment for patients is dependent on evidence from clinical trials. It is important that any trials that are being done are asking "realistic" questions and, if the trial shows that that a new treatment could improve outcomes for patients, that doctors are able to change their practice in a timely manner. The measurement of how and when practice changes following a trial is poorly done, if at all.

The aim of this proposal is to find out if, and how, oncologists in Scotland change the way they prescribe chemotherapy for patients after the results of a recent, large, international trial are published.

Specifically, the focus of the proposal will be on those patients with a cancer of the bowel that has been completely removed by an operation. It will focus on patients who receive chemotherapy after the operation (adjuvantly) with the aim of reducing the risk of cancer returning. Normally, these patients receive 6 months of chemotherapy treatment. The Short Course Oncology Trial (SCOT) has shown that, for most patients, using 3 months has comparable benefits. Changing practice to give 3 months rather than 6 months of chemotherapy may translate to patients having less side-effects (in particular, damage to nerve endings) and spending less time coming to hospital and it may have economic benefits for the nation.

Methods:
Initially, information will be collected on what type and the duration of chemotherapy that was prescribed by oncologists in Scotland between January 2006-April 2018. This information is held in a system called Chemocare. There are 5 different formats of this system across the country, each of which will need to be accessed. The information from this Chemocare system will be linked with routinely collected information from the Cancer Registry of Scotland to investigate if factors such as demographics, rurality, patient's baseline health status and the stage of cancer impacts on chemotherapy prescribing. Analysis will be done on data that has been anonymised.

The second part of the proposal will assess chemotherapy prescribing after the publication of the "SCOT" results. This information will be collected in the same way as the first part of the proposal but this will be done yearly from April 2018 to January 2021 to assess the rate of change over 3 years.

Summary:
It will be useful and reassuring for patients and health professionals to know that it is possible to report which chemotherapy drugs are being prescribed on a Scotland wide basis.

This proposal will provide understanding of the "real life" experiences for patients with bowel cancer. The aim is that this project will improve understanding of how a trial can have maximum "impact", with rapid uptake of results and that it will highlight improvements that could be made to similar trials in the future to improve impact.

1718-0266 Inna Thalmann
Trends and determinants of cardiovascular medication use for the secondary prevention of cardiovascular disease in Scotland

Although there is substantial evidence that cardiovascular medications such as cholesterol- and blood pressure-lowering drugs are clinically efficacious and cost-effective in reducing cardiovascular disease (CVD) risk, their use and compliance remain suboptimal.

However, knowledge regarding the underlying reasons for suboptimal drug use at different treatment stages, as well as variations in the uptake of interventions across socio-economic groups, is limited. This DPhil study aims to be the first comprehensive analysis to look at the complete treatment pathway for the pharmacological secondary prevention of cardiovascular disease in Scotland by examining three different treatment stages: (1) prescribing, (2) initiation of and (3) adherence to cardiovascular medications. In addition the study will investigate the role of both patient- and prescriber-related factors in the underutilisation of cardiovascular medications at each treatment stage.

The study will also examine the links between cardiovascular medication adherence and subsequent cardiovascular events (e.g. CVD death or hospital episode). As such, the research will identify population groups with higher likelihood of non-adherence and thus at higher risk of adverse CVD events that could be targeted for a future trial to improve medication adherence. Given the unique properties of the proposed Scottish datasets, which allow linkage of prescribing by a doctor, encashment by a patient and hospitalisation episodes, the research will generate large-scale data to inform novel effective policies for treatment improvement and could help to motivate a randomised controlled trial that aims to improve medication adherence.

1718-0274 Professor Patrick Doherty
National Audit for Cardiac Rehabilitation

The NACR, funded by BHF and hosted by the University of York, collects comprehensive audit data to support the improvement and monitoring of CR services in terms of their uptake, quality and clinical outcomes. The University of York is the Data Controller verified by NHS Digital. The NACR Team is based at the University of York in the Department of Health Sciences with a remit to support clinical CR teams in auditing their service. Under the guidance of a National Steering Committee which includes Scottish representation we have carried out this role since 2006.

The NACR, working with the BHF and the BACPR, has helped improve the quality of cardiac rehab services in England, Wales and Northern Ireland. This proposal seeks to work with the Cardiac Rehabilitation Interest Group Scotland (CRIGS) to do the same for cardiac rehab services in Scotland.

Cardiac rehab programmes in Scotland will utilise the secure NHS Digital-NACR online platform to input patient and service level data which can then be used by local programmes in Scotland to carry out local audit of their service but also be used by the NACR to help benchmark and quality assure services in Scotland. The act of registration and data entry into the NACR will also help programmes in Scotland meet one of the minimum standards set by the BACPR. Registration is via a User Registration form and sign up to NHS Digital's Single Sign On (SSO – which registers the email as logon name, and asks users to create their own unique password) on the database itself. The User Registration form must be authorised directly by the programme's Caldicott Guardian before access is granted. Users have access to patients (both in terms of NACR records, and 'raw data') that they

have had CR input with, and access patient details with CHI Number / Date of Birth information. All users of the database must have their own unique/personal logon.

1718-0280 Louise Cuthbertson
Scottish Cancer Patient Experience Survey

This application seeks permission for NSS Public Health & Intelligence PHI (ISD) to select a sample for the Scottish Cancer Patient Experience Survey (SCPES) from the national database of hospital discharge returns (SMR01); validate the sample against those who have a confirmed cancer diagnosis on the Scottish Cancer Registry (SMR06); use the CHI database to obtain up-to-date names and addresses for those sampled; and co-ordinate checks against the NHS Central Registry and the CHI database to check whether or not people in the sample are still alive.

The SCPES is commissioned by the Scottish Government (SG) as part of the Scottish Care Experience Survey Programme – a suite of national surveys which aim to provide local and national information on the quality of health and care services from the perspective of those using them. The survey programme supports the three quality ambitions of the 2020 Vision – Safe, Effective and Person-centred – by providing a basis for the measurement of quality as experienced by service users across Scotland. In particular, the surveys support the person-centred quality ambition which is focused on putting people at the centre of care; ensuring that care is responsive to individual personal preferences, needs and values; and assuming that individual values guide all care decisions. More information on the Scottish Care Experience Survey Programme can be found at www.gov.scot/Topics/Statistics/Browse/Health/careexperience.

The SCPES is a vital component of the programme – it will provide high quality and comprehensive information on peoples' experiences of cancer care and will repeat the first SCPES undertaken in 2015. Understanding the experiences of those who have received cancer care is an essential part of providing high quality cancer care – many important aspects of cancer care quality can only be assessed by asking those who have used the services to describe their experiences. Through listening to these experiences, cancer care providers and policy makers can better understand what works well and areas that need improvement.

The survey is run by SG and PHI(ISD) using a long standing partnership approach and is administered by post. In 2015, a response rate of 61% was achieved which indicates positive engagement and a desire of these individuals to provide feedback on their experiences and to contribute to service improvement. The survey is also supported by many third sector organisations – in particular, Macmillan Cancer Support who jointly fund the SCPES with the SG.

The outputs from the survey will be a range of analyses available at different levels of geography, containing robust and comparable information about peoples' experiences of cancer care. This analysis will be provided by PHI(ISD) via an interactive dashboard (using Tableau) which will allow local areas to interrogate the data in different ways to meet their particular needs. This will provide vital evidence locally and nationally to inform service improvement, leading to improved outcomes for patients. Infographic survey interpretations suitable for a lay audience were produced for the 2015 results (Annex Q). Similar infographic survey interpretations will be produced for the SCPES 2018 results.

Macmillan works to support people with cancer. The SCPES results really help them to understand the patient experience and what factors might lead to higher level of satisfaction with care. Macmillan will help to publicise the results more widely; will help to identify areas for improvement,

working alongside their partners within the NHS to make those improvements; and adapt and develop Macmillan support services where appropriate.

Macmillan will also analyse the survey results, to supplement the analysis published by SG/ISD. Undertaking their own analyses of the data, which will be subject to the disclosure controls outlined in Section 5.4.01b, will provide additional benefits and insights. Specifically, further analysis of the SCPES data can assist Macmillan with:

- Service planning and delivery. In particular, in identifying gaps in support, for example financial support, by geographical area and patient demographics.
- Understanding better the experiences that people have at different points of their cancer journey. Central to Macmillan's strategy is to help people affected by cancer at different times of need.
- Raising awareness about issues for patient advocacy.
- Developing training materials and content for Macmillan health and social care professionals.

Macmillan included discussion of the 2015 survey results in a range of events and training exercises. Some examples of these are:

- At an internal workshop for the Macmillan Service Team in Scotland. The team looked at the results for their Health Board area and hospitals, identifying areas for improvement and committed to work with partners to make improvements. For example, in one area, the results showed that a low proportion of people had received information about financial support – Macmillan drew this to the attention of their partners, a nurse consultant, and at a more strategic level and worked with them to draw up a plan of action to address this.
- With Macmillan professionals at the Macmillan's Professional Conference in 2016. This was followed up by professionals discussing what actions they had taken in light of the survey results at the Macmillan's Professional Conference 2017.
- At workshops for professionals about how to conduct a Holistic Needs Assessment.
- At Macmillan's Scottish Influencing Group.

More information on the SCPES can be found at www.gov.scot/CancerSurvey.

1718-0299 Dr Elizabeth Starkey
A Prospective Study of Acute Severe Poisonings in Children Listed under the BPSU Surveillance of rare disease approved application (1516-0292)

Accidental poisoning in children and young people is a common reason to attend hospital. Children, particularly those under 5 years, are naturally inquisitive and frequently taste and swallow products and substances in their homes, some of which may be harmful. Laws require the use of child-resistant packaging for some medications and chemicals, but not all. This has significantly reduced harm to children, however a large proportion of medications in blister packs are not covered by this legislation. One or two adult doses of certain medicines within a blister pack can lead to death in a baby or toddler. Teenagers involved in taking illicit drugs or alcohol are also in danger of poisoning themselves accidentally as a result of their risk-taking behaviour.

Most children who swallow a potentially dangerous substance do not require any specific treatment and may not need to even attend hospital. On occasion, however, a more serious outcome can occur, including death. There is very little information surrounding these serious accidental

poisonings in children in the UK. This study will aim to identify the substances and risk factors associated with these more serious outcomes.

This study will for the first time provide accurate information regarding serious accidental poisoning in children in the UK and Ireland. By identifying trends in serious poisoning events, in particular, specific substances that frequently cause significant harm, it is hoped that targeted public health campaigns can be used to address these areas.

1718-0305 Dr Devesh Dhasmana
Non-Tuberculous Mycobacteria infection in Scotland; the burden of M.abscessus and M.avium complex in Fife and Tayside (MAAFT)

Non-tuberculous Mycobacteria (NTM) present a significant global clinical challenge. Mycobacteria are a type of bacteria that are most well known to cause Tuberculosis and leprosy. However, other Mycobacteria in the same family cause other chronic, and often more insidious infections in vulnerable people. These bacteria are referred to as NTM. They cause significant harm and illness in those with such lung diseases as COPD (smoking-related lung disease) and bronchiectasis (repeated infections of the lung), and those with impaired immune systems such as those with HIV infection.

NTM are commonplace in the environment, commonly found in soil and water systems, and their increasing presence in disease may be linked to increased use of antibiotics and the aging population. NTM infection may be complex and may not always require antibiotic therapy. NTM may colonize and persist in sites without causing harm, and where current antibiotic regimens are long, potentially toxic, and often ineffective, treatment decisions must be considered carefully. This is most pertinent in NTM Pulmonary Disease (NTM-PD), where infection in the first place is intimately related to poor lung function, chronic ill-health and frailty. In this context, drug treatment to treat this may further jeopardize the patient's lung and general health. Therefore, decisions to treat must weigh up the potential harm of treatments against the harm of ongoing and persistent infection.

NTM infections can present in a variety of ways, including skin infections, lymph node infection, and rarely in the bloodstream in those who have profound deficits in their immune system. However, overwhelmingly NTM infection presents as lung disease. The most common of these bacteria is Mycobacterium avium complex (MAC), which represents 3 different species. Another Mycobacteria, although less common, is Mycobacterium abscessus (Mabs), however, this is relevant because in susceptible patients this can cause a devastating illness and is often fatal. Both bacteria are therefore relevant to diagnose in patients with chronic infections of unknown cause.

Drug treatment is typically at least 3 drugs for a total of 12-18 months in uncomplicated cases. M.abscessus is much more difficult to treat and requires a combination of intravenous treatment under supervision in hospital, and often inhaled antibiotics alongside tablet antibiotics. The drug treatments are difficult to tolerate and can cause significant harm. Treatment failure is common and can result from poorly tolerated treatment and/or failure to eradicate the infection.

This project will focus on establishing the burden of disease caused by these two significant infections in our region of Scotland. We plan to identify the number of positive cultures identified by all patients over a 6-year time frame, and then identify several features linked to these patients with respect to disease course and outcomes. We intend to describe the numbers of patients offered treatment, those completing treatment, treatment success, use of emergency services and overall survival.

With these results, we hope to better understand the size of the problem, the course of disease treated and untreated, and make recommendations for further service development and research proposals.

1718-0313 Dr Adriana Duta

Disentangling the importance of individual and family factors on educational outcomes using a sibling design

The family in which people are born has a strong influence on individual life outcomes, including educational and occupational outcomes (Shavit and Blossfeld, 1993; Breen, 2004; Iannelli and Paterson, 2007). Reducing social inequalities is a key policy agenda in Scotland and beyond. Our research aims to provide robust research evidence to help the design of policies aimed to tackle these inequalities.

Our project's central objective is to achieve a better understanding of the role of individual, family, social class and neighbourhood factors in young people's educational outcomes (i.e. exam results and curriculum choices). We will apply a sibling design which is superior to other research designs for its ability to capture the influence of the family environment in its totality, i.e. including all measured and unmeasured characteristics shared by siblings at birth and during their upbringing.

Research in the US showed that family background factors shared by siblings account for about half of the variance in educational attainment (Conley & Glauber, 2008). In England, a study of GCSE results found that 40% of the variation in siblings' outcomes was due to shared family factors, 22% to shared environment beyond the immediate family (e.g. school) and 38% to individual level factors (Rasbash et al., 2010).

To our knowledge no study of this kind has been carried out in Scotland. Linking data from the Scottish Longitudinal Study, Vital Events birth data, and ScotXed data will allow us to disentangle the relative importance of different factors in explaining educational inequalities.

References:

Breen, R. (Ed.) (2004) Social mobility in Europe. Oxford: Oxford University Press.
Conley, D., & Glauber, R. (2008). All in the family?: Family composition, resources, and sibling similarity in socioeconomic status. Research in Social Stratification and Mobility, 26(4), 297-306.
Iannelli, C. and Paterson, L. (2007) 'Education and Social Mobility in Scotland', Research in Social Stratification and Mobility, 25(3): 219-232.
Rasbash, J., Leckie, G., Pillinger, R., & Jenkins, J. (2010). Children's educational progress: partitioning family, school and area effects. Journal of the Royal Statistical Society: Series A (Statistics in Society), 173(3), 657-682.
Shavit, Y. and Blossfeld, H.P. (1993) Persistent inequality: Changing educational attainment in thirteen countries. Boulder: Westview Press.

1718-0324 Dr Colin Tilley
The retention of dentists in NHSScotland

A key factor in workforce planning is the rate at which health care professionals join and are retained in the workforce. In order to practise as a principal dentist in NHSScotland, dentists need to apply for and be issued with a Vocational Training Number (VTN) to indicate that they have satisfactorily completed Dental Vocational Training (DVT) or are exempt from the requirement to complete DVT because:

- they are from an EEA Member State (other than the UK) and hold a recognised European Dental Diploma;
- they have had a NHS board or Performer number within the last five years;
- they have practised in primary dental care in the Community Dental Service (CDS) or the Armed Forces for four years' full-time (or equivalent part-time), and for not less than four months during the past four years; or
- they have completed a course of vocational training under the voluntary scheme; or their experience or training during the previous five years is equivalent to DVT.

NHS Education for Scotland (NES) issues VTNs in Scotland and routinely collects information on recipients in the Scottish Dental Vocational Training Equivalence and Certification Committee (SDVTECC) database.

The purpose of this proposal is to link the SDVTECC data to the NHSScotland dental workforce data for two purposes:

1. To quality assure the dental workforce data; and
2. to examine the number and source of flows into the NHSScotland dental workforce.

1718-0325 Dr Zhiqiang Feng
Does commuting affect health?

Commuting is part of our daily life. The increasing of travel distances and the prevalence of car use in commuting have important health implications in addition to financial and environmental consequences. For example, previous research shows that long distance commuting is associated with poor psychological well-being. Exposure to air pollution is also part of the commuting process which may lead to adverse health outcomes. Active commuting, on the contrary, is beneficial because it appears to be exposed to the lowest level of pollution overall and involves physical activity on a daily basis. However, transport and health is still an understudied topic and some previous research has found no effects of commuting on health. In addition, previous studies tend to use survey data which have a small sample size and self-reported health measures that are subject to reporting bias. The potential causal link between active commuting by bike and mental health has not been examined.

In this project we propose to explore the association between commuting and health from different angles using objective health measures from NHS health data. We will aim at addressing the following research questions:

1. Is long distance commuting associated with poor mental health?
2. Does road congestion have negative effects on mental health?
3. Is using underground commuting related to birth outcomes?
4. Does active commuting by bike causally benefit mental health?

1718-0326 Professor Ian J Deary
Lothian Birth Cohort 1921(LBC1921) Study

Background:
LBC1921 is a longstanding multidisciplinary study of, principally, non-pathological cognitive and brain ageing, and health and social aspects of ageing. The project was designed to follow-up some participants of the Scottish Mental Survey of 1932 (SMS1932), which measured the intelligence of almost every child born in 1921 attending school on June 1st 1932 (age ~11). Nearly 70 years later, SMS1932 participants living in Edinburgh (and Lothians) were invited to participate in the LBC1921 study (Wave 1). From 1999-2001, 550 individuals were recruited (~age 79 years) and have been followed-up 4 further times.

Wave of LBC1921 testing & data collection	Year	Mean age at testing (years)	Number of participants tested
1	1999-2001	79.1	550
2	2003-2005	83.4	321
3	2007-2008	86.6	235
4	2011-2012	90.1	129
5	2013	92.1	59

Tracing, recruiting and re-testing surviving SMS1932 participants makes the LBC1921 cohort unusually valuable, especially due to the availability of childhood cognitive data. From Wave 1, a large amount of cognitive, psychosocial, lifestyle, health, medical, biomarker, genetic, brain imaging (Wave 2 & Wave 5) and other data have been consistently collected. Analyses are conducted to explore and identify factors among these that contribute to cognitive and brain ageing, and others aspects of ageing. The combination of early life intelligence data and broad range of retrospective and contemporaneously-collected life-course data offers a rare opportunity to examine: (1) the nature and determinants of non-pathological cognitive ageing from childhood to older age, and within older age; and (2) the influence of early-life cognitive ability and social background on later health and survival. Because participants have been followed up from their late 70s to early 90s, when risk of onset of cognitive impairment and dementia increases significantly, the study also has the potential to identify risk and protective factors which might inform interventions to reduce the risk of cognitive loss in later life.

Approval was granted (SR176) for linkages between LBC1921 participants and NRS deaths records. The study has benefited from this data linkage; regular flagging of this information has contributed to tracking of rates of chronic disease and survival in the LBC1921, and to identifying cases of dementia. Importantly, information about deaths provides information about whom not to contact in correspondence. Information relating to mortality has contributed towards evidence in the field of cognitive epidemiology, showing clear links between cognitive ability and health, illness, wellbeing and survival. Also, proximity to death is known to affect cognitive ageing and is an important consideration in this important outcome. This proposal seeks to renew approval for flagging of LBC1921 participants' death records, based on the existing data linkage. It will become more important as the cohort ages. We wish to highlight that the deaths data requested here should cause minimal privacy concerns due to their being publicly-available data.

1718-0327 Professor Ian Deary
Lothian Birth Cohort 1936 (LBC1936) Study

Background:
LBC1936 is a longstanding multidisciplinary study of, principally, non-pathological cognitive and brain ageing, and health and social aspects of ageing. The Age UK-funded project was designed to follow-up some participants of the Scottish Mental Survey of 1947 (SMS1947), which measured the intelligence of almost every child born in 1936 attending school on June 4th 1947 (age 11). About 60 years later, SMS1947 participants living in Edinburgh (and Lothians) were invited to participate in the LBC1936 study (Wave 1). From 2004-2007, 1091 individuals were recruited (~age 70 years) and have since been followed-up at ~3 yearly intervals. Wave 5 began in November 2017 and is testing the participants in their early 80s; wave 5 is due for completion in 2019.

Wave of LBC1936 testing & data collection	Year	Mean age at testing	Number of participants tested
1	2004-2007	70	1091
2	2007-2011	73	866
3	2011-2013	76	697
4	2014-2017	79	550
5	2017-2019	82	440 (expected)

Tracing, recruiting and re-testing surviving SMS1947 participants makes the LBC1936 cohort unusually valuable, especially due to the availability of childhood cognitive data. From Wave 1, a large amount of cognitive, psychosocial, lifestyle, health, medical, biomarker, genetic, brain imaging (from Wave 2) and other data have been consistently collected. Analyses are conducted to explore and identify factors among these that contribute to cognitive and brain ageing, and others aspects of ageing. The combination of early life intelligence data and broad range of retrospective and contemporaneously-collected life-course data offers a rare opportunity to examine: (1) the nature and determinants of non-pathological cognitive ageing from childhood to older age, and within older age; and (2) the influence of early-life cognitive ability and social background on later health and survival. Because participants have been followed up throughout their 70s and into their 80s, when risk of onset of cognitive impairment and dementia is increased, the study also has the potential to identify risk and protective factors which might inform interventions to reduce the risk of cognitive loss in later life.

Approval was granted (SR187) for linkages between LBC1936 participants and NRS deaths records. The study has benefited from this data linkage; regular flagging of this information has contributed to tracking of rates of chronic disease and survival in the LBC1936, and to identifying cases of dementia. Importantly, information about deaths provides information about whom not to contact in correspondence. Information relating to mortality has contributed towards evidence in the field of cognitive epidemiology, showing clear links between cognitive ability and health, illness, wellbeing and survival. Also, proximity to death is known to affect cognitive ageing and is an important consideration in this important outcome. This proposal seeks to renew approval for flagging of LBC1936 participants' death records, based on the existing data linkage The administrative and health, and will become more important as the cohort ages. We wish to highlight that the deaths data requested here should cause minimal privacy concerns due to their being publicly-available data.

It should be noted that we are requesting only information about deaths in this application. Though not requested as part of the current proposal, data linkages between LBC1936 participants and morbidity-related records from the Scottish Morbidity Record (SMR01; SMR04; SMR06) have also previously been approved (PAC ref no 2509); a request for an extension of this application might be submitted in the future. Future proposals might seek to renew approval for flagging of LBC1936 participants' morbidity records from the SMR, and request new linkages with other national datasets such as NHS NSS Prescribing Information System (PIS). The latter would have the potential benefit of providing information about dementia medications, and, for example cardiovascular and diabetic medications – conditions know to affect cognitive functions.

1718-0328 Dr Marisa Mason
Medical and Surgical Clinical Outcome Review Programme

HQIP commissions the Medical and Surgical Clinical Outcome Review Programme on behalf of NHS England, DHSSPS Northern Ireland, the Health Department of the Scottish Government, the Welsh Government, the Channel Islands and the Isle of Man. The Clinical Outcome Review Programmes were formerly known as the Confidential Enquiries, NCEPOD as an organisation was originally established in 1987 as a Confidential Enquiry into Surgical Deaths, but has since expanded its remit. All hospitals are expected to participate. In England the participation is recorded towards Quality Accounts. In the other countries the Governments support participation as a measure of quality and good clinical practice.

We work on a rolling work programme starting two new studies each year. The next ones to start data collection are:

- Pulmonary Embolism (Attachment C- Protocol)
- Acute Bowel Obstruction (just starting to be scoped)

We are applying for approval to use our standard method applied to all the studies, we will then supply a protocol for each topic as it is developed. This is the process adopted by the HRA-CAG in England and Wales. A summary of the standard methods we use form Attachment D and an overview of how we process the data and who has access to it is in Attachment Di.

Patient information is used to obtain a sample of patients and for ensuring that case notes are received for the correct patient. It can also be used to link to outcomes through routinely collected data sources or other health services to collect data for the whole patient pathway. Identifiers are kept no longer than necessary; all patients are included in the analysis as a whole sample, not published on an individual basis.

The patient information collected via the case notes is essential to this process as it provides a view of the detailed care received by each patient, which is richer than simply counting numbers; the qualitative approaches lets clinician make an informed assessment of what happened. Each case is reviewed but the data are aggregated to ensure confidentiality – all identifiable data is removed and destroyed once used.

The only time that individual cases are isolated, is where a case causes NCEPOD such concern that it raises the issue that current patients could be at risk. These cases are referred back to the Medical Director of the hospital concerned in order that appropriate action may be taken. This approach was given support by the GMC in 1998 and 1999 and was ratified by the NCEPOD Steering Group in March 2001, September 2003 and April 2006. More recently this process has been adopted by HQIP

across the whole CORP. This meets the requirements laid down by the GMC in Good Medical Practice.

1718-0329 Professor Lesley Colvin
Data and Measurement for Chronic Pain Services. A Project to Inform National Pain Service improvement

This project was established to address the lack of standardised measurement of chronic pain in Scotland, and of services provided to manage chronic pain. This is an important issue as there is no clear way of measuring the prevalence of chronic pain nationally, understanding the demographics and needs of the patient group, the impact chronic pain has on them, or the effectiveness of any service provision or service improvement initiatives which often presents a problem when funding services and treatments for patients. A Core Minimum Dataset has been developed as an earlier part of this project, based on validated measures and wide consultation, and is now ready for testing (feasibility, reliability, and validity).

1718-0330 Dr Shamez Ladhani
Severe complications of Enterovirus and human Parechovirus infections in children in UK and Republic of Ireland

Viral infections in children are generally mild and do not require any specific treatment. Enteroviruses and parechoviruses belong to the same family and usually cause flu-like illnesses or diarrhoea and vomiting in children. These infections are more common in the summer and autumn, but can occur throughout the year. Very occasionally, these viruses can cause severe illness that can affect the heart, liver, brain and nervous system. At present, we don't know how often these severe illnesses occur or how many of the affected children are able to recover entirely from their illness. We would like doctors from across the UK and Ireland to give us information about the children that develop such severe illnesses. At the same time, we have gathered a group of doctors who can provide specialist advice to help look after such children. With the help of the specialist doctors, at the end of the study, we hope that we will learn enough about this condition to write national guidelines to help doctors manage those patients across the nation.

1718-0333 Dr Artaban Jeldi
Investigation of outcomes of navigated TKA after 5 years

Joint replacements have become a common and successful procedure performed to relieve pain and enhance mobility in patients with advanced osteoarthritis. Around 8,000 primary knee replacements take place in Scotland annually, with nearly 2,000 of these performed at our institution. Our Orthopaedic department has been using the B Columbus® knee replacement implants since 2005 and performing around 500 replacements a year on average. Computer navigation for total knee arthroplasty (TKA) was introduced to increase the accuracy of implant positioning and enable proper overall alignment with the aim of achieving maximum biomechanical and ergonomic benefit from the artificial knee joint.

Along with overall alignment, the focus on outcomes of total knee replacements has moved from only survival to patient reported outcome measures (PROMs). It is therefore important to continue to measure how implants are performing not only in terms of clinical outcomes but also PROMs. There is also an increasing recognition of the importance of the level of function gained by patients and functional outcome is now considered to be a crucial component for measuring the success of a knee replacement.

Due to the numbers involved, it is important to be aware of the ongoing performance of this implant. As part of our continual review of clinical practice, we want to determine how well the computer navigated Columbus® knee replacement is performing in the medium to long term.

1718-0334 Aghimien Iyayi-Igbinovia
Hospice at Home data pilot

At the end of 2015, the Scottish Government (SG) released its Strategy Framework for Action (SFA) on Palliative and End of Life Care, based on the vision that 'by 2021, everyone in Scotland who needs access to Palliative Care will have access to it.' The SG has made 10 commitments to achieve this vision, and ISD is supporting commitment 9: to work with stakeholders 'to support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care'.

Hospice at Home care has been identified by the data sub-group of the National Implementation Advisory Group (NIAG) as being a significant data gap at national level (document 01, section 3.4). To begin addressing this, ISD propose a pilot data collection of patient level data with 3 hospices (see section 2.4).

ISD will create an Excel-based data collection tool which will be completed by staff at the pilot sites, capturing hospice at home activity between April 2017 and March 2018. This will be returned to ISD via secure file transfer (using Globalscape). ISD will quality assure, analyse and produce aggregate outputs using tables and charts. These outputs will be shared with the pilot sites, data sub-group and NIAG. No patient identifiable information will be shared. ISD will use the pilot data collection experience to establish the feasibility of a more systematic national submission in the future (subject to appropriate approvals).

1718-0341 Professor Esther Crawley
BPSU survey of severe Chronic Fatigue Syndrome/Myalgic Encephalopathy

Children with chronic Fatigue Syndrome or myalgic encephalitis (CFS/ME) have persistent disabling fatigue for at least 3 months. The fatigue and symptoms are made worse by activity (post exertional malaise) and are not relived by rest. Children with CFS/ME have other symptoms including muscle aches, headaches, and poor concentration.

Children with severe chronic fatigue syndrome or ME are only able to leave their house occasionally (if at all). They have severe fatigue and often severe pain, and many require help with daily activities such as eating and washing. At the moment, we do not know how often children develop severe CFS/ME or what treatment they receive. This means the NHS cannot organise treatment for them.

In this study, we will ask every children's doctor in the UK, through the BPSU, whether they have seen a child that month with severe CFS/ME. We will then ask the doctor about their symptoms, how disabled they are and how long they have been unwell. We want to know what treatment children with severe CFS/ME get and we will ask doctors what treatment children were offered and what treatment they received. We also want to know whether children with severe CFS/ME get better and we will go back to doctors after a year to find out what happened to children in terms of treatment offered and whether they got better (or not).

1718-0342 Dr Jonathan Mayes
End of Life Care in Critical Care Units

The number of people dying in Scotland is increasing each year. Half of these occur in hospitals despite many people expressing a wish to die at home. The government has aimed to reduce the medicalisation of death. Intensive care is an extreme form of medicalised death but basic statistics are not yet available. We aim to compare how many people die in intensive care units in Scotland compared with other locations (such as hospital, home or hospice), describe whether this changes depending on a person's age, sex and socioeconomic status, and find out whether the number of people dying in intensive care units has changed over time. We will also calculate the healthcare costs which accumulate in the period before death and identify factors the correlate higher costs.

This will be the first study undertaken in Scotland to report how intensive care is used at the end of life. It will provide important data needed to inform high priority Scottish Government policies. In addition, the Scottish Intensive Care community will use these data to drive improvements in care at the end of life in intensive care units.

1718-0354 Dr Riinu Ots
Quality and outcomes in global cancer surgery

The aim of this study is to understand how surgery for cancer is performed across the world. We will concentrate on the most common surgically treated cancers: breast, stomach and bowel cancer. Any hospital in the world can take part as long as they perform surgery for these cancers.

We will achieve this aim by studying the rates of death and complications arising from surgery. Most complications occur in the first 30 days of surgery – so we will focus on this time frame. The second aim is to understand the resources hospitals have to support cancer surgery (such as the equipment hospitals contain) and availability of these treatments. We will also try to see what barriers patients face to accessing cancer surgery (i.e. financial costs, distances travelled to the hospital).

Our main outcome will be the rate of death and complications in the first 30 days after cancer surgery. We will compare these across countries, by first grouping countries into their level of development. This will be determined using a measure developed by the United Nations called the Human Development Index –which measures life-expectancy, education and income.

We will include all patients who undergo surgery in the study period at each participating hospital. The study will run from 1st April 2018 to 31st October 2018 (with the last follow-up period ending on 30th November 2018). Data will be collected on all patients receiving their initial surgery for breast, stomach or colon cancer during the time-period with follow-up to 30-days after their operation.

To help with this, we have broken the study up into 4 week 'chunks'. Surgeons and doctors across the world will form small teams to spread the workload. Several teams collecting data over multiple four-week chunks will be encouraged.

We will check the accuracy of the data by performing a 'data validation' study. This will be a second study, split into two parts. First, the hospital teams will self-report the methods used to identify and follow-up patients (i.e. calling the patient or clinical notes). Secondly, independent validators, who are separate from the hospital teams, will repeat the study on a selection of patients. This data will be then compared to the original data to see how accurate it is.

1718-0356 Dr Will Atkinson
MR110 UKAEA Mortality and Morbidity Study

Study MR110 is part of a long standing study of the effects of occupational radiation exposure in the UK nuclear industry. Much of the knowledge in this area has been gained from studies of the survivors of the two atomic bombs detonated over Japan at the end of the war. However, it is not clear how relevant the Japanese study, of high doses received instantaneously, is to those exposed at work, or as members of the public, to much lower doses received over many years. This is why studies of nuclear workers have been, and continue to be, important in setting acceptable exposure levels at work and for the public in the wider environment. MR110 is part of a study of mortality and cancer morbidity in the past and present employees of the UK Atomic Energy Authority, the government organisation responsible for the initiation and technical and scientific development of the UK's civil nuclear energy programme. It is among the small group of UK studies that lead the world in this area partly because of the quality of the national mortality and cancer registration systems.

1718-0357 Dr Will Atkinson
MR183 Atomic Weapons Research Establishment Worker Study

Study MR183 is part of a long standing study of the effects of occupational radiation exposure in the UK nuclear industry. Much of the knowledge in this area has been gained from studies of the survivors of the two atomic bombs detonated over Japan at the end of the war. However, it is not clear how relevant the Japanese study, of high doses received instantaneously, is to those exposed at work, or as members of the public, to much lower doses received over many years. This is why studies of nuclear workers have been, and continue to be, important in setting acceptable exposure levels at work and for the public in the wider environment. MR183 is a study of mortality and cancer morbidity in employees of the Atomic Weapons Establishment (AWE), the government organisation responsible for the technical and scientific development of the UK's nuclear deterrent. It is among the small group of UK studies that lead the world in this area partly because of the quality of the national mortality and cancer registration systems.

1718-0358 Koen Rietdijk
Multimorbidity in Scottish ICUs

The Scottish Intensive Care Society Audit Group (SICSAG) database collects information on all patients admitted to critical care units in Scotland in order to improve the quality of care. This study aims to improve the quality of the SICSAG audit.

Doctors and nurses working in critical care are increasingly caring for critically ill patients who are older and have multiple pre-existing health problems (multimorbidity). Patients with a greater number of pre-existing health problems are more likely to die or, if they survive, have additional health problems. Only a limited number of pre-existing health problems are recorded in the audit database, as this was set up in 1995 at a time when patients admitted to critical care were younger with fewer health problems.

This project will look at changes in multimorbidity in the Scottish ICU population over time and assess how well recorded these conditions are in comparison with a separate database of hospital discharges (SMR01). The project will also investigate whether the addition of a measure of multimorbidity derived from the hospital database (SMR01) could be used to improve the statistical model currently used by SICSAG to benchmark death rates in each unit against the national average.

The project will be undertaken under the supervision of the SICSAG team in the Information Services Division in collaboration with researchers and clinicians. It should improve quality of the database in the following ways:

1. Reporting how common multimorbidity is will allow better planning of services in the future.
2. Comparing multimorbidity recording in the SICSAG database with the hospital database will allow quality of current data recording to be assessed.

Improving the performance of the current statistical model will allow more accurate benchmarking of quality of care in the future.

1718-0359 Dr Martin McCoy
Distress Brief Interventions (DBI) Programme Data Collection

Distress Brief Interventions (DBIs) are an innovative way of supporting people in distress. The DBI approach emerged from the Scottish Government's work on the Suicide Prevention and Mental Health strategies. The DBI approach is initially being piloted over 53-months (November 2016 to March 2021) in four sites across Scotland: 1. Penumbra in Aberdeen, 2. Support in Mind in Inverness, 3. Scottish Borders Joint Mental Health Service 4. North & South Lanarkshire.

The DBI Programme is for people who present or are referred for help and which does not require (further) emergency service response. A Distress Brief Intervention is a time limited and supportive problem solving contact with an individual in distress. It is a two-level approach. DBI level 1 is provided by front line staff (specifically, A&E, Primary Care, Scottish Ambulance Service, Police Scotland, and Social Work) and involves a compassionate response, signposting and offer of referral to a DBI level 2 service. DBI level 2 is provided by commissioned and trained third sector staff who would contact the person within 24-hours of referral and provide compassionate community-based problem solving support, wellness and distress management planning, supported connections and signposting for a period of up to 14 days. Therefore DBI is an additional option in support of, but not replacing the need for clinical support or the management of risk by other services and systems.

Distress is being defined as 'An emotional pain for which the person sought, or was referred for, help and which does not require (further) emergency service response'. The initial test period will focus on people aged 18 and over. A DBI central team has been established by the host organisation, NHS Lanarkshire. To evaluate the effectiveness of the approach the Scottish Government has commissioned an independent evaluation to be conducted by the Nursing, Midwifery and Allied Health Professions Research Unit (NMAHP-RU), informed by an evaluability assessment completed by NHS Health Scotland. The DBI package and training programme was in place for a very controlled implementation in Lanarkshire beginning in June 2017, with incremental up scaling across all four partnership sites from October 2017 in preparation for full implementation in April 2018. NSS ISD are directly involved in the DBI Programme to provide analytical support and the ISD Principal Information Analyst is seconded to NHS Lanarkshire for the duration of the DBI Programme as the Principal Information Analyst for the DBI Central Team. As part of this the DBI (Level Two) data collection and linkage of data at person identifiable level, as well as the very limited sharing of this personal information, as described in application, and the slightly more wide sharing of the high level aggregate anonymised information with designated colleagues from the organisations listed in Section 2.3 will take place, in order to meet the aims and objectives as described below.

This new PBPP application (eDRIS-1718-0359) for the DBI data collection, will cover the data collected from the 25th May 2018 onwards (i.e. when the GDPR comes into force and the new conditions for data processing as listed in Section 3.2.02). The DBI data collected during the early implementation period from the 23rd June 2017 until the 24th May 2018 (date to be confirmed based on final PBPP sign off of eDRIS-1718-0359) is covered by the previous PBPP application (eDRIS-1718-0020) for the DBI data collection, which was approved on the 10th October 2017 with conditions. No record level data will be received by ISD until all approvals are in place. The eDRIS-1718-0020 PBPP application was based on an explicit consent model for the DBI data collection.

1718-0364 Karen Smith
Improving the Cancer Journey (ICJ) Invite letter service

Improving the Cancer Journey' (ICJ) is a new service which was developed and launched by Glasgow City Council (GCC), Macmillan Cancer Support (MCS) and NHS Greater Glasgow & Clyde (GGC) in 2014, with Information Services (ISD) of NHS National Services (NSS) joining this partnership in April 2016 that utilises pioneering modules and techniques to develop a Holistic Needs Assessment (HNA) service by delivering support and interventions to people affected by cancer.

Dundee City has now been launched with Fife following shortly and other local authorities showing interest. The ICJ work is funded by Macmillan but neither Macmillan nor any other 3rd party staffs are involved in the invite process that this proposal covers.

ICJ service is designed to proactively support people affected by cancer. The service provides direct assistance, advice and information to cancer persons, as well as their families and carers to ensure no one faces cancer alone.

ISD Cancer Registration staff currently provides administration support to the ICJ service by screening patients and where suitable issuing invite letters. Access has been approved by ISD Caldicott, NHS GG&C, NHS Tayside & NHS Fife for the usage of NSS held Cancer Waiting Times (CWT) data and SMR01 data to use this data for case ascertainment and screening purposes.

This contains information on persons who have appeared on a cancer waiting list and/or have been admitted to hospital and where on discharge a cancer diagnosis.

1. This data is then reviewed by the health board based, ISD Cancer Information Officers (CIOs) to screen the persons using strict criteria to see if the patient should be issued an ICJ invitation letter. Screening involves access to the health boards systems, which they currently access for their day to day work and cross checking the information against the criteria for inclusion/exclusion.
2. The Cancer Information Officers (CIOs) are highly experienced staff who are considered to be cancer coding experts they collect information on a daily basis on the incidence, characteristics, stage and treatment of all newly diagnosed cancers in Scotland. The CIOs have in-depth knowledge of the disease of cancer and are specifically trained in cancer coding through for example the International Classification of Disease 10th revision (ICD10), International Classification of Diseases for Oncology (ICDO3) and extensive knowledge of clinical and pathological TNM Classification of Tumour Staging. This will be critical when determining which patients should be included and excluded.
3. ISD staff are highly trained in interrogating and interpreting clinical data and combining this with their understanding of tumour behaviour, grade, staging, treatments and the outcomes of the disease they are ideally placed to make decisions.

This letter offers an invitation to contact the ICJ service and undertake a HNA assessment with a named link officer. This assessment identifies any concerns and then a care plan is put into place to support their concerns. This involves signposting and referral to various organisations across the city. To our knowledge, it is the first cancer service in the UK to deliver HNA in a community setting.

Proposal
ISD wish to extend the extract of cohort lists from NSS data marts to include other local authorities data/NHS Boards data for screening purposes as these parties show and interest in establishing an ICJ service within their area.

1718-0365 Dr David Carslake
SR152 Glasgow Students Study

Our health in middle and old age can be affected by our environment, health and behaviour in childhood and early adulthood. However, most people now in middle or old age did not have information collected when they were young, and recollected information can be unreliable and/or incomplete. Between 1948 and 1972, about 16,000 students at Glasgow University completed detailed questionnaires about their current health, lifestyle and family background, and were examined by a doctor. Linking this information to their subsequent health records provides a valuable resource allowing us to examine associations between factors present in early adulthood and lifelong health. Further value has been added by a follow-up questionnaire sent to the former students in 2001 to measure their health and lifestyle in middle age. Results from the study will help us to understand what steps we can take when we are young, to improve our health throughout life.

1718-0368 Pallavi Tyagi
Incidence of retinal dialysis in United Kingdom

The retina is a thin layer of tissue that forms the inner lining of the back of the eye. The retina receives light from outside and send signals along nerves to the brain to see images. Rarely, the retina may separate from the back of the eye, which is known as retinal detachment resulting in loss of vision if not treated. ‘Retinal dialysis’ is one of rare causes of retinal detachment which is most

commonly associated with injury to eye. It is more commonly seen in children and young adults as a result of sports or accident related blunt eye injury. Blunt injury to eye is most important cause of retinal dialysis however it may be caused by other factors. The condition may require treatment including laser or surgery.

Retinal detachment is an important cause of vision loss in any age group. 'Retinal Dialysis' is rare cause of retinal detachment more commonly seen in sports and accidents related eye injury. It can result in loss of vision in younger and working age group individuals. So far the exact extent of disease burden is unknown. The study would help to identify number of individuals newly affected by the condition and its treatments.

1718-0370 Stephen Riddell
NHS Information Services Division/Alan Turing Institute Collaboration – SPARRA Algorithm Development

NHS NSS are responsible for the 'Scottish Patients at Risk of Readmission and Admission' (SPARRA) model. This predicts the risk of a patient being admitted to hospital in the coming year. A risk score is calculated monthly for around 4.2 million patients in Scotland using logistic regression. GPs use SPARRA scores to stratify patients by risk of emergency admission. This aids them in selecting patients with complex care needs for consideration of Anticipatory Care Plans/poly-pharmacy review. This data is used by GPs alongside their own data and professional expertise.

The current iteration of this model was developed in 2012 and it's desirable for work to be done to improve the predictive ability of this model. Resource constraints within NHS NSS have meant that this work has been postponed in order to focus on other priorities.

The Alan Turing Institute is the UK's new national institute for data science, bringing together leading talents in data science research who are focussed on innovative and collaborative approaches, to create theoretical development and to generate impact by applying it to real-world problems. In September 2017, the Turing ran a week-long Data Study Group in which NHS ISD participated, which succeeded in identifying approaches to building and refreshing the SPARRA model, as well as in creating a UK-wide expert community interested in the project.

Jointly with NHS researchers, this community of experts is planning to investigate the most promising modelling avenues identified during the Data Study Week, through collaborative work in 2018-19.

1718-0379 Professor Tom McMillan
The relationship between recorded hospitalisation and self-report of head injury in male and female prisoners in Scotland

The Scottish Government have a current focus on the development of health services for prisoners. A recent report to the SG on Brain Injury and Offending [http://www.nphn.scot.nhs.uk/wp-content/uploads/2016/07/NPHN-Brain-Injury-and-Offending-Final-Report.pdf] recommended investigation of systems to identify head injury in prisoners and a determination of persisting effects including disability to inform the development of services. This includes the validation of screening tools for head injury that could be used in prisons. These tools are based on self-report by the prisoners and we have carried out studies looking at these tools and the relationships between self-

report of head injury and persisting disability in an attempt to validate this as a part of a system for triage to indicate service need. This has involved individual assessments with consent for medical records to be accessed. However there is little data in the literature to guide on the relationship between self-report and hospital admission; for example the extent to which there are admissions that are not self-reported (perhaps for reason of memory), or if there are head injuries where hospital admission did not occur. An understanding of relationships between self-report and hospitalised records of admission with head injury will inform the validity of self-report in relation to objective evidence from hospital records. We have permissions to interview and assess prisoners in several Scottish prisons and have currently assessed 250. We seek permission to obtain SMR-01 & A&E data on admissions to hospital and attendances to A&E with head injury to compare with self-report and our assessments of persisting effects of head injury.

The funding for the study is partly from the Scottish Government (Health and Justice departments) and partly by the University of Glasgow. The work has been developed in collaboration with the NHS National Prisoner Healthcare Network, although the University of Glasgow has responsibility for the research and will have sole access to individual data arising from the project.

1718-0380 Dr James Wilson
Harmonisation of Record Linkage in Two Northern Isles Cohorts – “Viking"

The aim of this proposal is bring the governance of linked NHS data for two population cohorts from the Northern Isles of Scotland together into a single unified programme. All the participants have consented to electronic medical record linkage. Linkage to routine NHS data for ORCADES participants from the Orkney Islands was approved by the PAC and actioned by ISD in 2013 (Ref: XRB13177), and record linkage in the Viking Health Study–Shetland was approved by PBPP in December 2017 (Ref 1516-0567/Wilson). We now request approval for a single data release for the two cohorts, to harmonise the two approved record linkages. The same variables are requested and the objectives are the same, with the cohorts in combination named “Viking”.

This proposal is part of a research programme at the University of Edinburgh that aims to identify genes which influence risk factors for common diseases such as diabetes and heart disease. Finding the genes (and variants in them) which predispose to such conditions is a first step to new treatments and methods of diagnosis. The proposed project will use routine NHS medical data from consented volunteers already recruited in Orkney and Shetland to help towards the identification of new biological mechanisms and genetic risk profiling.

The populations of Shetland and Orkney have several characteristics, including the large number of distant relatives, which are favourable for finding genes involved in common diseases. Over 2,000 people were recruited to each cohort (ORCADES and Viking Heath Study-Shetland), and a very wide range of measures underlying susceptibility to a variety of medical conditions were collected. These include blood measures such as cholesterol, biochemical markers of kidney and liver function, blood pressure, body fat and cognitive traits. Although the research data is broad and deep, it represents a single point in time. This proposal will allow information to be gained on the conditions that the 4,000 participants have been diagnosed with in the past, the medicines they have been prescribed and any hospitalisations they have had.

Genetic analysis has been done on DNA extracted from blood samples provided by over 4,000 participants with ancestry from the Northern Isles of Scotland. Together with data from studies run by the investigators in Croatia and mainland Scotland, this provides statistical power to identify new rare genetic variants associated with disease. The addition of linkage to NHS “routine” data as

requested in this application will considerably enhance and extend these analyses. Future updates to the NHS data over the next five years will also allow the health of the participants to be tracked over time, adding new clinical measures and providing information on treatment and health outcomes.

1819-0005 Amelia Rudd
Establishing the incidence of Tako-tsubo Cardiomyopathy in Scotland – the STARR study (Scottish Tako-tsubo Network/Registry) – Phase 1

Acute stress-induced (Takotsubo) cardiomyopathy presents like a heart attack and is triggered by intense emotional or physical stress. Although heart arteries are unobstructed, the risk of death is similar to a heart attack. There is little understanding of this strong brain-heart interaction with harmful cardiac consequences and little knowledge about any predisposing factors. We plan to conduct a Scottish-wide study to determine if patients who presented with an acute episode of Takotsubo or their immediate relatives carry a genetic susceptibility to developing this condition. In order to plan this study it is essential to know how many cases we can identify yearly in Scotland, which is the aim of this project. Applications 1718-0186 and 1617-0025 relate to the identification of past (from the 1st of January 2010) and future (until 31st of December 2023) cases of Takotsubo cases by requesting the CHI numbers of all patients coded under Code 142.8, which is for “Other Cardiomyopathies” in the ICD-10 and future code (BB43.8) in the ICD-11 , which should be implemented by NSS soon. As part of these applications we will also be requesting the CHI numbers of all patients coded under Code I21 in NHS Grampian (MI controls) annually. The purpose of this new application is to apply for a control group (to be supplied by eDRIS) and to also have access to the High-STEACS dataset (containing the same variables as the STARR dataset). We would also like to extend the number of linked datasets included.

1819-0006 Amelia Rudd
Is there a genetic predisposition for acute stress-induced (Takotsubo) Cardiomyopathy?

Acute stress-induced (takotsubo) cardiomyopathy presents like a myocardial infarct, is triggered by intense emotional or physical stress, and can have catastrophic and potentially fatal consequences. Despite data linking takotsubo cardiomyopathy with conditions that have a recognised genetic predisposition (such as mental health and neurological problems), a systematic and comprehensive characterisation of the genetic-epidemiologic factors in takotsubo is lacking. Using our Scottish-wide, recently established takotsubo cardiomyopathy registry, we propose to further investigate this disorder by collecting blood from probands and characterising the genotype of patients with takotsubo cardiomyopathy in a large scale, nationwide genome wide association study. We will also archive DNA for identification for future candidate genetic variants. Ultimately, understanding the underlying predisposition of this poorly understood neuro-psycho-cardiac disorder is essential if we are to move this field forward.

1819-0007 Kenny Haining
Socioeconomic outcomes measurement in survivors of major illness

People who have had a major illness, such as cancer or life-threatening critical illness, tell us they keep having problems with their health for months or years afterwards. We need to better understand how major illness affects people over this longer timeframe, not just on health services, but on social care, welfare services, and on patients, families and their carers.

Gathering this information is very important, especially when new treatments are being developed. The project also gives us the opportunity to improve care to people who have survived a major illness. Information we gather can help improve the design of health services and how they work.

This project will use NHS databases containing patient information: the Scottish Cancer Register and the Intensive Care Register. Using these we can identify groups of patients who have been diagnosed with a major illness and link them to other Scottish databases containing health, social care and employment information.

The project aims to:

1. Measure how much health and social care people use in the years after experiencing a major illness, and how much it costs.
2. Identify factors that lead to higher use of health and social care.
3. Understand how major illness affects someone's ability to stay in employment.
4. Understand how health and social care costs change over time.

1819-0011 Dr Libby Morris
NHS Scotland Managed Services Network for Children and Young People with Cancer (NHS Scotland MSN CYPC)

The Managed Service Network for Children and Young People with Cancer (MSN CYPC) will provide a patient app with secure and confidential access to medical information for selected children and young people who are survivors of cancer in Scotland. This specialised 'patient portal' or 'app' will allow chosen patients to be able to view selected information about their own treatment and care on their own device using a secure gateway provided by NHS Scotland. Suitable patients will be identified by the MSN specialist after care nurse practitioners, and will be advised by them on confidentiality and help them to understand the information. Most of the medical information will be available as a 'read only' service, for example lab results, treatment summaries and diagnosis but there will also be a facility for patients to message their nurse specialist and receive replies. The patient information will be extracted from NHS Scotland Health Board 'SCI stores' and will be chosen for each patient by their specialist MSN after care nurse and stored on the patient platform developed and provided by ATOS. The patients will be instructed in password management and security and will be in control of their own data on the system.

1819-0015 Dr Richard Haylock
British Nuclear Fuels Ltd. workers epidemiological cohort study

The BNFL epidemiology cohort study is a long-term prospective follow-up study examining the long-term health effects of occupational exposure to ionising radiation in a UK population.

The work provides knowledge that supports – or challenges - the radiation protection standards applied for occupational exposures to radiation. Current occupational exposure limits for ionising radiation are based mainly on scientific evidence arising from the study of the long-term health of the populations exposed to the atomic bombings in Hiroshima and Nagasaki and from patients medically treated with X-rays. Analyses of the cohort can provide reassurance that the UK protection standards derived largely from the Japanese cohort studies are transferable to occupational exposure scenarios, i.e. lower and protracted external exposures and exposures to internally deposited radionuclides such as plutonium, uranium and tritium, experienced by such UK radiation workers.

While the study is long-running, specific analysis projects are undertaken at intervals to examine the status of the cohort - or sub-cohorts - and to report findings.

The work was originally established in the late 1970s by the then BNFL (British Nuclear Fuels Limited) and the LSHTM {London School of Hygiene and Tropical Medicine).

Under contract with BNFL the work was subsequently privatised out to Westlakes Scientific Consulting (WSC), a company which closed in 2010.

The Energy Act 2004 led to the dismantling of BNFL and the creation of the Nuclear Decommissioning Authority (NDA), a non-departmental public body supported by the Department for Energy and Climate Change {DECC}. As a result of these changes, the NDA are now the owners of the BNFL epidemiological database.

Having previously supported WSC, from 2011 NDA have contracted with PHE (Public Health England) to manage the radiation epidemiology programme that includes the BNFL worker study. LSHTM now plays no part in the study.

1819-0019 Hima Daby

Analysis on childhood cancer incidence around nuclear installations in England, Wales and Scotland

In 1983, a cluster of childhood leukaemia was identified by the media near the Sellafield nuclear plant, north-west England. Similar situations have been observed in other countries and for other childhood cancer types. Up until today, several factors have been suggested to influence this risk, and the most accepted idea is that there are multiple factors involved, with radiation potentially being one of them. Despite the fact that there has been a lot of studies specifically assessing the role of radiation, results are still controversial. This study will allow us to examine incidence of all types of cancer and leukaemia and non-Hodgkin lymphomas (LNHL) in children aged 0-15 years old living in the vicinities (i.e. 25km) of 28 nuclear installations in England, Scotland and Wales, between 1994 and 2016.

We will conduct the analyses separately for power plants and other nuclear installations, as they have different characteristics that could influence the potential effect on health. Sellafield and Dounreay will be looked into separately as they have historically been shown to have an excess risk of LNHL. Observed cases of cancer will be compared to those expected in the general population to detect excess risk, if existent. We will also investigate the risk in relation to distance to the nuclear installations. All analyses will be adjusted for population structure and socio-economic characteristics of the areas.

1819-0026 Dr William Whiteley
Long term follow-up of ASCOT trial into Electronic Health Records (LATER)

Large studies have shown that people with higher blood pressure and higher cholesterol in mid-life have a higher risk of dementia and other illnesses in later life. However, there is little support from randomised trials or genetic studies that lowering midlife blood pressure, or prescribing statins prevent dementia, or have a later effect in the reduction in the risk of heart attack or stroke. Therefore, more data is needed in order to support public health interventions to prevent dementia.

Dementia is an insidious condition, and probably develops over many years. Very long-term trials may not be feasible, would be extremely expensive, and would take many years before they could have an impact on public health. In order to lengthen the follow up period of existing trials, we propose to follow up UK participants in ASCOT by using information in the electronic health records of the UK national health systems and to measure the development of dementia and other conditions over the very long term.

1819-0031 Professor Daniel Rea
aTTom-Extended: Extended follow-up of patients enrolled in the Adjuvant Tamoxifen - To Offer More? (aTTom) trial

aTTom: adjuvant Tamoxifen Treatment offer more is a randomised study (commenced 1991) of continuing tamoxifen for 5 additional years vs stopping treatment when there was uncertainty of the benefits and risks of continuation. Most women were randomised after around 5 years of tamoxifen. Preliminary results have shown that taking tamoxifen for 10 years is better than 5 years in reducing breast cancer recurrence.

Differences in deaths only emerge after many years. We need longer follow-up data to fully assess the benefits and safety of longer treatment. Approval for this (aTTom-Extended) was obtained from REC and CAG in England, giving us permission to continue to receive data from ONS. We now seek permission from NRS/PBPP to continue to collect information about Scottish aTTom-Extended participants.

We seek permission for:

1) Continued collection of data on new cancers, date and cause of death from the NRS for a further 10 years. This information (for Scottish patients) was previously collected as part of the aTTom trial from hospitals, GPs and NRS (last data collected 2016).
2) A research sub-study 'Trans-aTTom', is planned within the aTTom-Extended study. Longer anti-hormone therapy is now a recognised standard of care. But there are no validated diagnostic tests available to inform patients if they will benefit from longer therapy.

The Trans-aTTom sub-study will collect tumour blocks from pathology archives to validate a candidate diagnostic test. This will require access by named site staff to patient records to identify suitable tissue blocks for this sub-study.

1819-0041 Professor Austyn Snowden
A comparison of wider health service usage in two matched cohorts

'Improving the Cancer Journey' (ICJ) was launched in Glasgow, in 2014. ICJ is a health and social care community based cancer service designed to proactively support people affected by cancer.

This proposal sits within a wider research project (see supporting document 'research protocol'). We are in year 3 of a 5 year evaluation exploring the impact of ICJ on people affected by cancer. The focus of this application is to obtain a comparator sample (people who have not used ICJ) to investigate if individuals use health services differently when they have accessed ICJ compared to people who have not. We will compare the use of Accident & Emergency (A&E), NHS 24, prescribing information, ambulance call outs, in-patient services and the time that an individual spends in a series of unscheduled care services that occur within 24 hours of each other (e.g. A&E, NHS 24, Scottish ambulance service).

The ICJ sample consists of 4,300 people who have used the service from 2014 to April 2018. 53% are female, 47% male. Most common cancer types are lung, breast, colorectal and prostate and the majority are in the 50-64 age band. 61% of ICJ users are in SIMD 11 meaning they live within areas of high deprivation.

We wish to use two comparator samples. The first, will be individuals from Glasgow who were diagnosed with cancer before the launch of ICJ (for example in 2012/13). The second, will be a sample of individuals who live elsewhere in Scotland. These comparator samples will be matched to the ICJ sample on; cancer type, sex, age, deprivation category and time from diagnosis.

1819-0048 Dr Clare Frobisher
Cohort study of mortality and cancer incidence in UK oil refinery and petroleum distribution workers (1951-2016).

The original recruited cohort consisted of 34,569 oil refinery workers and 23,358 petroleum distribution workers in the UK. In 1995 the cohort was redefined to those workers first employed after 1st January 1946, had a minimum of 12 months employment, and with some employment after 1 January 1951. The cohort now consists of 28,554 oil refinery workers and 16,467 petroleum distribution workers first employed in the period 1946-1974 in the UK. Office of National Statistics (ONS) and the General Register for Scotland (GRS) have provided vital status and cancer registration information previously on this cohort. The latest Energy Institute (EI) report updates on mortality and cancer registration data for UK refinery and petroleum distribution workers was up to 2011 and published in 2016. The proposed work here is to maintain and further update the outcomes for the cohort with mortality and cancer registration data up to the end of 2016 and then beyond (subject to funding). We will investigate if this particular cohort are at an increased risk, compared to the general population, of specific types of deaths and specific types of cancers.

1819-0052 Dr Abigail Short
Liberation from Mechanical Ventilation Audit

Invasive mechanical ventilation (IMV) is an important and common therapy used within intensive care. Although life sustaining it can be a burden on the patient and there are well identified risks associated with IMV. Patient readiness for IMV liberation (also known as extubation) can be difficult

to assess. There are publications regarding physiological measures and the use of spontaneous breathing trials (SBT) to use as predictors for successful discontinuation of IMV. Further to this SBTs can take on varying meaning and range from no physical support in assisting inspiration to small amounts of support via ventilators to overcome the resistance from the breathing tube. Recent guidelines from the American Thoracic Society and American College of Chest Physicians make some suggestions towards IMV liberation but few strong recommendations.

This audit is aiming to assess what the first time success rate of liberation from IMV is within the Scottish ICU population and whether units are using SBTs within their assessment of patient readiness. Further to this we are reviewing whether there are any links between initial indication for intubation, certain physiological variables such as sedation scores and respiratory secretion load and this success of ventilator liberation. Any associations found for improving success of extubation has the potential to guide practice to reduce unnecessary prolonged IMV but also reduce the risk of need to reintubate the patient, which will have a burden to both patient and their family as well as increased risk of complications such as ventilator-associate pneumonia.

1819-0055 Professor Marion Bennie
Cancer Medicines Outcomes Programme (CMOP)

In recent years, several new medicines have been introduced within NHS Scotland for the treatment of cancers. In order to support patients and clinicians in making informed decisions about treatment plans, monitoring the benefits and adverse effects of cancer medicines in real life is important.

This proposal, focusing on a variety of cancers, is aimed at gaining insights into treatment pathways as well as analysing the effect certain treatment options have on patients.

The first study will look at patients with a range of gynaecological cancers, and will map out treatment options and their sequencing. In addition, it aims to determine the clinical benefits of neo-adjuvant chemotherapy – that is, chemotherapy intended to shrink tumours prior to other treatments such as surgery.

The second study will focus on patients with multiple myeloma, a type of bone marrow cancer. In addition to describing patients' treatment pathways, the main aim is to analyse disease progression and survival among patients receiving novel treatments that have been approved for use in Scotland since late 2014.

And finally, the third study will evaluate outcomes in patients receiving immunotherapies, i.e. medicines that help the immune system recognise cancer cells. Focusing on patients with lung, kidney, and head & neck cancers, it aims at analysing patient survival, as well as determining the occurrence of adverse events.

1819-0057 Dr Richard Haylock
Nuclear Weapons Test Participants Study (NWTPS)

Thousands of UK personnel were involved in the UK's atmospheric nuclear weapons test programme in Australia and the South Pacific in the 1950s and 1960s.

In the 1983 following a media campaign that highlighted potential issues with the test veteran's health the Ministry of Defence (MoD) commissioned the National Radiological Protection Board (NRPB) to undertake independent research to investigate whether attendance at the tests could have detrimentally affected their health.

As a result a long term epidemiological study of the health of the UK participants was set up by NRPB (now part of PHE) to examine mortality and cancer incidence in a representative group of participants and a similarly sized group of controls who were military personnel serving abroad at the same time but who did not visit the test sites. The control group was needed as simply comparing disease rates in this group to that in the standardised UK population could have provided a biased result as veterans were selected to be healthy enough for overseas military service.

The veteran's group consists of 21,357 men and the control group numbers 22,333 men. The cohort has been analysed three times to date. The analyses compared the rate of occurrence of various cancers and non-cancer diseases between the veterans and the controls by deriving relative risks. In addition standardised mortality ratios were derived for each of these groups compared to the UK population.

At the time of the last (3rd) analysis in 2003 which followed the cohort to 1998 only 23% of each group had died and a large proportion of those deaths occurred among cohort members who died relatively young. In order to provide a more definitive analysis of whether attendance at the tests has impacted on the lives of the veterans it is necessary to follow the cohort until the vast majority of cohort members are deceased.

Thus we seek permission to continue to receive mortality and cancer incidence information directly from National Records for Scotland.

1819-0066 Dr Shadrach Dare

Social Inequalities in Educational Attainment: An Investigation into the Mediating Role of School Absenteeism

Significant social inequalities in educational attainment are well-established in Scotland and elsewhere. Closing the poverty-related attainment gap has therefore been identified as the key priority in Scottish education policy. The literature on the mechanisms underpinning socio-economic differences in educational attainment has not yet seriously considered school absenteeism. Yet missing out frequently from school may hinder children's ability to develop to their full academic potential and may therefore be detrimental not only for individuals' life courses but also for Scotland's economy and society. Investigating the prevalence, determinants and consequences of school absenteeism in Scottish schools is therefore an essential requirement for evidence-based changes in policy and practice.

This project aims to investigate whether differences in school attendance account for social inequalities in educational attainment and post-school destinations among pupils in Scotland. Due to differences in health-related behaviour, residential and school mobility, family structure and environment, and parental employment characteristics, children from lower socio-economic backgrounds may be more frequently absent from school than children from higher socio-economic backgrounds. In turn, missing out on important parts of the curriculum due to lower attendance, truancy, or exclusion may result in lower performance in school exams, decreased likelihood of continuing school after the compulsory schooling age, and lowering the likelihood of progressing to higher education. In addition, we will investigate whether school absenteeism is more detrimental to

pupils from lower socio-economic backgrounds than to pupils from higher socio-economic backgrounds. Our results will have important implications for policy and practice.

1819-0073 Professor Ian Deary
Mental health within the family and between generations – Phase 1: Linking the Scottish Mental Survey 1947 cohort to mental health outcomes

Incidence and prevalence of mental health conditions (e.g., depression and anxiety) increases with age. Older adults are at particularly risk due to challenges faced in older age, including bereavement and disability. Previous work demonstrated that risk of mental health condition onset, and conversely, resilience to mental health morbidity, can be predicted by life course factors including childhood and adulthood socioeconomic circumstances.

This study represents phase one of a larger project to trace mental health outcomes both within and between families using research data and routinely-collected healthcare and administrative data. Phase one focuses on tracing later-life mental health outcomes of a cohort of individuals now in their 80s, who took part in the Scottish Mental Survey 1947, and have previously been linked to administrative and healthcare records. They are ideal for addressing questions regarding later-life mental health in two ways. (1) Childhood cognitive ability measurements, when combined with routinely-collected administrative and health data, allows accurate and detailed reconstruction of an individual's life course. This allows for the examination of associations of childhood cognitive ability and socio-economic status (among other predictors) with later-life mental health. (2) The cohort's age and size, and the accuracy of administrative tracing, makes them ideal for pursuing further linkage to novel mental health outcomes. Future phases of the project aim to trace SMS1947 cohort members' spouses and children, and similarly link them to mental health outcomes to examine the causes and consequences of mental health problems within family structures and the transmission of mental health problems between generations.

1819-0077 Dr Tamsin Newlove-Delgado
Modern illness or a thing of the past? Surveillance study of childhood/adolescent Sydenham's chorea in the UK and the Republic of Ireland

Sydenham's chorea is a disease affecting the brain that usually occurs in children and adolescents and causes abnormal movements, emotional and behavioural symptoms. The condition is associated with prior infection with the bacteria streptococcus and may severely impact on the child's ability to carry out activities of daily living. Whilst Sydenham's chorea may resolve within six months, it can follow a relapsing course for up to two years. In Western Europe Sydenham's chorea is considered a 'rare disease', but little is known about how frequently the disorder now occurs in the UK and the Republic of Ireland (ROI). We plan to study the numbers, characteristics, management and outcomes of new cases of Sydenham's chorea aged between 0 and 16 years in the UK and ROI. We will use the rare disease surveillance methodology set up by the British Paediatric Surveillance Unit and the Child and Adolescent Psychiatry Surveillance System. This involves asking paediatricians and psychiatrists to report cases when they first see a child or young person with symptoms of Sydenham's chorea in their service. We will then send follow-up questionnaires to these clinicians at one year and two years after initial notification of the case to ask about investigations, management, recovery and other outcomes such as whether the case has a statement of special educational needs or equivalent (see BPSU and CAPSS case notification and follow-up questionnaires for details). Our

findings will fill the gap in scientific knowledge about the current pattern of Sydenham's chorea in the UK and ROI, support service development and planning, contribute to improving recognition of the disorder and facilitate pathways to appropriate investigation and treatment.

1819-0079 Professor Jennifer Kurinczuk
A confidential enquiry of intrapartum-related perinatal deaths in births planned in midwifery-led settings in Great Britain (ESMiE)

Every year in the UK around 400 babies are born around their due date who were alive at the start of care in labour but then died either during labour or in the first month after birth, as a result of problems during labour or birth. The aim of the ESMiE enquiry is to identify ways in which care during labour and birth might be improved to prevent similar deaths in the future.

A national enquiry into these types of deaths was undertaken in 2017 as part of the UK-wide Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) run by the MBRRACE-UK collaboration. The MNI-CORP programme is commissioned by NHS England, and the devolved governments to ensure that women and their families are receiving safe maternity care. In this national enquiry panels of health professionals, including midwives and doctors specialising in the care of pregnant women (obstetricians) and the care of newborn babies (neonatologists), and other specialist doctors and nurses, looked at the medical records of a number of babies who died in 2015, and those of their mothers, to see where improvements in care were needed to prevent similar deaths in the future. However, because most babies in the UK are born in hospital labour wards where obstetricians work, most of the deaths the MBRRACE-UK enquiry reviewed occurred in these types of birth settings. But women's birthing choices are changing in the UK, and an increasing number of women now plan to have their babies at home or in midwifery units, where obstetricians don't work, and where there is less medical intervention during labour and delivery.

The causes of baby deaths during labour in these less medicalised settings may be different and are important to know about to ensure that we are providing the best possible care for mothers wherever they decide to give birth. The ESMiE enquiry is using the same review methods as the MBRRACE-UK enquiry but is focusing on babies who died during or shortly after birth, in the years from 2013 to 2016, where the mother received care in labour in a midwifery unit or at home. It will:

Carry out an in-depth confidential enquiry to review the quality of care of around 100 cases, where a baby died, to identify how care might be improved. We will look for instance at whether clinical guidelines were followed, whether staffing was adequate and staff were properly trained and supported.

Evaluate the quality of the investigations (known as a 'local review') the hospitals themselves undertook into these deaths when they occurred. To address such questions as: did hospitals identify where gaps in care existed, for instance? And was there an action plan to ensure these gaps were addressed?

The purpose of the ESMiE enquiry is to find out how the quality of care can be improved to prevent similar baby deaths in the future.

This project was commissioned by the Department for Health and Social Care England as part of the work of the DH-funded Policy Research Unit in Maternal Health and Care which is based in the National Perinatal Epidemiology Unit, University of Oxford. For this reason the original plan was to only include baby deaths which occurred in England and Wales. This is unlike the MBRRACE-UK

enquires which cover the whole of the UK. When the Chief Medical Officer for Scotland (Dr Catherine Calderwood) heard that the ESMiE enquiry was being carried out she got in touch with the ESMiE team personally to ask if Scotland could be included in the ESMiE enquiry since this service evaluation is as relevant in Scotland as in England and Wales.

The deaths that will be included in the enquiry will include a random sample of 5-10 eligible baby deaths from Scotland over the period 2013-2016.

1819-0080 Professor Joan Morris
Follow Up of Participants in the Randomised Trial of Helicobacter Pylori Screening (HPSS)

Aims
To determine if screening for and the treatment of Helicobacter pylori infection of the stomach in middle age reduces the incidence of, and mortality from stomach cancer.

Background
A randomised controlled trial recruited 62,454 people attending ten BUPA Wellness Centres from 1997 to 2006, the H Pylori Screening Study (HPSS). Those attending in screened weeks were offered serological testing for H pylori and, if they were positive, a one week course of eradication treatment. Blood was collected and stored from all participants. All participants were flagged with Health and Social Care Information Centre (HSCIC) and information on their deaths and cancer notifications has been supplied since 1997. It was expected that the length of follow-up would be a minimum of 20 years.

Methods
We are applying to NHSCR Scotland to continue to receive this information for participants in Scotland every 6 months electronically. When a sufficient number of participants have developed stomach cancer for the results of the trial to have sufficient statistical power the serum samples from all persons who developed stomach cancer and a random sample of those who did not will be retrieved from freezers in the Wolfson Institute and tested for H. pylori. It is estimated that a sufficient number of cancers will have occurred by 2021. The final comparison will be between the incidence of stomach cancer in the screened and control groups among H pylori positive persons only (rather than all persons).

1819-0089 Dr Lynne Warrander
Determining incidence and survival rates in extreme early onset fetal growth restriction

The failure of a developing baby in the womb to reach its growth potential is termed fetal growth restriction (FGR), and this has a strong association with stillbirth. FGR can occur at any time during pregnancy, but in a small number of pregnancies, it happens very early on and can result in a baby weighing only 600g by 28 weeks of gestation; this is termed eFGR. With eFGR, the baby is almost certain to die unless the problem is identified, and intervention occurs. There is currently no treatment to alter growth in eFGR, other than optimising the timing of delivery. eFGR therefore presents a great challenge to obstetricians, who must weigh up the risk of stillbirth when continuing with the pregnancy, against the risks of infant death or long-term complications which are

associated with delivery at such extremes of gestation and birthweight. The is a lack of research in various aspects of eFGR, which this project aims to address. Currently, data on such pregnancies is not routinely collected, and subsequently it is difficult to determine the size and scope of the problem. Access to the Scottish Maternity data set will allow the incidence of eFGR to be calculated as a proportion of the total births prior to 32 weeks', and provide the data required to calculate current stillbirth and infant death rates attributable to eFGR. This will improve the counselling given to parents receiving a diagnosis of eFGR and will help to target future research in antenatal management of FGR.

1819-0092 Caroll Brown

Linkage of patients using Home and Mobile Health Monitoring technologies for Respiratory diseases (COPD and Asthma) in NHS Greater Glasgow and Clyde, NHS Ayrshire & Arran and NHS Highland

Information Services Division (ISD) provides analytical and economic support to the Technology Enabled Care (TEC) programme. Home and Mobile Health Monitoring (HMHM) for Respiratory diseases; COPD and Asthma are two of the services funded by the TEC programme to support citizens to better manage their own health by helping them to learn about their own condition, the changes in health that they experience and establishes links between these changes and their personal choices about adherence to treatments and lifestyle. With this information and knowledge, citizens acquire a greater confidence in making decisions and taking responsibility for managing their health and lifestyle choices on a daily basis. This data linkage to ISD health data is part of the economic evaluation and will be used to evidence the perceived benefits for the cohort of patients, i.e. whether self monitoring changes patterns in accessing health services and whether citizens do become more confident in managing their condition.

1819-0098 Dr Fozia Roked

Surveillance of Congenital Ichthyosis in UK and Ireland in neonates. Listed under the BPSU Surveillance of rare disease approved application

Ichthyosis is a group of incurable genetic conditions with abnormally thick, scaly skin[1]. The most severe types, known as "autosomal recessive congenital ichthyosis" (ARCI) are present at birth. The most severe type of ARCI is harlequin ichthyosis (HI) where thick scales (plaques) encase the baby, causing problems with breathing, feeding, movement, eye closure and temperature control. Historically such babies died at birth or in the first month of life (neonatal period) but they can survive with modern treatments.

Babies with HI and CM are very rare. Staff in maternity units recognise them but need help from skin specialists to care for them. Theris no proven correct treatment so practice varies; some babies remain in the neonatal intensive care unit for weeks whilst others are nursed within a more normal setting. Some health professionals express the view that babies with HI should be left to die, unaware that the condition is now treatable.

Our proposed study will establish the number of new cases and early death rates. We will record key components of management, complications and age on discharge from hospital. This information will support an application to NHSEngland for a Highly Specialised Service and may help us understand why some babies die. Ichthyosis is considered a European public health priority[2] . Ultimately, we aim to improve care for these children and families, reducing misconceptions about the disease, variation in practice, and avoidable deaths.

1. Ichthyosis support group website link: www.ichthyosis.org.uk
2. European Reference Network for rare skin disease: http://skin.ern-net.eu/

1819-0099 Professor Colin McCowan

Population-Based Research on the Incidence, Prevalence, Patient Characteristics Treatment patterns & Outcomes in Patients with Coronary Artery Disease, Peripheral Artery Disease & Heart Failure in Scotland

Heart disease and diseases of the arteries are one of the biggest causes of death in Scotland. We still do not know enough about what happens to patients once they are initially diagnosed with conditions such as heart failure, coronary artery and peripheral arterial disease and what treatment they then receive. We plan to look at a large group of patients with the three diseases, examine what drugs were used to treat them and see whether there were differences in which patients died and those who did not. This work will use anonymised health records of people who have had these conditions but will help doctors decide what are the best drugs to manage patients developing these diseases in the future.

1819-0102 Dr Claudia Geue

Estimating the value of Precision Medicine Technologies: Developing a Scottish Toolkit

The full potential of personalised and precision medicine (PPM) goes further than just targeting treatments for patients who already suffer from certain diseases. PPM also includes our ability to diagnose or identify individuals, who have not developed a disease, but who are at risk of disease. This way, preventive measures can be taken to target individuals, who would benefit most. Hence, estimates of the potential value of PPM technologies can be valuable in improving the targeting of research efforts and investment and facilitating the evaluation of candidate technologies.

In 2015 Victor Dzau published a paper that includes estimates of the potential impact of precision medicine using a US based burden of disease model and considers two scenarios representing a 10 or 50% reduction in incidence across broad disease categories. However, the credibility of these scenarios have been questioned on the basis that there is currently little evidence that the provision of genomic information will overcome the limitations of current lifestyle interventions. McKinsey have published a report considering the impact of precision interventions of personalized medicine categorising across specific disease targets according to feasibility and potential impact of precision interventions. The aim of our study is to develop a toolkit to support the estimation of the potential value of precision medicine technologies efforts within a Scottish context.

1819-0105 Dr Norah Palmateer
Record linkage initiative to monitor hepatitis C testing, diagnosis and treatment of children born to hepatitis C infected mothers in Scotland

The Scottish Government's Sexual Health and Blood Borne Virus Framework (SHBBV) (2015-2020) aims to reduce newly acquired blood-borne virus (BBV) infection, reduce the health inequalities gap in BBV infection and ensure people infected with BBVs lead longer, healthier lives. Health Protection Scotland (HPS) have responsibility for generating data and information to measure progress on achieving the aims of the Framework. For HCV these include (for different risk groups) outcomes relating to testing, diagnosis and treatment.

An estimated 34,500 people are living with chronic hepatitis C virus (HCV) infection in Scotland; children born to HCV-infected women are at risk of vertical transmission (mother-to-child transmission during pregnancy or at the time of birth). National guidelines state that children of HCV-infected mothers should be tested, and if infected, should be monitored to determine whether they are candidates for HCV treatment. However, it is currently not known whether children are being tested or treated in line with the national guidelines. Given their toxicity, the old interferon-based therapies were only recommended for treating children in cases of advanced disease; but given that the new, highly effective antiviral therapies for HCV have recently been approved for use in children aged 12+, the importance of HCV testing and diagnosis in children is now timelier than ever.

The proposed initiative will comprise the linkage of the HCV diagnosis database, held at HPS, to maternity records, held at Information Services Division (ISD), in order to identify women who have been diagnosed with chronic HCV and who have one or more records relating to the birth of a live child. Subsequently, linkage of identified children to the HCV (test/diagnosis/clinical) databases, hospital discharges, treatment for drug misuse records, and deaths, will allow us to establish the extent to which they are being tested, diagnosed, and treated for HCV, and experiencing liver- and non-liver-related health outcomes.

1819-0108 Dr Christopher Verity
Progressive Intellectual and Neurological Deterioration - PIND Study

The study into Progressive Intellectual and Neurological Deterioration (PIND) remains the only way to search for variant Creutzfeldt Jakob Disease (vCJD) cases in the complex group of children/young people with progressive neurological disease under the age of 16 years. It collaborates with the National CJD Research and Surveillance Unit (NCJDRSU) in Edinburgh to ensure that no child is missed with this diagnosis. The NCJDRSU is only able to perform surveillance in adults.

Paediatricians continue to co-operate with us when we contact them to obtain data about reported cases of PIND and so do the various laboratories that are involved in the investigation of children with neurodegenerative disease.

The PIND study methodology allows the PIND Expert Group to review the anonymised clinical data on diagnosed and undiagnosed children with progressive neurological disease and thus search for possible cases of vCJD in children, who may have a clinical presentation different from that in adults. If the PIND study finds no cases in this age group it provides supportive evidence that public health measures are effective in preventing the spread of vCJD, which has implications for public health policy in the UK and abroad.

Over the nearly 20 years that the PIND study has been running it has provided unique data on the many different causes of progressive neurological disease in children and the variation in the incidence of these disorders in different ethnic groups. These findings are important for epidemiological reasons and contribute to the appropriate planning of diagnosis, clinical management and the provision of services.

All necessary ethics approvals are in place.

1819-0123 Dr Gary Stiefel
Surveillance of Food Protein Induced Enterocolitis Syndrome (FPIES) presenting to paediatricians in UK and Ireland.

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

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

Food Protein Induced Enterocolitis Syndrome (FPIES – pronounced F-pies) is a delayed type of food allergy which leads to repeated vomiting and other gastrointestinal symptoms up to several hours after a problem food (or baby formula) is eaten.

Delays in diagnosis are frequent, since many frontline healthcare providers are not aware of the condition, and presenting clinical features can mimic more common paediatric presentations, such as sepsis and surgical abdominal emergencies. Consequently children with FPIES often have multiple episodes, additional investigations and hospital admissions before a diagnosis of FPIES is made.

There is very limited data on FPIES in the UK and this study is intended to improve our knowledge of the incidence, clinical presentation and management as well as improve awareness amongst paediatricians. This has the potential to benefit patients and families through quicker diagnosis and instigation of effective management of FPIES.

1819-0125 Dr Stephen Pavis
Exemplar project for Scottish Medical Imaging (SMI)

The Scottish Medical Imaging (SMI) project (1718-0316) has been set up to deliver a Minimum Viable Product (MVP) to provision de-identified images for research within the National Safe Haven. The project is a collaboration between the University of Dundee, the University of Edinburgh and eDRIS/NSS.

The purpose of this application is the testing of de-identification of clinical images using algorithms developed and tested under 1516-0350.

The algorithms measure simple parameters in CT images (for example the diameter of the airways) and the reason they are a good test for the Minimum Viable Produce is:

- they have already been developed and validated against image data (removing this as a cause of any defects in the de-identification process)
- prove that de-identified images from the MVP are useable for this type of research

The permission to create a research-ready, national image dataset and for the copy and transfer of the clinical images is covered by PBPP application 1516-0486.

1819-0147 Dr Yvonne Bramma
WoSTRAQ: Post-operative Cognitive Impairment and Delirium in the West of Scotland

WoSTRAQ are the West of Scotland Trainee Research, Audit and Quality Improvement Network – we are a network of anaesthetic trainees in the West of Scotland School of Anaesthesia (encompasses NHS Greater Glasgow and Clyde, NHS Lanarkshire, NHS Ayrshire and Arran, NHS Forth Valley, NHS Dumfries and Galloway, and NHS National Waiting Times Centre).

The development of delirium or Post-operative Cognitive Impairment (POCI) is an increasing concern in elderly patients undergoing anaesthesia and surgery. Pre-operative identification of those at risk is important in planning anaesthetic interventions and peri-operative care in order to reduce the risk of these patients developing POCI.

We are planning to conduct an audit of patients across all hospitals within the school looking at the presence of risk factors for POCI. This will be the beginning of a quality improvement project. The data collected in this project will give us an idea of how many surgical patients have risk factors for POCI and how many patients are on medications or receive anaesthetic techniques that may increase their risk of POCI. Following the audit, we hope to be able to introduce some educational sessions and simple screening tools in line with the Health Improvement Scotland/Scottish Delirium Association's guidance on the identification and management of acute delirium in hospital patients (Supporting Document 6). We hope that this will improve the peri-operative care of patients at risk from POCI.

1819-0150 Dr Peter Murchie
National Cancer Diagnosis Audit (NCDA) Scotland – Analyses

The National Cancer Diagnosis Audit (NCDA) for Scotland collected information about what happens to patients before they get diagnosed with cancer. This included information on symptoms patients experience, how often they see their GP, what tests they have done, and when and how they are referred to a specialist. This kind of information can help to understand what works well and where there is room for improvement, so that cancer can get diagnosed earlier in future.

The NCDA dataset for Scotland includes information on more than 2,000 cancer patients diagnosed in 2014. The primary purpose of the audit was to inform local improvement work and to this end, all participating practices and related organisational levels were supplied with a tailored feedback report and advice about how this information could be used. An overview of the data collected in Scotland was published on the ISD website in March 2018:

http://www.isdscotland.org/Products-and-Services/Consultancy/Surveys/National-Cancer-Diagnosis-Audit-Scotland.asp

In this project, analysts from the Universities of Aberdeen and Edinburgh want to look at the information in depth to understand more about how patients get diagnosed with cancer in Scotland, what factors can influence how quickly someone is diagnosed, and where the challenges and bottlenecks are, with a view to improving services for patients and families in future.

1819-0153 Dr Alastair Ross
FACTORS- (Fluoride Application: a Co-designed Toolkit of ORganisational Strategies)

Under Scotland's national Childsmile programme, dental practices providing NHS care are expected to deliver Fluoride Varnish for preventing dental decay twice a year for young children from the age of two years old. Monitoring data we use as part of our evaluation of the programme shows that delivery of this evidence-based preventive treatment is still variable. As part of our ongoing Childsmile implementation and evaluation contract at Glasgow Dental School, we have co-designed with dental professionals a 'toolkit' of help for dental teams to support fluoride varnish application in General Dental Practice.

The package contains: a) personal feedback on fluoride varnish application rates in comparison to national norms; and b) a quality improvement exercise including tips, advice and strategies to enhance application in practice.

The toolkit is being developed along with a third party- APS Group (Scotland) Limited, who are contract suppliers to the Scottish Government, NHS Education for Scotland NES and universities and colleges, under the national framework for the provision of publishing, print, design and associated services (PPDAS).

1819-0172 Dr Marisa Mason
Child Health Clinical Outcome Review Programme

NCEPOD are undertaking a study to explore the quality of care received by young people (up to their 25th birthday) who are receiving long-term ventilation (LTV).

A local contact in every hospital across the UK, Guernsey, Jersey and the Isle of Man will help us identify all patients whose data could potentially be included in this the study.

We will ask the contact for a list of all patients on LTV, aged 0-24, known to them during 1st April 2016 to 31st March 2018. This information will be supplied to us on a password-protected spreadsheet, and will include NHS/CHI number, hospital number and date of birth. It will not include names or addresses and we will not contact any patients directly.

From this big sample we will randomly select a smaller sample of cases to be reviewed in more detail by clinicians. For each of the included sample cases we will collect:

1. Questionnaires completed by the clinicians involved in the patient's care. These will not contain any patient details
2. Copied extracts of case notes, reports and test results, and copies of letters and medical records from other clinicians such as physiotherapists. The patient information collected via the case notes is essential to this process as it provides a view of the detailed care received by each patient, which is richer than simply counting numbers. All patient identifiable

information will be removed before the case is reviewed and all copies of case notes are destroyed at the end of the study.

1819-0186 Professor Richard Anderson
Reproductive outcomes in survivors of childhood, adolescent and young adult cancer in Scotland: a population based cohort study

Continuing advances in therapy mean that many children and young people can now expect long term survival following a diagnosis of cancer, and increasing emphasis is placed on the 'late effects' of the diagnosis and particularly the treatment received. The impact on fertility is one of the consequences of cancer treatment of greatest importance to patients. The needs of childhood cancer survivors in this respect have been acknowledged by the recently updated Scottish Intercollegiate Guidelines Network (SIGN) guideline on 'Long term follow up of survivors of childhood cancer'; the UK Royal Colleges have also produced a guideline on the management of the effects of cancer treatment on reproductive function in adults. Both of these highlight the importance of having accurate information to inform patients about risks, but the information currently available is often very limited. In particular, there are no population-based studies that have assessed fertility and pregnancy outcomes in cancer survivors in both childhood and adulthood, thus providing accurate and unbiased data across a range of ages and diagnoses.

1819-0189 Michael Blayney
Multimorbidity in Scottish ICUs

The Scottish Intensive Care Society Audit Group (SICSAG) database collects information on all patients admitted to critical care units in Scotland in order to improve the quality of care. This study aims to improve the quality of the SICSAG audit.

Doctors and nurses working in critical care are increasingly caring for critically ill patients who are older and have multiple pre-existing health problems (multimorbidity). Patients with a greater number of pre-existing health problems are more likely to die or, if they survive, have additional health problems. Only a limited number of pre-existing health problems are recorded in the audit database, as this was set up in 1995 at a time when patients admitted to critical care were younger with fewer health problems.

This project will look at changes in multimorbidity in the Scottish ICU population over time and assess how well recorded these conditions are in comparison with a separate database of hospital discharges (SMR01). The project will also investigate whether the addition of a measure of multimorbidity derived from the hospital database (SMR01) could be used to improve the statistical model currently used by SICSAG to benchmark death rates in each unit against the national average.

The project will be undertaken under the supervision of the SICSAG team in the Information Services Division in collaboration with researchers and clinicians. It should improve quality of the database in the following ways:

1. Reporting how common multimorbidity is will allow better planning of services in the future.
2. Comparing multimorbidity recording in the SICSAG database with the prescribing database will allow quality of current data recording to be assessed.

3. Improving the performance of the current statistical model will allow more accurate benchmarking of quality of care in the future.

1819-0229 Viktoria McMillan
National Asthma and COPD Audit Programme (NACAP) – pulmonary rehabilitation audit

The Royal College of Physicians is commissioned to deliver NACAP. This programme, which launched in March 2018, is funded by HQIP.

NACAP is a continuation of the National COPD Audit Programme. This three year 'extension' involves the addition of audits of adult and paediatric asthma to form a combined airways audit, which will also be delivered in Scotland.

This proposal requests permissions for NACAP to deliver a continuous audit of PR services (i.e. patients referred to PR) in Scotland. This audit will launch in March 2019 (in all nations).

This audit will operate under a patient consent model (given the comparatively low acuity of the patient cohort and their prolonged exposure to the service). In other words, patients will consent for their PID to be collected and linked to external sources.

1819-0232 Emily Petch
Each Baby Counts ascertainment using NNRD data

This proposal is to allow continued participation of Scottish units as part of Each Baby Counts. Each Baby Counts is a UK-wide quality improvement programme led by the Royal College of Obstetricians and Gynecologists (RCOG). The programme seeks to reduce the incidence of intrapartum stillbirth, early neonatal death and severe brain injury as a result of events in labour by 50% between 2015 and 2020. The project currently collects data on eligible infants directly from maternity providers using an online system. This data is subsequently validated using the data collected in the National Neonatal Research Database (NNRD) to ensure no eligible infants are missed and that all infants eligible for the programme are included.

1819-0234 Dr Kenneth McLean
REspiratory COmplications after abdomiNal Surgery (RECON)

The aim of this study is to better understand how to reduce respiratory complications (aka postoperative pulmonary complications) after major abdominal surgery across the UK and Ireland. This can include lung collapse (atelectasis), lung infection (e.g. pneumonia), or lung inflammation (acute respiratory distress syndrome – ARDS). Any hospital in the UK and Ireland can take part as long as they perform eligible surgical procedures on a routine basis.

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

We will include all patients who undergo surgery in the study period at each participating hospital. The study will run from Monday 21st January 2019 to Sunday 17th March 2019 (with the last follow-up period ending on 16th April 2019). Data will be collected on all patients receiving their initial surgery during the time-period with follow-up to 30-days after their operation. This will include all adult patients undergoing emergency or elective abdominal surgery (including complete or partial abdominal organ removal, reversal of stoma, open vascular surgery, anterior abdominal wall hernia repair, or transplant surgery) through any operative approach.

1819-0256 Professor Gerald Humphris
A pilot trial of the Mini-AFTERc intervention to manage Fear of Cancer Recurrence in breast cancer patients

People treated for breast cancer often live with an ongoing fear that the cancer will recur. Mini-AFTERc is brief nurse-led telephone counselling intervention, designed to reduce fear of cancer recurrence (FCR) in breast cancer patients.

This study aims to determine the acceptability and practicality of introducing the Mini-AFTERc intervention into everyday practice, and inform the development of a full randomised controlled trial.

Phase 1 includes the development and delivery of the Mini-AFTERc intervention training package for breast cancer nurses.

Phase 2 includes patient recruitment and data collection. There will be 2 intervention centres and 2 control centres across NHS Scotland. Patients who have completed their breast cancer treatment, will be screened for moderate FCR at follow-up appointments. Breast cancer nurses will deliver the intervention by telephone in intervention centres. Patient satisfaction with the intervention will be measured. Follow-up questionnaires measuring FCR, anxiety and depression and quality of life outcomes will be delivered via a smartphone app at 2 weeks, 1 month and 3 months following intervention or 3 weeks, 5 weeks and 13 weeks following screening for control patients. Semi-structured interviews with patients and nurses will assess experiences and acceptability of the intervention.

Phase 3 will analyse the information produced from the outcome measures and interviews, and asses the study using a process for decision making after pilot and feasibility trials (ADePT).

The findings will determine if Mini-AFTERc can be implemented in everyday practice, can reduce FCR. They will also inform the practicality of implementation of a larger-scale randomised trial.