2019/20 Applications approved by HSC-PBPP

2019/20 Applications approved by HSC-PBPP to 31st March 2020

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Application Reference	Applicant	Title of Study	Level of Approval	Outcome	Clocked time (days)
1819-0251	Professor Steve Turner	What was the effect of the "Take it Right Outside" public health campaign on paediatric hospital admissions?	Tier 1 Review	Approved	22
1617-0266	Peter Murchie	Does increased distance to services lead to different treatment and follow-up for cancer in Scotland? Creating and analysis a Scottish Cancer and Residence (SCOTCAR) dataset	Tier 1 Panel Meeting	Approved with conditions	13
1819-0293	Marisa Mason	Medical and Surgical Clinical Outcome Review Programme	Tier 1 Panel Meeting	Approved	9
1617-0314	Dr Bonnie Auyeung	Understanding the effects of prenatal maternal infections on developmental outcomes, autism spectrum disorder and learning disabilities.	Tier 1 Review	Approved with conditions	26
1718-0332	Mina Khezrian	Polypharmacy; prevalence , predictors and its effect on health outcome in the Aberdeen Children of Nineteen Fifties Cohort (ACONF)	Tier 1 Review	Approved	25
1819-0169	Linsey Galbraith	National Cancer Diagnosis Audit (NCDA) 2019 – Scotland	Tier 1 Panel Meeting	Approved with conditions	16
1819-0009	Jade Hooper	Social and locality variations in dog bites and strikes in Scotland: Analysis of linked by-product datasets	Tier 1 Review	Approved	20
1819-0262	Heather Wotherspoon	Head and Neck Population Analysis	Tier 1 Panel Meeting	Approved	11
1819-0213	Elaine Glass	Rates of recurrent S.aureus bacteraemia infections associated with long line risk factors – survival analysis of surveillance data in Scotland	Tier 1 Review	Approved	31

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1819-0072	Professor John Cleland	Clinical Research in Heart Failure – Long-term follow-up	Tier 1 Review	Approved with conditions	24
1718-0219	Dr Christine Campbell	Scottish Cervical Screening and Ethnicity (SCREEN)	Tier 1 Panel Meeting	Approved with conditions	18
1819-0033	Dr Alexander J Fowler	Defining the high-risk surgical population in the National Health Service	Tier 1 Panel Meeting	Approved	10
1718-0238	Prof James Lewsey	TRends and Inequalities in Prescribing for Alcohol Dependence in Scotland (TRIPADS)	Tier 1 Panel Meeting	Approved	17
1819-0235	Lee Barnsdale	Scottish Public Health Drug Linkage Programme	Tier 1 Review	Approved	19
1819-0194	Professor Ian Deary	Mental health within the family and between generations – Phase 2: Linking Scottish Mental Survey 1947 members and their families	Tier 2 Out of Committee	Approved	72
1819-0224	Archie Campbell	Generation Scotland linkage	Tier 1 Review	Approved	19
1819-0263	Dr Ceilidh Grimshaw	HIV in the era of Pre Exposure Prophylaxis (PrEP): An evaluation of characteristics of people who have acquired HIV prior to and since the launch of a national NHS-delivered PrEP programme in Scotland	Tier 1 Review	Approved	25
1617-0324	Dr Louise Marryat	The development of a cohort of children born to opioid dependent mothers in Scotland	Tier 1 Review	Approved	19
1819-0236	Fiona Campbell	Excellence in Care (EiC) – Generic Application	Tier 2 committee	Approved with conditions	78
1819-0051	Professor Sally-Ann Cooper	Health, death, and cancers in people with learning disabilities and people with autism	Tier 2 committee	Approved with conditions	107
1819-0184	Dr Alastair Philp	Developing an all-Scotland consistent minimum dataset for neonatal care – Phase 1	Tier 1 Panel Meeting	Approved	16

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1819-0333	Sally Stewart	ECONI Phase 4 Modelling Project End	Tier 1 panel meeting	Approved with conditions	13
1718-0177	Dr Angela Lucas-Herald	The long term cardiovascular complications associated with hypospadias	Tier 1 Review	Approved	41
1819-0349	Nicola Starkey	Child Adolescent and Psychological Therapy National Dataset	Tier 1 Panel Meeting	Approved with conditions	6
1819-0321	Dr Amanda Cross	Multicentre randomised controlled trial of ‘once only’ flexible sigmoidoscopy in prevention of colorectal cancer morbidity and mortality. Short Title: The UK Flexible Sigmoidoscopy Screening Trial (UKFSST)	Tier 1 Review	Approved	45
1819-0315	Professor Helen Colhoun	SDRN Type 1 Bioresource Data Linkage	Tier 1 Review	Approved	36
1819-0270	Su-Gwan Tham	Suicide by middle-aged men	Tier 1 Review	Approved with conditions	22
1819-0340	George Ramsay	Characterising cause of mortality trends of patients admitted to Emergency General Surgery in Scotland	Tier 1 Panel Meeting	Approved	14
1718-0220	Dr Eve Miller-Hodges	Circulating biomarkers to predict cardiovascular, kidney and all-cause outcomes in kidney transplant recipients	Tier 1 Panel Meeting	Approved with conditions	7
1819-0183	Lucy Irvine	The transfer, use, and retention of anonymised cancer data from the Scottish Cancer Registry, Population Health to enable the National Cancer Registration and Analysis Service (NCRAS), Public Health England (PHE) to collate a UK dataset and carry out analysis needed for the “UK Children, Teenage and Young Adults (CTYA) cancer statistics annual report 2019”	Tier 1 Review	Approved	28
1617-0283	Nazir Lone	Maternal critical care: identifying at-risk women and understanding the short and long term consequences of critical illness in pregnant or recently pregnant women	Tier 1 Review	Approved	24
1718-0233	Dr David Preiss	ORION-4 trial	Full committee	Approved with conditions	109

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1819-0204	Dr Larry Doi	A realist evaluation of the Universal Health Visiting Pathway	Tier 1 Review	Approved with conditions	40
1920-0058	Dr Alice Jackson	The epidemiology of peripartum cardiomyopathy in a Western European country: An analysis of the Scottish population from 1986-2017 (Children)	Tier 1 panel meeting	Approved	13
1819-0253	Julia Dudley	Enhanced surveillance of neonatal herpes simplex disease in UK and Irish infants less than 90 days of age	Tier 1 review	Approved with conditions	59
1819-0157	Dr Gemma Archer	Epidemiological studies of the Porton Down veterans	Tier 1 panel meeting	Approved with conditions	10
1920-0104	Richmond Davies	NSS Public Health & Intelligence Data Quality and Terminology Services Caldicott approval for rolling access to patient level data for auditing and improving quality of clinical coding and data recording.	Tier 1 panel meeting	Approved with conditions	12
1819-0163	Joanne McPeake	The impact of alcohol minimum pricing in the critical care context	Tier 1 Review	Approved with conditions	27
1819-0328	Laura McIver	Rheumatology Quality Registry Pilot	Tier 1 Review	Approved	69
1819-0306	Dr Claire Niedzwiedz	Prescribing for common mental health disorders amongst people diagnosed with cancer: data linkage study of the Scottish population	Tier 1 Review	Approved with conditions	36
1617-0148	Meryl Heggeland	SCI-DIABETES Minimum dataset	Tier 1 Review	Approved with conditions	28
1920-0066	Dr Alice Jackson	The epidemiology of peripartum cardiomyopathy in a Western European country: An analysis of the Scottish population from 1986-2017 (CHI no for mother)	Tier 1 Review	Approved	34
1819-0226	Professor Sally-Ann Cooper	Mothers with learning disabilities and mothers with autism: prevalence and outcomes	Tier 1 Review	Approved with conditions	24

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1718-0316	Jackie Caldwell	Scottish Medical Imaging (SMI) project – development of a suite of tools to de-identify clinical images	Tier 1 Panel Meeting	Approved with conditions	8
1819-0276	Cara Richardson	Application to Access the ScotSID Database	Tier 1 Panel Meeting	Approved	14
1920-0001	Dr Jessica Butler	Mapping the healthcare journeys of people with fibromyalgia	Tier 1 Review	Approved with conditions	23
1819-0332	Dr Zoë Burton	PErioperAtive CHildhood ObesitY (PEACHY)	Tier 1 Review	Approved	41
1819-0264	Dr Charis Marwick	Antibiotic Research in Care Homes (ARCH): unscheduled care use as a safety outcome measure	Tier 1 Panel Meeting	Approved	16
1819-0093	Dr Katherine Keenan	Social inequalities in chronic disease trajectories in mid and later life: taking account of multimorbidities	Tier 1 Review	Approved	28
1819-0160	Joanne O'Donnell	SCOTS Surgical Obesity Treatment Study	Tier 1 Review	Approved with conditions	23
1920-0005	Sarah Martin	Scottish Health Survey child boost eligible sample	Tier 1 Panel Meeting	Approved with conditions	9
1718-0054	Dr Sarah Stock	Benefits and Harms of Antenatal Corticosteroid Therapy (ACT)	Tier 1 Panel Meeting	Approved	18
1819-0054	Dr Ewen Johnston	Outcome of resuscitated term babies with no heart rate detected at 10 minutes of age (A British Paediatric Surveillance Unit project)	Tier 1 Review	Approved with conditions	27
1819-0050	Karen Clements	The Sloane Project – a prospective audit of screen-detected non-invasive carcinomas and atypical hyperplasias of the breast.	Tier 1 Review	Approved with conditions	25
1920-0068	David McDonald	Standardised Pathways of Care	Tier 1 Review	Approved with conditions	41

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1819-0357	Dr Shamez Ladhani	Characteristics of Children with Pneumococcal Meningitis in the United Kingdom and Republic of Ireland	Tier 1 Review	Approved	30
1819-0176	Professor Duncan Porter	Scottish Early RA inception cohort	Tier 1 Review	Approved	34
1819-0001	Dr Scott Cunningham	Digital Health Technology Catalyst: MyDiabetes IQ	Full Committee	Approved with conditions	207
1920-0004	Susan McVie	Violence and underlying vulnerability	Tier 1 Panel Meeting	Approved with conditions	11
1920-0099	Dr Liam Mullen	RIPCORD 2	Tier 1 Review	Approved	13
1920-0046	Danny McGee	SNBTS Transfusion Team Audit Programme	Tier 1 Panel Meeting	Approved with conditions	23
1819-0159	James Chal	National Cardiac Audit Programme (NCAP)	Tier 1 Review	Approved with conditions	76
1718-0318	Linda Cullen	Development of (electronic data collection system for theScottish Electro-Convulsive Therapy Network (eSEAN))	Tier 1 Review	Approved with conditions	39
1819-0345	Ann Banfield	ISCHEMIA-Extend: Long Term Follow Up of ISCHEMIA Trial Participants	Tier 1 Review	Approved	17
1819-0336	Dr Timothy Cheetham	Symptomatic glucocorticoid induced adrenal suppression in the United Kingdom and Ireland	Tier 1 Review	Approved	34
1819-0030	Jenny Simons	PARD – Persons at Risk Distribution	Tier 1 Review	Approved	29
1920-0080	Dr Anoop Shah	Population trends and outcomes following hospitalisation with cardiovascular disease	Tier 1 Review	Approved	38
1718-0376	Dr Roxanne Hastie	Using big health data in the prevention of preeclampsia	Tier 1 Review	Approved	43

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1819-0069	Dr Rosemary Hollick	Effective healthcare delivery in rare rheumatic disease: evaluating models of care for systemic vasculitis	Tier 1 Review	Approved	40
1920-0144	Dr Michael Fleming	Investigating the relationship between health and educational outcomes in children	Tier 1 Panel Meeting	Approved	7
1819-0358	Professor Maggie Cruickshank	Thermocoagulation of CIN	Tier 1 Review	Approved with conditions	33
1819-0314	Professor Malcolm G Dunlop	Colorectal Cancer Genetic Susceptibility Programme	Tier 1 Panel Meeting	Approved	9
1819-0148	Dr Alastair Philp	AHP Operational Measures – Phase 3	Tier 1 Panel Meeting	Approved	20
1718-0331	Dr Robert Flynn	Evaluating Diuretics in Normal Care (EVIDENCE) - a cluster randomised evaluation of hypertension prescribing policy: Pilot phase	Tier 2 out of committee	Approved with conditions	97
1819-0282	Dr Annemarie Docherty	Critically ill patients with co-existing cardiovascular disease: short and long term consequences of critical illness	Tier 1 Panel Meeting	Approved	11
1920-0101	Dr Lucy Plumb	A prospective surveillance study of conservatively managed children with end-stage kidney disease in the United Kingdom and Republic of Ireland	Tier 1 Panel Meeting	Approved	19
1819-0117	Dr Jill Ireland	SPARRA and High Health Gain predictive modelling	Tier 1 Panel Meeting	Approved	19
1819-0323	Dr Peter Gallacher	Incidence and outcomes of acute coronary syndrome in dialysis and renal transplant patients: a national, longitudinal data-linkage study	Tier 1 Review	Approved	24
1920-0093	Lorraine Donaldson	Scottish Intensive Care Society Audit Group Application for linkage within NSS	Tier 1 Review	Approved with conditions	21
1819-0310	Karen Crawford	Best Services Trial (BeST?)	Tier 1 Panel Meeting	Approved	14
1920-0128	Dr David Walsh	Understanding the health benefits of active commuting in a Scottish context	Tier 1 Review	Approved	37

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1920-0127	Professor Frank Sullivan	ECLS Data Sharing Project	Tier 1 Review	Approved with conditions	26
1920-0125	Ronan McCabe	The health impact of Scotland's Baby Box scheme	Tier 1 Panel Meeting	Approved	7
1920-0207	Dr Stephen Knight	ELF 2 – Defining the Denominator	Tier 1 Review	Approved	11
1819-0131	Chris Gourley	Social Transformation for Wellbeing	Tier 2 out of committee	Approved with conditions	68
1920-0131	Professor Jennifer J Kurinczuk	MBRRACE-UK – Delivering the UK Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP)	Tier 1 Panel Meeting	Approved with conditions	20
1920-0028	Carolyn Wilson	Family Nurse Partnership (FNP)	Tier 2 OOC	Approved with conditions	50
1920-0057	Fabia Cientanni	Understanding Uptake, Adherence, and Outcome in cCBT Services: Evidence from Socioeconomic, Clinical, and Healthcare-Belief Perspectives	Tier 1 Review	Approved	41

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Lay summaries of approved applications

1617-0148 Meryl Heggeland
SCI-DIABETES Minimum dataset

SCI-Diabetes is a national database which records diagnoses cases of Diabetes in Scotland. As the SCI-Diabetes database gives the best Diabetes diagnoses coverage for Scotland, it is very useful for researchers to assess which individuals have been diagnosed with Diabetes, when they were diagnosed and what type of Diabetes. This level of detail and population coverage is not available in any NSS dataset. SCI Diabetes will make this data available to other researchers via eDRIS rather than requiring separate applications to SCI Diabetes for every use by external collaborating researchers. We are proposing to have the SCI-Diabetes dataset CHI seeded and available for eDRIS analysts. Researchers would then be able to apply for linked data with the SCI-Diabetes data in PBPP applications, which could then in turn be provided by eDRIS. In order to keep the dataset up to date, we would require annual updates with CHI seeding.

It makes sense to combine these updates with other SCI Diabetes linkage projects (National Diabetes Database - 2019/20 update eDRIS-1819-0271 and SDRN Type 1 Bioresource Data Linkage eDRIS-1819-0315) and receive the CHI seeded cohort once and use it for the three linkage projects. This would reduce the need for eDRIS to run the same CHI linkage and extraction for multiple projects.

1617-0266 Peter Murchie
Does increased distance to services lead to different treatment and follow-up for cancer in Scotland? Creating and analysis a Scottish Cancer and Residence (SCOTCAR) dataset

The North of Scotland Cancer and Residence (NASCAR) project found where a person lives affects their cancer journey. NASCAR used data on the cancer journey for over 12,000 people diagnosed with cancer from 2007-2014, including diagnosis, treatment and outcome. Using Geographic Information Technology (GIS) software we calculated each person's travel-times from home to their GP and nearest hospitals. We then explored if where they lived affected their cancer experiences. The results were surprising. People living >1hour from Aberdeen hospital were diagnosed most quickly. However, they were more likely to die within a year of diagnosis than people living closer to Aberdeen. This suggests people living further away are at an advantage in getting cancer diagnosed and treated, but still do worse long-term.

We now want to conduct SCOTSCAR, throughout Scotland, to see if it is the same. We want to look at how people are treated, and followed-up after treatment, to see if treatment and aftercare received is determined by where Scots live. We will identify all Scots diagnosed with one of eight cancers between 2008 and 2018 using the Scottish Cancer Registry and then match to information on how often people were seen in hospital, what prescriptions they received, and the route each person followed to their cancer diagnosis. We will then use GIS software to work out how far each person lives from their GP, local hospital and nearest cancer centre. The results will help us to ensure all Scottish cancer patients are treated the same.

1617-0283 Nazir Lone Maternal critical care: identifying at-risk women and understanding the short and long term consequences of critical illness in pregnant or recently pregnant women

About 1-in-100 women experience life-threatening illness ('critical illness') during pregnancy/childbirth. Recent reports suggest that the care that critically ill pregnant women receive could be improved. However, we have little research to guide these improvements in care. Our project aims to provide high quality data to inform development and implementation of these recommendations.

Aims
We aim to measure the number of pregnant women who need critical care, identify women at highest risk of needing critical care, and report the short and long-term health consequences of surviving critical care for pregnant women and their babies.

Methodology
We will use routinely recorded and linked clinical datasets to answer our research questions.

We will link the national maternity database to the critical care database, which contains additional information about those admitted to critical care. This combined dataset will then be linked to other sources of information, including mental-health admissions and pharmacy prescriptions. This final dataset will be anonymised so that researchers cannot identify individual women. The data will be analysed in a secure environment, which only the research team can to access.

Expected outcomes
Our project will help us i) find out how often pregnant women need critical care; ii) identify risk factors for critical illness, leading to better recognition of women who may need critical care; iii) identify the major problems that women and their babies experience after surviving critical care which will enable researchers/health workers to develop targeted interventions/services to improve care; and iv) provide important data to improve maternal critical-care audits.

1617-0314 Dr Bonnie Auyeung

Understanding the effects of prenatal maternal infections on developmental outcomes, autism spectrum disorder and learning disabilities.

Prenatal mental and physical health are important factors associated with later child development. Infections during pregnancy are a common occurrence[1] and have been associated with a higher risk of specific disorders in offspring, such as Autism Spectrum Disorders and Schizophrenia [2-3]. Rates of depression during pregnancy are substantial[4]. Associations between maternal prenatal and postnatal depression and adverse child development have been established[5-6], highlighting the importance of taking maternal mental health into account when examining prenatal effects on offspring development. Recent research has shown that effects of prenatal infections were diminished when maternal mental health was taken into account[7].

The main drawbacks of previous studies on links between prenatal infections and developmental outcomes have been that they rely upon hospital admission data for information on maternal infections and clinical diagnosis of difficulties for the children3, omitting mothers who receive healthcare treatment from their local doctor, and children who have developmental difficulties that are not captured in a central register.

To address these limitations, we propose to analyse data that captures milder occurrences of both maternal infections and children's developmental outcomes, and those considered more severe.

Data will include:

- Maternal NHS records during pregnancy, childbirth, obstetric care and history of major physical and mental illness.
- Child NHS records from birth to date
- General Practice records on prenatal infections, child diagnoses and maternal history of major physical and mental illness
- Strengths and Difficulties Questionnaire data at ages 30 months, 5, 7 and 10 years.
- Deprivation Indexes (SIMD and GIMD).

References:

1. Collier et al. (2008). Prevalence of self-reported infection during pregnancy among control mothers in the National Birth Defects Prevention Study. Birth Defects Res A Clin Mol Teratol, 85(3).
2. Knuesel et al. (2014). Maternal immune activation and abnormal brain development across CNS disorders. Nat Rev Neurol, 10.
3. Lee et al (2015). Maternal hospitalization with infection during pregnancy and risk of autism spectrum disorders. Brain Behav Immun, 44.
4. Bennet et al. (2004). Prevalence of Depression During Pregnancy: Systematic Review. Obstet Gynecol, 103(4).
5. Field, T. (2011). Prenatal depression effects on early development: A review. Infant Behav Dev, 34(1).
6. Kingston & Tough (2014). Prenatal and Postnatal Maternal Mental Health and School-Age Child Development: A Systematic Review. Matern Child Health J,18(7).
7. Green et al. (2017). Childhood developmental vulnerabilities associated with early life exposure to infectious and noninfectious diseases and maternal mental illness. J Child Psychol Psychiatry, 59(7).

1617-0324 Dr Louise Marryat

The development of a cohort of children born to opioid dependent mothers in Scotland

In Scotland, c.500 children a year are born to women who use opioid drugs. Evidence exists that these children experience poorer physical and mental health, however research on this group is limited due to the chaotic nature of their lives, making it near impossible to follow them up beyond birth. This project will follow a group of children who were born to opioid dependent mothers, using routinely collected data from health records, to explore what happens to them in the first two years. This will be used to answer two questions: firstly, data from birth records and neonatal care records will be explored to find out about outcomes for children born to opioid using mothers, compared with those whose mothers do not use opioids. The second question looks at early health outcomes up to the age of two year. To answer this question we will explore data collected by health visitors, and hospital admissions. This study will lead to a bigger proposal which will explore longer-term health, social and educational outcomes

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1718-0054 Dr Sarah Stock

Benefits and Harms of Antenatal Corticosteroid Therapy (ACT)

Antenatal corticosteroid treatment (ACT) is given to pregnant women thought to be at high risk of preterm birth (i.e. birth <37 weeks gestation) to help mature a baby's lungs. ACT can be lifesaving for babies who deliver early. However, as preterm birth is difficult to predict, many women are given ACT just in case of early birth. We do not know if ACT has side effects if the pregnancy continues and early birth does not occur. Some evidence suggests that ACT may have effects on growth and development, stress responses and mortality rates. We also do not know if ACT has the same benefits in all babies born early or if effects are different in different types of pregnancy eg in twins, or when infections are present.

Our aims are to find out the short-term and long-term outcomes of ACT in women and babies who are treated and subsequently deliver close to their due date (unnecessary treatment). We also want to find out which conditions influence mother and baby's response to ACT, so we can find out the best way to prescribe them.

We will use data from Scottish Maternity records to study what happens to mothers and babies after ACT, particularly if they do not deliver early. We will combine Scottish data with data from maternity records from other countries, and data from completed research studies. We will find out which women and babies benefit most from ACT, and which may not. The results will improve prescribing in pregnancy.

1718-0177 Dr Angela Lucas-Herald

The long term cardiovascular complications associated with hypospadias

Hypospadias is a birth defect in boys in which the opening of the tube that carries urine from the body (the urethra) develops abnormally, anywhere from just below the end of the penis (mild hypospadias) to the scrotum (severe hypospadias). In Scotland, with an estimated birth incidence of 56,000 per year, approximately 280 boys are born with mild hypospadias and 56 boys are born with more severe hypospadias every year. In many boys with hypospadias, although their testosterone levels may be normal after birth, some studies suggest that exposure to the male hormone, testosterone, may have been inadequate during vital periods of sex development during foetal life. Testosterone is essential for maintenance of blood vessel health and our pilot data have demonstrated that the blood vessels of young boys with hypospadias do not narrow and relax in the same way as the blood vessels of boys without hypospadias. In addition, preliminary review of hospital admission data from one hospital in Glasgow, suggests that as many as 11% of men (n=163) with hypospadias have a subsequent admission with a heart attack (myocardial infarction), which is 10 times higher than the current rate of myocardial infarction seen in the normal population (1.7%) [1]. We wish to link men with a diagnosis of hypospadias with hospital admission data and death records in Scotland via the NHS Information Services Division (ISD). With this information we would be able to determine an accurate incidence of cardiovascular disease in men with hypospadias, therefore informing us regarding the need for cardiovascular surveillance in affected boys and men.

Reference: Bhatnagar P, Wickramasinghe K, Wilkins E, et al. Trends in the epidemiology of cardiovascular disease in the UK. Heart 2016;102(24):1945-52 doi: 10.1136/heartjnl-2016-309573[published Online First: Epub Date]|.

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1718-0219 Dr Christine Campbell
Scottish Cervical Screening and Ethnicity (SCREEN)

Cancer of the cervix can largely be prevented by cervical screening, yet in Scotland in 2015, 379 women were diagnosed with, and 116 women died, from invasive cervical cancer. Previous work by the Scottish Health and Ethnicity Linkage Study (SHELS) has shown breast and bowel screening participation in Scotland varies by ethnic group: we now wish to document to what extent this is the case for cervical cancer screening, and develop interventions to support the NHS in offering screening in culturally sensitive and appropriate ways. We will (1) describe patterns of attendance to cervical screening by ethnic group using anonymised linkage of cervical screening programme data and self-reported ethnicity in the 2011 Census; (2) obtain the views of ethnic minority populations about barriers and facilitators to cervical screening; (3) summarise the evidence in the scientific literature; and (4) design new more inclusive ways of offering screening to women, with input from ethnic groups, the NHS, the Scottish Government, and relevant charities. This PBPP application is relevant only to the first aim listed above.

In addition, and also part of this PBPP application, we will update the previous findings on bowel screening participation by ethnic group in Scotland, using the 2011 Census population. Scotland's ethnic minority population grew from 600,000 to 850,000 between 2001 and 2011, a 29% increase. For example, the 2011 Census identified that at 61,000, the Polish population are the second largest minority group. This updated analysis will provide important new information on bowel screening participation in several additional ethnic minority groups in Scotland.

1718-0220 Dr Eve Miller-Hodges
Circulating biomarkers to predict cardiovascular, kidney and all-cause outcomes in kidney transplant recipients

Patients with kidney disease are at greatly increased risk of cardiovascular disease (heart attacks, cardiac death, heart failure and strokes). Even after kidney transplantation their risk remains five times higher than the general population. Cardiovascular disease is the most common cause of death in kidney transplant patients.

At present, we have no specific methods to assess cardiovascular risk in patients receiving kidney transplants. We aim to determine whether novel cardiac biomarkers (substances measurable in blood) can predict long term cardiovascular and kidney outcomes in patients assessed for kidney transplant.

Cardiac troponins are proteins released by injured heart muscle cells. We have shown that high-sensitivity troponins accurately stratify risk in patients with kidney disease, over both the short and long term.1 However, we know little about their role in patients with kidney transplants . We hope they could identify those at greatest risk of cardiovascular disease around the time of transplantation, and in the longer term.

All patients assessed for kidney transplantation have blood samples taken and stored for tissue-typing (matching). We will use small amounts (aliquots) of these blood samples to measure cardiovascular biomarkers (particularly high-sensitivity troponin) prior to and at transplantation.

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1718-0233 Dr David Preiss

ORION-4 trial

Lowering bad (LDL) cholesterol with statins reduces the risk of heart attacks and strokes. However, among individuals with a history of vascular disease, the risk of further vascular events remains high, even after years of statin treatment. Inclisiran is an investigational drug given by subcutaneous (under the skin) injection which lowers LDL cholesterol. The ORION-4 study aims to find out whether inclisiran, given every 6 months for about 5 years, safely reduces the risk of heart attacks, strokes or the need for urgent coronary angioplasty or bypass grafts. People can join the study if they are aged 55 years or older and have vascular disease (i.e. they have had a heart attack, stroke or leg artery bypass or angioplasty, or aortic aneurysm repair). The study will involve 15,000 participants. Half will receive inclisiran injections and half will receive dummy injections (placebo). Which treatment each participant receives will be decided by randomization (like tossing a coin). Neither the participants, nor study staff, will know which treatment they are receiving (but this can be found out if needed). Participants will continue their usual medication prescribed by their GP or other doctors. ORION-4 clinics will be run by trained research staff in NHS and academic institutions. Participants will attend the study clinic 3 times in the first 5 months and then once every six months. At clinic visits participants will be asked questions about their health, will have a blood sample taken and will be given an injection of inclisiran or placebo.

1718-0238 Prof James Lewsey

TRends and Inequalities in Prescribing for Alcohol Dependence in Scotland (TRIPADS)

More than 15,000 prescriptions are issued every month in Scotland to treat alcohol problems (‘AUDs’). However, high-quality evidence that these drugs are effective is very limited. Our study will address this by researching large national databases, without identifying individuals.

Clinical trials are well established as the best way to determine whether new treatments work. However, it is also known that such trial populations are often not representative of the general population. Our study avoids this problem by covering all patients in Scotland who have had a hospitalisation related to an alcohol problem. It also benefits from involving members of the public who will draw on their experience of alcohol treatment to inform the direction and nature of the research.

Although guidance exists on what medications to use to help those who are dependent on alcohol to stop drinking initially, it is unclear how to treat people in the longer term to reduce their chances of drinking again, or how to treat other people who want to cut down, but not stop, drinking or who have had a severe alcohol-related hospital stay. In this study, we will research individuals prescribed medications for AUD, after a hospital stay related to AUD or alcohol dependence between 2010 and last available date at date of extraction. We will describe prescribing levels and how associated short-term health outcomes (alcohol-related hospital admissions and deaths) have changed over time and whether important variations exist, both in different health board areas, or for people of different ages, sex and socio-economic deprivation levels. Further, we will evaluate whether the introduction of minimum unit pricing for alcohol in May 2018 has changed prescribing levels for alcohol dependence and management of harmful drinking in Scotland.

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1718-0316 Jackie Caldwell

Scottish Medical Imaging (SMI) project – development of a suite of tools to de-identify clinical images

PACS is the software used by Scottish health boards to store, retrieve, and display digital patient images. Currently, with permission from PBPP, (Ref 1516-0486) a copy of identifiable PACS images for the whole of Scotland from is held within the National Safe Haven infrastructure.

This application seeks permission to access the above copy of identifiable PACS data so that technical developers can develop and test the tools necessary to de-identify PACS images and create useful meta-data about them in order to create a new national data resource, Scottish Medical Imaging (SMI). Research ready image data and metadata is required to meet the intelligence requirements of a range of stakeholders including NHS Boards, Scottish Government and researchers. It will allow de-identified clinical image data to be linked to other health datasets such as inpatient episodes, prescribing and outpatient clinics, subject to relevant approvals from PBPP, ethics etc.

This development process will be an ongoing iterative process over the next 5 years. Each release of metadata and research ready images to be made available over this period will be subject to successful testing by members of the eDRIS team, a de-identification report (Ref Supporting Document 1718-0316 – Caldwell – Anondoc- early draft) and sign-off by the SMI Strategic Oversight Group.

Initially only a limited amount of metadata will be developed. Over time it is expected that this will increase from work generated by:

- requests from researchers to improve cohort selection criteria e.g. more detailed information on radiation doses; and
- increasing sophistication of the de-identification tools to correctly develop new metadata as knowledge increases.

This is an enabling application. It will not deliver benefits to the public by itself; however it will enable new, and strengthen existing areas of, research which inherently will be of benefit to the public.

1718-0318 Linda Cullen

Development of (electronic data collection system for the Scottish Electro-Convulsive Therapy Network (eSEAN))

The plan is to upgrade and replace the existing SEAN electronic data collection system to a web based version which will be more efficient and user friendly to facilitate the ongoing collection of data from the 18 hospitals in Scotland delivering ECT as a treatment. The system will be developed by an external company called CORTEX World Wide that has been selected by a formal NHS NSS procurement process.

The requirements of the system have been established by review of the current system and several scoping exercises with clinical staff in collaboration with the SEAN Steering Group. The system will allow the collection and storage of data pertaining to all patients who receive ECT in Scotland. It will also include the ability to collect some of the data required for the SEAN national evidence based standards, which will allow local and national monitoring of adherence to standards via a data extract facility. This will streamline the peer accreditation visits by making them more time efficient.

Access to this electronic system will be tightly controlled with varying levels of security access depending on the individual’s location and role.

Potential impacts of not undertaking this development may lead to ECT clinics having no system in future due to failure of the current system leading to:

- No clinical care pathway;
- No data collection or validation system;
- Loss of valuable historical data; and
- Inability to respond efficiently and timeously to future information needs of the Scottish Government and NHS Boards across Scotland.

Additional background information:
In 1996 the Scottish Electroconvulsive Therapy (ECT) Audit Network (SEAN) instigated a national audit project to answer questions pertaining to the clinical practice of ECT. Since then, SEAN has continued to grow and has developed into a national clinical network moving from an audit of the service to an accreditation network whilst retaining the acronym SEAN and moving to the Information Services Division of NHS NSS in 2008.

Since 2005 a Microsoft Access electronic clinical care pathway/ database has been set up in every hospital which delivers an ECT service in Scotland. Data are collected for every aspect of the patients’ clinical journey from consent and legal status through to treatment, side effects & outcomes. In the current system the data are collected via the existing SEAN database in each of the 18 ECT clinics in Scotland. The system is not networked and is stored on the individual secure NHS Board Networks. The data are collected for clinical reasons and to provide data to measure performance against nationally agreed evidence based standards. The required dataset is sent to Information Services Division (ISD) at the end of every month. The current process is that data are automatically anonymised prior to export via a secure transfer system called SWIFT (Submission with Internet File Transfer).

1718-0331 Dr Robert Flynn

Evaluating Diuretics in Normal Care (EVIDENCE) - a cluster randomised evaluation of hypertension prescribing policy: Pilot phase

For many common health conditions doctors have a choice of drugs, each developed by a different pharmaceutical company but with a similar mode of action. There are few market incentives to encourage clinical trials comparing these medicines against each other in terms of safety and effectiveness. As a result, doctors and patients are left to make prescribing decisions based only on cost, availability or anecdotal evidence. Given the widespread use of such medicines in the NHS, there is a public health case for identifying even small differences in effectiveness and safety.

The Evaluating Diuretics in Normal Care (EVIDENCE) study will test a way of comparing two similar medications that are commonly used for high blood pressure, by combining randomisation of prescribing policy at GP practice level and analysis of routinely collected patient-level administrative health data. The study will randomly assign GP practices to one of two prescribing policies. Doctors in participating GP practices will use the assigned policy when deciding which medicine to use for patients who require treatment. Patients will have their regular medications altered in line with the policy, only where clinically appropriate. All analyses will be done using routinely collected anonymised NHS data.

We anticipate that this method will be transferable to allow the assessment of many other diverse medications and devices in current use where there is insufficient evidence to guide informed shared decision making.

1718-0332 Mina Khezrian

Polypharmacy; prevalence , predictors and its effect on health outcome in the Aberdeen Children of Nineteen Fifties Cohort (ACONF)

Taking many medications at once is known as polypharmacy (Masnoon, Shakib et al. 2017). Polypharmacy has become a more common in older people cause of side-effects and harmful drug interactions (Maher, Hanlon et al. 2014). This study will address a number of gaps in our understanding of polypharmacy. While poor health is the main reason for occurrence of polypharmacy in older adults, it is not known whether other factors, like socioeconomic factors, could be linked with polypharmacy occurrence (Patterson, Cadogan et al. 2014, Fillenbaum, Horner et al. 1996, Lim, McStea et al. 2017). In addition, the relationship between polypharmacy and long term health outcome such as hospital admission, and survival is complex and yet to be fully understood. Studies that follow the same group of people over time (cohorts) are needed to investigate the consequences of polypharmacy on health outcome in late life.

This project will use data collected during the long-term Aberdeen Children of the 1950s Cohort (ACONF) (https://www.abdn.ac.uk/birth-cohorts/1950s/). ACONF has already been linked to Scottish Morbidity Records (SMR01/04/06) - and the National Records for Scotland (NRS) death for the study of chronic multiple disease. Here, we will add NHS Prescribing Information System (PIS) to the previously linked ACONF dataset.

This linked dataset will provide rich information of early life and reliable history of chronic disorders and medications which enables us to investigate the frequency and predictors of polypharmacy, and its relationship with hospital admission and survival in older adults.

1718-0376 Dr Roxanne Hastie

Using big health data in the prevention of preeclampsia

Preeclampsia - an age-old disease with no treatment. Preeclampsia is a hypertensive disorder of pregnancy which is responsible for 60,000 maternal deaths and over 500,000 neonatal deaths annually. Delivery remains the only definite treatment. Identifying effective preventative medications would greatly improve the management of preeclampsia and reduce the maternal and neonatal mortality related to this disease.

Preventing preeclampsia. Through laboratory investigations we and others have found a number of potential treatments for preeclampsia, including metformin, proton pump inhibitors, sulfasalazine, statins and antiplatelet agents. Importantly, many of these drugs are already safely used during pregnancy for other complications.

Using the national health database of Scotland, we propose linking maternity, neonatal/Scottish birth records and NRS, stillbirths and infant deaths records, to the prescribing information system, to investigate the incidence of preeclampsia among women who have taken these medications for other complications during pregnancy. The use of national level data will allow us to investigate whether any of these drugs are able to prevent preeclampsia. Additionally, we will also be investigating whether there is harm associated use of any of these drugs during pregnancy. If preeclampsia is reduced among women taking these drugs this will provide further evidence for the use of these medications to treat and/or prevent preeclampsia.

This proposal may significantly improve the management of preeclampsia and reduce both maternal and neonatal mortality.

1819-0001 Dr Scott Cunningham
Digital Health Technology Catalyst: MyDiabetes IQ

Artificial Intelligence (AI)/ machine learning could transform personalised healthcare. By predicting complications and health consequences (thereby enabling early and appropriate intervention), AI has the potential to significantly improve health outcomes, reduce waste and provide significant cost savings and wider societal benefits.

This project brings together a unique partnership of niche expertise across NHS, academia and the commercial sector to create a new and world leading diabetes artificial intelligence product (MyDiabetesIQ) driving tailored decision-support for clinicians and patients. This project aims to design, develop, test, implement and evaluate MyDiabetesIQ in Scotland and northwest (NW) London to demonstrate its commercial potential.

Data modelling will focus around key areas of diabetes care including i) prediction of drug response in individual patients: to increase efficacy of prescribing; reduce waste; and reduce side effects ii) prediction of chronic complications (including lower limb/ cardiovascular disease), iii) prediction of acute complications to demonstrate clinical efficacy; safety and commercial potential, such as hypoglycaemia (low blood glucose) and ketoacidosis to enable early intervention, and iv) prediction of diabetes type to prevent misclassification, and thereby supporting accurate and safe treatment.

This proposal is highly innovative; it moves beyond records linkage, information sharing and static algorithms. MyDiabetesIQ will facilitate prediction of multiple diabetes-related outcomes using multi-task machine-learning, creating a sophisticated learning health system for diabetes. The outputs will drive practical evidence based advice via individual and population based alerts, reports, and dashboards, to clinicians and patients, breaking AI out of the realms of academia into everyday practice, with the potential to re-model for other long-term conditions.

1819-0009 Jade Hooper

Social and locality variations in dog bites and strikes in Scotland: Analysis of linked by-product datasets

Rates of hospital admissions due to dog bite incidents have risen considerably over the past years (HSCIC, 2015). Of particular concern is the finding that hospital admissions for dog bites are highest in the most deprived areas (HSCIC 2014; 2015). However, there is a paucity of research which aims to explore why this may be or how this issue may be addressed. Whilst there is a public interest in these figures in Scotland, thus far there has been no rigorous empirical investigation into social inequalities in dog related injuries. Through an innovative and ambitious analysis of linked by-product data, the current study hopes to address this gap.

The study will use a range of data sources to examine both individual and area-based characteristics which may help uncover some of the reasons why these patterns may exist, and how they can be addressed. Health data from dog bite incidents will be requested and linked with census records. This will enable the researcher to gain a rich and wide-ranging account of potential risk factors for dog bites. Microchip data will also be requested in a bid to account for dog populations which in the past have not be considered when links with social disadvantage and dog bite injuries have been found.

Through this analysis, the study aims to help inform policy for the reduction of dog bites and aid in effective identification and targeting of interventions for areas and individuals most at risk.

1819-0030 Jenny Simons

PARD – Persons at Risk Distribution

PARD is a Scottish Government and NSS led project to enable Local Authorities (LAs) to rapidly identify where people are at risk during an emergency. Allowing LAs to prioritise interventions to save life and minimise harm to the most vulnerable members of society. The Civil Contingencies Act (2004) requires each LA to have an effective system, but many current systems take days and are frequently ineffective. There are 3 local functioning PARD systems within Scotland currently.

The Act also places the responsibility to share information and cooperate in an emergency on both the LA and the NSS. PARD can only be used in emergencies. Emergencies could include a flooding, power outages, a terrorist attack or industrial incident, which may require shelter and support to a local community.

PARD provides considerable public benefit in using existing health and social care datasets to rapidly identify the vulnerable affected by an emergency in order that assistance can be provided to them. The system already exists in three LA areas. The project is to expand access to this system to all Scottish LAs.

PARD uses 10 indicators of vulnerability from NSS datasets and, currently, 7 from the Local Authority datasets, listed in 4.3. Only the minimal personal data is displayed by the system.

This application covers access to the NHS NSS datasets and is being made collectively on behalf of all LAs. Each LA will have to satisfy the requirements of the ISA and also provide details of their data managers and IG training.

1819-0033 Dr Alexander J Fowler

Defining the high-risk surgical population in the National Health Service

More than 5 million surgical procedures are performed in the NHS in the United Kingdom each year, with 49,000 deaths within 30 days of an operation. NHS UK spend £9.5 billion a year on surgical treatments (8% of NHS budget), yet we know surprisingly little about the patients who undergo surgery. Some specialities, like cardiac surgery, collect and analyse detailed data on their patients, but this does not occur for most procedures. We therefore lack the most basic information describing numbers of patients who undergo different types of surgery, their age, and how many die.

Importantly, a sub-group of around 250,000 high-risk surgical patients is concealed within the larger surgical population. These patients are typically older with complex long-term illnesses. They often experience poor outcomes, accounting for four out of five deaths after surgery, and are likely to have increased healthcare needs in the months after their operation. We know that high throughput NHS services struggle to provide the individualised care these patients require.

To plan safe and effective care for this important patient group, we need up to date information describing the number of patients having surgery, those who are at risk, the short-term harms of surgery, and the long-term success in terms of quality of life and survival across the NHS. This information will help patients to make better choices about surgical treatments, support doctors to care for individuals with complex needs, and inform policy makers in planning cost effective surgical services which deliver better patient outcomes. This work is part of a wider programme of work aiming to develop a shared decision making tool for patients considering high-risk surgery (the OSIRIS project: Optimising Shared Decision-Making for High-risk Surgery).

1819-0050 Karen Clements

The Sloane Project – a prospective audit of screen-detected non-invasive carcinomas and atypical hyperplasias of the breast.

The Sloane Project (www.sloaneproject.org.uk) is a UK prospective audit of screen-detected non-invasive carcinoma and atypical hyperplasia of the breast. It was established in 2003 and all breast screening units were invited to take part. 5 out of 6 of the breast screening programmes in Scotland participated in the audit submitting data on1583 patients between 2003 and 2016. The primary data submitted included patient identifiers and radiological, surgical treatment, pathology and radiotherapy data on Sloane Project data collection forms (copies attached).

Ductal carcinoma in situ (DCIS) comprises 20-25% of screen-detected breast cancer. The clinical behaviour of DCIS is unpredictable, challenging clinical decision-making. Recently, concern regarding the over-treatment of DCIS (1), has been fuelled by large retrospective series demonstrating excellent (>95%) long term survival 10-20 years after diagnosis, although others have suggested that detection and treatment of screen-detected DCIS may prevent subsequent invasive disease (2-4).

Breast cancer specific and all-cause mortality following a diagnosis of screen-detected DCIS differ little compared with that of unaffected women, and there remain concerns regarding over-diagnosis and consequent over-treatment of DCIS.

Prospective data are lacking and the clinical significance of early detection and treatment for DCIS remains unclear. Adding the Scottish follow-up data to the English data already collected will give us a cohort of over 10,000 women with a likely median follow-up of 9 years. We are currently publishing on UK data already analysed but with median of 5 years follow-up, to describe the features and outcomes following screen-detected DCIS.

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1819-0051 Professor Sally-Ann Cooper

Health, death, and cancers in people with learning disabilities and people with autism

This project aims to investigate health and health-care inequalities in people with (a) learning disabilities, and (b) autism, compared with (c) other people.

People with learning disabilities die 25 years earlier than other people, but studies are methodologically limited1. Probably, >40% of early deaths in this population would have been amenable to health care. Autism is also thought to be associated with premature death, though studies are limited.

Health profiles of people with learning disabilities, and autism, differ from other people, and the commonest causes of death are likely to differ. For example, people with learning disabilities have high rates of epilepsy, mental illness, gastrointestinal disease, antipsychotic use and polypharmacy, which may be associated with admissions and death. They may have higher diabetes rates, due to sedentary lifestyles, obesity, and antipsychotics, but may receive poorer health-care, causing more complications, admissions and deaths. They may have more gastrointestinal cancer due to poor diets, lifestyle and high helicobacter pylori and GORD rates, but participate less in bowel screening.

Gender distribution differs in people with learning disabilities, and autism (more males), and population age structure is younger than the general population. Gender influence on health also differs due to exposure to different risks.

Scotland's Census includes 5,295,402 people. Although only 26,349 have learning disabilities and 31,712 autism, it has power to answer questions on cancer incidence and mortality, as well as more common conditions important for these minority populations.

Better understanding of causes of deaths, and determinants of health, health-care, death, and survival should reduce premature deaths.

1819-0054 Dr Ewen Johnston

Outcome of resuscitated term babies with no heart rate detected at 10 minutes of age (A British Paediatric Surveillance Unit project)

Sometimes, babies encounter problems during labour and delivery and their hearts stop beating. These babies have a reduced supply of blood and oxygen to their brain and require help in getting their heart to start again. This process is known as resuscitation and is required immediately after birth. If the lack of blood and oxygen is severe, it can cause injury to the brain that can be fatal, or may leave survivors with long-term disabilities.

International guidance advises clinicians to consider stopping resuscitation if the heart beat does not return by 10 minutes. This is based on studies reporting that the risk of death or serious disability for these babies is very high. However, the studies describe babies born more than 10 years ago. In recent years, the introduction of cooling treatment for babies who suffer a brain injury around the time of birth has improved the outlook for survivors. It may be that this guidance is no longer appropriate.

We aim to identify babies born at term in the United Kingdom and Republic of Ireland who receive prolonged resuscitation after delivery and have no heart rate detected at 10 minutes. We will describe how many of these babies survive and whether or not they have long term problems with development as they grow up.

This study will provide important information on the outlook for these babies and help to ensure that decisions regarding resuscitation and ongoing intensive care are made in the best interests of babies and their families.

1819-0069 Dr Rosemary Hollick

Effective healthcare delivery in rare rheumatic disease: evaluating models of care for systemic vasculitis

People with rare rheumatic diseases report an uphill struggle to navigate healthcare systems not designed to manage complex diseases. A good example is systemic vasculitis, a group of devastating but treatable multi-organ illnesses caused by inflammation of the blood vessels. There are significant differences in how vasculitis is looked after in specialist centres across the UK.

Our pilot study has revealed important differences in patient outcomes such as heart disease, stroke and infections between some specialist centres. However, no studies have looked at the way care is organised and how this relates to health outcomes for people with vasculitis in a national population.

Our study aims to understand which key elements of care delivery are associated with health outcomes of prime importance to patients with vasculitis. This information will be used to help us better design services and ensure equal access to effective, coordinated care and support for patients.

This application covers the first part of the study. Here we will identify all patients with systemic vasculitis in Scotland using specific codes. We will then look at their healthcare records in national databases to understand which healthcare professionals they have consulted, when and how often, treatments received and other information such as cancers, deaths and infections. This will enable us to look at differences in outcomes across different health boards in Scotland.

We will combine this with information gathered separately on how vasculitis services are currently organised and delivered in Scotland. This will help us compare health outcomes to the ways in which services are set up, and look for patterns.

1819-0072 Professor Tom Cleland
Clinical Research in Heart Failure – Long-term follow-up

A series of studies was conducted between 1994 and 2006 inviting i) a cross-section of the Glasgow population and ii) patients with a known heart problem to have a panel of tests to assess heart function. Patients agreed to follow-up at the time, although not explicitly through access to electronic health records. We want to find out what happened to these (consented) patients and how accurately their heart test results predicted outcome. In particular we wish to find out:-

a) death and its place and cause (most of the people screened will now be dead)
b) hospitalisations and their duration and causes, with a special interest in heart attacks, stroke and heart failure
c) the results of further NHS investigations (these can be obtained by linking to local electronic health records held by Greater Glasgow & Clyde Health Board)
d) amongst patients surviving beyond 2009 (when national prescribing records became available), what medicines patients were taking.

This information will be used to describe the incidence (new-onset) of disease (especially heart disease), how well the heart tests could predict events and the pathways by which patient's health deteriorated (for instance, NHS tests may show the patient developed heart rhythm problems or worsening heart or kidney function).

1819-0093 Dr Katherine Keenan
Social inequalities in chronic disease trajectories in mid and later life: taking account of multimorbidities

With increasing life expectancy, many middle aged and older adults can expect to spend a larger proportion of life suffering with more than one chronic disease. The project will investigate how multiple chronic diseases develop and progress over time in middle aged and older adults in Scotland (i.e. taking a longitudinal perspective).

The existing evidence on multimorbidities is overwhelmingly based on cross-sectional studies, and multimorbidity measures reflect this. By considering multimorbidity in individuals over time, we will gain a more nuanced picture by taking into account the order of diseases developing, the time spent in each disease state, and how diseases cluster together over time.

Current knowledge on inequalities in multimorbidity in Scotland (based on cross-sectional data) suggests that those who live in more deprived neighbourhoods are more likely to suffer multimorbidity; the international evidence suggests other social inequalities exist. The study will add to the international evidence base on inequalities in multimorbidities by patterns according to social, demographic factors at individual and household level including household characteristics (living alone), marital status (including widowhood) as well as education, ethnicity and socio-economic factors. The study will do this by following a cohort of individuals identified through the 2001 census at middle age (40 and over) and following them for 20 years (2001-2021).

1819-0117 Dr Jill Ireland
SPARRA and High Health Gain predictive modelling

NHS NSS are responsible for the SPARRA (Scottish Patients at Risk of Re-admission and Admission) and HHG (High Health Gain) models. These are risk prediction tools which generate lists of patients primarily intended for General Practitioners to review, in order to decide whether any patients registered with their practice would benefit from anticipatory care planning or another intervention. This is to support the shift from a reactive system focussed on hospital-based treatment to a community-based system with a preventative approach.

The SPARRA model predicts an individual's risk of emergency hospital admission in the next 12 months. A SPARRA risk score is calculated automatically every month by the NHS NSS Business Intelligence team, for around 4.2 million individuals, using patient level hospital and prescribing data.

The HHG model predicts the likelihood of an individual being amongst the highest financial resource users in the next year, for around 4.2 million individuals. An HHG risk score is calculated by analysts in NSS ISD every quarter, using hospital and prescribing data and the costs associated with them. The model is being continually developed by analysts in NSS ISD to improve its performance.

GPs are encouraged to review SPARRA and HHG patient lists for their practice and, applying professional judgement, consider whether patients identified would benefit from an early intervention, in order to reduce cost to the NHS.

The purpose of this proposal is to ensure that we continue to have appropriate Information Governance approvals for work relating to these two tools.

2019/20 Applications approved by HSC-PBPP

1819-0131 Chris Gourley
Social Transformation for Wellbeing

Inequality in society emerges as a result of many factors and it is not a simple matter to narrow the gap between rich and poor. It requires use of methods which influence how the many drivers of inequality interact and reinforce each other.

Fortunately, Scotland has experience of using such methods such methods to improve patient safety and reduce infant mortality. This proposal will narrow inequalities by using new ways of working to help people living difficult lives by supporting them to take control of their problems and feel more in control of their lives. This method involves citizens and front line staff working together to develop and test interventions and share learning across systems.

To inform and measure effectiveness of this work we will analyse relevant datasets using data science tools to enable changes in the drivers of outcome to be accurately observed.

Assessment of success cannot be made by using single, predetermined outcomes. The complexity of SDH and the many ways they affect people, mean that they touch every facet of our health and social care system (and data collected therein).

Attempts to improve educational attainment, for example, might take many years work with children and families for outcomes to be apparent. Typically, such projects, subjected to conventional academic assessment find no significant change and the project ends.

This programme will help realise the potential of contemporary big data analytics to inform new ways of working that combat inequality and deprivation, supporting people across Scotland.

1819-0148 Dr Alastair Philp
AHP Operational Measures – Phase 3

Allied Health Professionals are health and care practitioners who support people to live healthy, active and independent lives. These practitioners play an important role in health and wellbeing but their contribution in Scotland is not as well understood as other types of health and care service. This may be in part due to a lack of consistent data on the services Allied Health Professionals deliver.

To address this, a project has been commissioned to establish a routine all-Scotland data collection from Allied Health Professionals working in NHSScotland Boards and Local Authorities. Data will be collected from individual Allied Health Professionals on the treatment they provide at patient level; this information will be collated centrally and aggregated. This aggregated data will be made available to service managers and planners to help them manage and improve services. The Information Services Division may also produce high level statistics that describe Allied Health Professional activity at a national level.

1819-0157 Dr Gemma Archer

Epidemiological studies of the Porton Down veterans

This study is an update of an original study which investigated whether military veterans who were exposed to chemical agents as part of the ‘human volunteer programme’ at the UK government's research establishment at Porton Down, had unusual rates of cancer incidence or mortality compared to veterans who did not attend Porton Down, and the general population.

During 2002-07, the University of Oxford assembled a cohort of c20,000 Porton Down veterans who took part in the ‘human volunteer programme’ between 1941 and 1989. The veterans’ records were linked to routine data held by the Office for National Statistics to compare their pattern of deaths and cancer registrations up to 2004, with that of a comparison cohort of c20,000 non-Porton Down military veterans. The study established that, although there was a small (6%) excess of all-cause mortality, which could not be attributed to any specific exposure at Porton Down. There was no excess of cancers.

In the subsequent 10 years, chemical warfare agents have been used by rogue states and new questions have been posed about whether low-dose exposure to these agents might have a long-term effect on health. This study will update mortality and cancer registration data by at least 10 years. This new data will allow us to repeat the analyses carried out previously, but with increased statistical power so we can examine more fully the impact of rare exposures and outcomes at a level of detail not possible in the original study.

1819-0159 James Chal

National Cardiac Audit Programme (NCAP)

The Scottish Government has commissioned and funded a mandatory national clinical audit programme called National Cardiac Audit Programme (NCAP) along with NHS England and the Welsh Government via Health Quality Improvement Partnership (HQIP). The purpose of NCAP is to benchmark against the national standards the quality of patient care provided by hospitals and clinicians in Scotland and the UK.

The National Institute for Cardiovascular Outcomes Research (NICOR), hosted at Barts Health NHS Trust, is responsible for the delivery and management of the NCAP. The data controller for NCAP data is HQIP.

NICOR has section 251 support in England and Wales to receive patient identifiable data (PID) for NCAP, without informed consent. NICOR is therefore seeking national approval from PBPP to receive PID from all Scottish hospitals for NCAP.

NICOR has managed the national clinical cardiovascular audits since 2011, initially at UCL and since 1 July 2017 at Barts Health. During 2017 all participating centres confirmed agreement for their patient data to be transferred from NICOR at UCL to NICOR at Barts Health.

The six national cardiac audits (now called specialist domains of NCAP) include the following categories of patients:

1. Adult Cardiac Surgery Domain – All adult patients undergoing major heart surgery.

2. Congenital Heart Disease Domain – All cardiac or intrathoracic great vessel procedures carried out in patients under the age of 16 years. All adult congenital cardiac procedures performed for a cardiac defect present from birth.
3. Cardiac Rhythm Management (CRM) Domain- All adult patients with implanted devices or receiving interventional procedures for the management of cardiac rhythm disorders.
4. Adult Cardiac Interventions Domain- All adult patients who receive an angioplasty/ percutaneous coronary intervention (PCI) procedure.
5. Heart Failure Domain - All adult patients with an unscheduled admission to hospital with heart failure.
6. Myocardial Ischaemia National Audit Project (MINAP) Domain – All adult heart attack patients.

There are four main purposes of NCAP:

1. The delivery of cardiovascular Quality Assessment and Quality Improvement for the NHS by benchmarking against the national standards the quality of patient care provided by hospitals and clinicians in the UK.
2. The analysis of existing datasets is undertaken to provide comparative baseline data for the audit and further enrich the cardiovascular disease audit data. Hospital Episode Statistics (HES) and ONS mortality data are linked at patient level to provide information on trends in patient characteristics, treatments received and outcomes (complications, readmissions and mortality). We anticipate similar equivalent linkages with the patient data from Scotland (subject to availability).
3. Other extended uses of the audit data, under contract to improve the cost-effective delivery of cardiovascular NHS care, as well linking the NCAP data with other speciality domains within NCAP and with other patient data contained in other registries/databases such as cardiac rehabilitation registry, cancer registry, renal registry, UK TAVI Registry etc.
4. Approved research, clinical trials and surveillance/observational studies by using the audit data.

1819-0160 Joanne O'Donnell
SCOTS Surgical Obesity Treatment Study

We plan to conduct a 3 year prospective cohort study of patients who have undergone bariatric surgical procedures in Scotland recording mortality, morbidity including diabetes complications and cardiovascular disease, nutritional deficiencies, quality of life and surgical complications, both immediate and medium term. This study will collect data on the medium term outcomes of bariatric surgery in a cohort of 450 individuals. All patients who planned to have a surgical bariatric procedure in Scotland between January 2014 – January 2017 (study recruitment period) were invited to participate by a bariatric surgeon – both NHS and private sector. All patients were asked to consent to participate in the study.

Written consent was sought from patients to access their electronic health records. Patient identifiable information provided by the patient themselves will be used to link to pre-existing NHS Scotland IT systems including SCI-Diabetes which is the database of all diabetes patients and their treatment in Scotland. This will allow clinical outcomes for nutrition and diabetes to be recorded by record linkage.

Recruitment has now stopped on the study and patients will be followed up for a mean of three years.

1819-0163 Joanne McPeake
The impact of alcohol minimum pricing in the critical care context

Patients who are admitted to intensive care with a background of alcohol misuse are at an increased risk of both short and long-term mortality, as well as poor functional outcomes following critical care discharge. As a result, we assess every patient for alcohol use disorders on admission to our Intensive Care Unit (ICU) at the Glasgow Royal Infirmary (GRI).

There are two main research objectives of this study:

1. We will compare our local data with nationally collected data, to understand if there is a difference in the assessment process (nationally collected data vs locally collected data). We will look at data from a single centre only (GRI).
2. This study will also aim to understand the impact if any, of recent government policies around the introduction of minimum unit pricing for alcohol, in the critical care environment. This will be achieved by exploring admissions, pre and post implementation of this policy.

To undertake this process, we will link our ICU patient list and relevant clinical data (using the CHI number) with SMR01 and SMR04 datasets. We will also explore death records and pharmacy data for this patient group. The Lead for this project is a member of the direct clinical care team in the ICU.

1819-0169 Linsey Galbraith
National Cancer Diagnosis Audit (NCDA) 2019 – Scotland

This proposal relates to the delivery of the Scottish part of the UK National Cancer Diagnosis Audit 2019. The primary purpose of the audit is to facilitate local improvement activities around cancer diagnosis; practices and related organisational levels will be provided with tailored feedback reports based on the cases they have audited. Secondary to this, the audit will create a valuable research dataset.

Cancer Research UK (CRUK) is leading a partnership with Macmillan Cancer Support and the Royal College of General Practitioners (RCGP) to deliver the UK wide audit of cancer diagnosis in primary care in 2019, with the active involvement of NHS partners.

The audit will:

- Create a unique collection of linked primary and secondary care data, from patients first diagnosed with cancer between autumn 2018 and autumn 2019;

- Allow investigation of cancer diagnosis across the whole clinical pathway, for different cancer types, across the UK; and
- Highlight diagnostic challenges, good practice across the clinical pathway and strategically influence policy changes and changes to clinical care.

It will run for 12 months during 2019 and 2020, following a successful audit in 2017 in which 73 Scottish GP practices participated, submitting primary care data about 2,014 diagnoses (around 6% of total diagnoses in the audit timeframe). A summary is available on the ISD website: NCDA Scotland 2017.

The proposal also incorporates in-depth analyses of the Scottish audit data by analyst colleagues at the universities of Edinburgh and Aberdeen.

1819-0176 Professor Duncan Porter

Scottish Early RA inception cohort

The Scottish Early Rheumatoid Arthritis (SERA) study recruited patients with newly diagnosed rheumatoid arthritis (RA) from across Scotland in 2011-15, and has followed these patients up thereafter every 6-12 months. The purpose is to collect prospective data on important clinical outcomes, including remission, radiographic progression, drug response, toxicity, comorbidity, surgical intervention and mortality from an inception cohort. In parallel, an extensive biobank was collected, and stored in the NHS GGC bio-repository. Participants provided enduring and generic consent for their personal (including linked) data and samples (including DNA) to be used now and in the future for research.

The purpose of the current application is to renew permission to link the SERA database to nationally held datasets, and to add an age, gender and post code matched cohort of five subjects for each SERA participant. Linking data will allow exploration of the relationship between clinical, demographic and/or biomarker data with a variety of patient outcomes, while the addition of matched controls will allow studies into the magnitude of risk of important outcomes in RA patients when compared to the general population.

Applications to use the SERA data and/or samples are governed by the SERA Access Policy which is described in detail below. We request that the same process be used to authorize access to the enhanced (i.e. including the linked data) SERA dataset, where the analysis planned would be entirely within the University of Glasgow Safe Haven. Any application to export linked data would remain subject to a separate PBPP application.

2019/20 Applications approved by HSC-PBPP

1819-0183 Lucy Irvine

The transfer, use, and retention of anonymised cancer data from the Scottish Cancer Registry, Population Health to enable the National Cancer Registration and Analysis Service (NCRAS), Public Health England (PHE) to collate a UK dataset and carry out analysis needed for the “UK Children, Teenage and Young Adults (CTYA) cancer statistics annual report 2019”

The aim of the “UK Children, Teenage and Young Adults (CTYA) cancer statistics annual report 2019” is to provide standardised national data relevant for the distinctive spectrum of cancers that occur for this age group. Currently there are limited CTYA statistics available of this nature. The report will be a key source for clinicians, scientists, researchers (both domestic and international), charities, NHS and families throughout the UK. NCRAS (National Cancer Registration and Analysis) PHE (Public Health England) will collate the data extracts from each UK nation (Scotland, Northern Ireland, Wales and England) to create a UK dataset. The data extracts will be provided to and collated by named analysts in the National Cancer Registration and Analysis Service, Public Health England. NCRAS will produce the statistical analysis of anonymised data for the UK-wide analysis of cancer in CTYA, as agreed by all the 4 UK countries. The data will be used to produce a national report and related outputs containing the most recent UK statistics for cancer incidence, mortality and survival – so that the report provides a valuable overview of CTYA (0-24 year olds) cancer statistics. The contents of the report will be similar to the report published by NCRAS, PHE this year called ‘Childhood Cancer Statistics, England Annual report 2018’ (see Supporting documents). Similar UK level statistics are not currently available. The statistics provided by the countries will be produced with a standardised approach. The report will be published on the NCRAS, PHE website and other relevant websites suggested by the other UK nations.

Where number counts are reasonable to use and as agreed by contacts in each nation, the report will include statistics for the UK, and by UK nation i.e. England, Northern Ireland, Scotland and Wales. Anonymised cancer case level data are needed to run the standardised and consistent analysis by the agreed definitions and variables, particularly for the survival calculations.

1819-0184 Dr Alastair Philp

Developing an all-Scotland consistent minimum dataset for neonatal care – Phase 1

ISD currently holds extensive information on mothers and babies; however previous work has shown that there are deficits and gaps in these data. This includes data on specialist neonatal care for ‘sick’ babies. There is currently a risk to national neonatal data as SBR data returns to ISD are slowly diminishing across boards. The creation of a new national minimum neonatal dataset would ensure ISD continues to be able to report on key national information around ‘sick babies’. It is anticipated, this improved dataset will also provide opportunities to improve the national data we hold on neonatal care. This will allow for more robust analysis, national reporting and the ability to answer key questions around this subject at a Scottish level.

Linked to another project currently underway in ISD, the development of a national maternity and neonatal care data hub, the Scottish Government has commissioned ISD Scotland to develop an all-

Scotland minimum dataset for neonatal care, and to provide a detailed costed proposal laying out options for work to establish routine collection of such a dataset (exploratory – phase 1)

This proposal describes a test collection of data representing a minimum dataset for neonatal care, from the existing clinical information system used in all neonatal units in Scotland, BadgerNet Neonatal. We wish to understand whether the data items in a draft data set can be collected from the existing BadgerNet reporting database, how data definitions align, and how much data mapping will be required. This data will then be analysed to see if sample questions (e.g. what types of babies, what levels of care, which presenting problems, what therapies) can be answered. Findings will be used to inform development of a proposal for implementation of a new national data return from neonatal care on an ongoing basis. A separate PBPP application will be submitted in due course when a dataset for routine data collection has been tested, agreed and ready for implementation: this application only covers transfer of a one-off extract of test data to ISD (exploratory phase 1).

1819-0194 Professor Ian Deary

Mental health within the family and between generations – Phase 2: Linking Scottish Mental Survey 1947 members and their families

Incidence and prevalence of mental health conditions such as depression and anxiety increase with age. Older adults are particularly at risk of mental health conditions due to type of challenges they face, such as bereavement and disability. Risk of/resilience to onset of these conditions can be predicted by life course factors such as socioeconomic circumstances and family circumstances. For example, children and spouses of depressed individuals are at increased risk of being diagnosed with depression during their lifetime. However, few studies have attempted to examine transmission of risk within families and across generations, possibly due to large, multigenerational cohorts being required and the methodological challenges associated with the construction of family units

This proposal represents Phase 2 of a project to trace mental health outcomes within and between families of Scottish Mental Survey 1947 (SMS1947) participants. The size, age, and availability of administrative and healthcare data for the SMS1947 cohort makes them ideal as a basis for this project. Phase 1 linked SMS1947 cohort data to administrative and healthcare data to investigate life-course determinants of mental health in older age. Phase 2 of the project will trace and flag the spouses and children of SMS1947 cohort members as part of the SMS1947 family dataset, and will trace the records of SMS1947 cohort members, their spouses and children in administrative and healthcare data sets, to construct a linked family dataset with mental health outcomes. This dataset will allow researchers to address questions regarding mental health within families and between generations.

Given the effort involved in tracing the spouses and children of SMS1947 cohort members, the flags will be retained by relevant data controllers. This will allow future research to request the records of the 'SMS1947 family dataset' without the need to re-trace individuals.

1819-0204 Dr Larry Doi

A realist evaluation of the Universal Health Visiting Pathway

This proposal outlines a case note review proposed as part of a service evaluation of the Universal Health Visiting Pathway (UHVP) in Scotland. Changes introduced to the health visiting pathway in Scotland have refocused the role of the health visitor and include changes to caseload weighting and management; interventions; education, training and resources; and visiting patterns. Evaluation of the enhanced pathway was commissioned by the Scottish Government and is being undertaken by a team led by researchers at the University of Edinburgh.

The evaluation will use a theoretical and methodologically rigorous approach to capture impacts resulting from the implementation of the UHVP. The study will involve a process and outcome evaluation using a range of methods including a case note review; stakeholder interviews; parent and staff surveys; and routinely collected data analysis.

The findings of the evaluation will 1) provide an understanding of how the UHVP works, 2) evidence the impact of increased investments in health visiting for children and families across Scotland, and 3) provide recommendations on how the service can be improved.

This is the first proposal for the project and is at this stage seeking only to gain approval for the case note review component of the study to be conducted in five study sites (NHS Lothian, NHS Tayside, NHS Grampian, NHS Ayrshire and Arran, NHS Borders). An additional application for routine data collection will be made to the Public Benefit and Privacy Panel once all data sources and requirements have been identified.

1819-0213 Elaine Glass

Rates of recurrent S.aureus bacteraemia infections associated with long line risk factors – survival analysis of surveillance data in Scotland

As part of my MSc Epidemiology (distance learning) with the London School of Hygiene and Tropical Medicine (LSHTM), I will be performing a survival analysis of surveillance data through the mandatory enhanced surveillance of *S.aureus* bacteraemia (SAB) programme by Health Protection Scotland (HPS). This project aims to answer whether the presence of a long line (Central Venous Catheter (CVC), Dialysis line, Peripherally Inserted Central Catheter (PICC line) or Midline) upon primary SAB infection, increases the rate of a recurrent SAB episode, amongst all those with a confirmed SAB in Scotland. The enhanced SAB data is kept by the Scottish Surveillance of Healthcare Associated Infections in Scotland (SSHAIP) team makes up the bulk of the dataset, and through linkage to SMR datasets, additional co-morbidities can be identified and controlled for within multivariable cox regression analysis, with NRS death data providing censorship points. Results of the analysis, along with a detailed background taken from a review of appropriate literature, will inform the interpretation of results and conclusions from this research. After completing the research as per the requirements of the MSc programme, results will be disseminated to local NHS Health Boards and published in a peer-reviewed journal to inform local action plans on the use & care of long line devices among those with SABs.

2019/20 Applications approved by HSC-PBPP

1819-0224 Archie Campbell

Generation Scotland linkage

Generation Scotland (GS) is a bioresource of data and samples for medical research, with over 300 applications to use the resources. GS has consent from participants to link study data to their medical records for research purposes, and several projects accessing GS have received approval from the PAC/PBPP to receive linked data including hospital inpatient, dental and prescribing data. These include XRB14041, XRB14048, XRB14198 and 1617-0157. GS is now applying to receive regular annual updates of linked data to keep the longitudinal follow up of its participants up to date.

GS will use the data internally to assess the scope and viability of potential projects, e.g. by counting the number of cases of a condition (or unaffected controls). GS will also make this data available to other researchers approved by the GS Access Committee, rather than requiring separate applications to PBPP for every use by external collaborating researchers. The GS Access Committee will apply the same requirements for data security and training as PBPP, and only release de-identified data.

1819-0226 Professor Sally-Ann Cooper

Mothers with learning disabilities and mothers with autism: prevalence and outcomes

Mothers with learning disabilities are a priority in Scotland's new Keys To Life implementation framework, 2018-2022, the national learning disabilities strategy. Some research suggests a very high proportion have their children removed, and those who raise their children are under-supported and have poor health1. In Scotland, anecdotal reports and limited available evidence support this: Scotland's Census, 2011 includes only 312 mothers with learning disabilities who lived with a child at home, whilst one Australian study reported 6.5% of births were to women with learning disabilities2. An English study reported 0.09% of births were to mothers with learning disabilities, but covered 1970-1989, when many women with learning disabilities lived in long-stay 0hospitals3. A Swedish study covering 1999-2007, reported 0.1% of births were to women with learning disabilities, who experienced more stillbirths and perinatal deaths than other women4. The Australian study revealed that pregnant women with learning disabilities were more likely to smoke, experience pre-eclampsia, and their babies were more likely to be low birth-weight and admitted for special care than other women and their babies2. The English study also reported that low birth-weight was more common, and more women with learning disabilities were smokers and unmarried compared with other women3.

Scottish policy and interventions for this group are severely hampered in view of there being no available record of the number of mothers with learning disabilities in Scotland, nor their circumstances. Similar issues may well be relevant also for women with autism. We therefore aim to address this evidence gap.

2019/20 Applications approved by HSC-PBPP

1819-0235 Lee Barnsdale

Scottish Public Health Drug Linkage Programme

In collaboration with colleagues from Health Protection Scotland and NHS Health Scotland, Information Services Division’s Health & Social Care team propose to use existing national datasets to construct a linked dataset based on a cohort of individuals representing Scotland’s population of people who use drugs.

Individuals will be included in the cohort on the basis of drug use-related events resulting in:

- specialist drug treatment (identified in Scottish Drug Misuse Database (SMR25a/b));
- general acute or psychiatric hospital inpatient or day case record associated with illicit drug use (SMR01/SMR04);
- prescribing for opioid dependence or over-prescribing of medications with abuse potential (Prescribing Information System); or;
- drug-related death, as defined by National Records of Scotland (SMR99).

This dataset will include some information on characteristics associated with illicit drug use (e.g. injecting behaviour) and outcomes (e.g. death) and other relevant datasets will be seeded with an anonymous index number generated from this dataset. This dataset will be retained for future linkages and analysis and will be updated annually.

This innovative resource will be a key asset in developing Scotland’s substance use-related health data and intelligence. From a public health surveillance perspective, it will facilitate improved analysis of people with a drug problem, enabling PHI/Public Health Scotland to deliver on a range of strategically important themes in relation to one of Scotland's public health priority areas. Examples of how this resource may be used include estimating how many people in Scotland use drugs problematically, health-related activity (e.g. hospital admissions) among this group and how many people who use drugs die prematurely.

1819-0236 Fiona Campbell

Excellence in Care (EiC) – Generic Application

Excellence in Care for Nursing and Midwifery programme, which forms part of the government’s response to the Vale of Leven Hospital Inquiry Report, covers nursing and midwifery in all hospitals and community services, from A&E to mental health, and care of older people to children’s services. The aim is that when fully implemented all NHS boards and integrated joint boards will have consistent and robust processes and systems for measuring, assuring and reporting on the quality of nursing and midwifery care and practice.

According to the Chief Nursing Officer (CNO) for Scotland Excellence in Care "*will make a real contribution to improving care by ensuring consistency of standards across Scotland without losing the essence of individualised person-centred care. These standards will reignite in nurses and midwives the passion for excellence that brought them into these professions in the first place*."

Attachment 1 – CAIR screenshots shows the dashboard and the data available

1819-0251 Professor Steve Turner

What was the effect of the “Take it Right Outside” public health campaign on paediatric hospital admissions?

Exposure to second hand smoke (SHS) harmful to everyone and particularly to children who are not able to escape from SHS at home, where they spend most of their time. Consequently, children who are exposed to SHS are more likely to be admitted to hospital with many respiratory conditions such as asthma compared to those who are not SHS exposed. The good news is that public health initiatives can protect children from the harmful effects of SHS. The introduction of “smoke free” legislation in Scotland in March 2006 was followed by a reduction in the number of children exposed to SHS and who were admitted to hospital with asthma. In March 2014 the Scottish Government funded the “Take it Right Outside” campaign which was aimed at reducing children’s SHS exposure in the home. The proportion of children with reported exposure to SHS at home in Scotland reduced from 11% in 2014 to 6% in 2015. What remains unknown is whether the Take it Right Outside campaign was followed by a reduction in hospital admissions for children, and our study will answer this unknown question. We will use routinely collected hospital admission data from between 2000 and 2018. We will use a tried and tested method to see if there was a fall in all hospital admissions and also specifically admissions for asthma after March 2014. The findings of our study may encourage other countries to deliver a “Take it Right Outside” campaign.

1819-0253 Julia Dudley

Enhanced surveillance of neonatal herpes simplex disease in UK and Irish infants less than 90 days of age

Herpes simplex virus (HSV) is a very common virus which causes benign cold sores in adults, but dangerous illness and death in young infants. There is a treatment for HSV disease in infants but it needs to be started promptly in order to be effective; this often does not happen as babies present with non-specific signs of illness and it is not clear why they are unwell.

In the decade since the last national UK surveillance there have been significant changes in the way we detect the virus, how common the virus may be in the adult population, and how we manage both pregnant women and babies who are affected. We need more information about which babies are at risk of HSV disease, and about how they present to hospital, in order to improve practice and outcomes for affected infants.

This study aims to explore the current burden of herpes simplex virus disease in UK and Irish infants less than 90 days of age. It will also examine virus and disease types, risk factors and current management strategies.

Information will be collected from paediatric consultants across the UK and Ireland, through the British Paediatric Surveillance Unit (BPSU). Clinicians will be asked to notify the BPSU of every case that they see of HSV disease in babies under the age of 90 days. They will then be sent a questionnaire by the study team asking them to provide details about the case; minimal patient identifying information will be collected.

2019/20 Applications approved by HSC-PBPP

1819-0262 Heather Wotherspoon
Head and Neck Population Analysis

This proposal seeks approval for named individuals within the West of Scotland Cancer Network (WoSCAN) to access and link Quality Performance Indicator (QPI) data from West of Scotland (WoS) Boards (Ayrshire and Arran, Forth Valley, Greater Glasgow and Clyde, and Lanarkshire) to data from GRO, SMR01 and SMR06 via the Information Services Division (ISD) of NHS Scotland.

Returned data will enable WoSCAN to assess factors impacting upon the care of patients with head and neck cancer nearing end of life, and to identify variance between Boards. Outcomes will be explored and non-patient identifiable data discussed with relevant clinicians. Our aim is to evidence the impact of current practice and where relevant, propose new ways of working which tackle variation, prevent crises and improve quality-of-life for patients and carers.

Any generated reports will only detail non-identifiable data.

Specialist Palliative Care Clinicians working within the WoS feel this work is justified due to clinical experience and limited service provision. Published evidence also suggests early palliative care involvement can significantly improve mood and quality-of-life amongst patients, and overall survival. A recent project in Fife echoed these findings and revealed a spend to save investment (out-of-hours support, electronic flagging of admissions and improved care co-ordination across boundaries), resulted in fewer hospital admissions, shorter length of stay, more anticipatory care plans and more people dying in their preferred place of care.

N.B: WoSCAN is responsible for data governance, analysis and reporting of cancer QPIs on behalf of Health Boards within their region. QPI data is stored in eCASE.

1819-0263 Dr Ceilidh Grimshaw
HIV in the era of Pre Exposure Prophylaxis (PrEP): An evaluation of characteristics of people who have acquired HIV prior to and since the launch of a national NHS-delivered PrEP programme in Scotland

Pre-exposure prophylaxis (PrEP) for prevention of HIV infection was launched on the NHS in Scotland for individuals at high risk of acquiring HIV in July 2017. It is a combination of antiretroviral medication which is effective at reducing the risk of HIV infection. Uptake in Scotland has exceeded expectations, however despite the availability of PrEP alongside other risk reduction strategies, individuals are still presenting with newly acquired HIV infection.

This study is a retrospective case note review of all people diagnosed with HIV between July 2015-July 2018 (pre and post PrEP). Demographic, sexual health and HIV data will be collected using the HPS database and the case notes on NaSH. The researchers will categorise infections into whether they could have been averted by PrEP with the current service model or not. The data will be analysed, including examining for any changes in common characteristics among people who have acquired HIV pre and post PrEP delivery in Scotland. This is to determine whether there are missed opportunities for HIV prevention and whether this is affecting individuals with particular common characteristics.

The findings from this study will be presented to The Scottish PrEP Monitoring and Evaluation group, The West of Scotland Managed Clinical Network, The PrEP Impact Trial Management Group, and The HIV and STI department at Public Health England. The researcher also will submit the manuscript of the study for publication in a relevant journal and for presentation at suitable conferences for dissemination of the information.

1819-0264 Dr Charis Marwick

Antibiotic Research in Care Homes (ARCH): unscheduled care use as a safety outcome measure

Antibiotics are essential medicines but bacteria develop resistance to them. Antibiotic use among care home residents is high, as is antibiotic resistance. There is general agreement that antibiotic use in care homes could and should be safely reduced but there is limited evidence about how this can be achieved.

The ARCH study as a whole will systemically examine the epidemiological, social, cultural and behavioural determinants of antibiotic use in care homes through a collaborative multidisciplinary project including four work packages (WPs). The results of WP1-3 will be used to inform the development and co-design of an intervention aimed at safely reducing antimicrobial use in care homes, which will be feasibility tested in WP 4.

The data requested in this application is for WP1 which involves analysis of data from NHS Tayside and NHS Fife that is mostly already held in the Health Informatics Centre (HIC), University of Dundee, with the necessary approvals in place (supporting documents NHS Tayside Approval WP1 and NHS Fife Approval WP1 attached, HIC has approval from the East of Scotland REC and Caldicott Guardians for studies that follow Standard Operating Procedures and are made available for audit so individual REC and Caldicott approvals are not required).

The analysis in WP1 includes examination of antibiotic prescribing rates and antibiotic resistant infections across all care homes in these two health boards; selection of care homes for invitation to participate in WP2&3 (ethics approval in place); design of intervention elements, and; development of trial outcome measures. The trial outcomes will include safety measures, to ensure that reductions in antibiotic prescribing do not lead to increases in unscheduled healthcare contacts. Some unscheduled care data (Scottish Ambulance Service call outs, NHS24 and GP out-of-hours) are not held locally in HIC so we are requesting these from NSS.

1819-0270 Su-Gwan Tham

Suicide by middle-aged men

Since the early 1990s, men have accounted for around 75% of all suicides. Across the UK, male suicide rates are consistently higher than female rates. UK data from the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) show that the average number of deaths by suicide annually is 561 in men aged 40-44, 516 in those aged 45-49, and 441 in those aged 50-54. Altogether, this is an average of 1,500 deaths annually in middle-aged men (aged 40-54 years). Generally, the increase in the male suicide rate in those aged 45-54 in England has been maintained annually since around 2006 – a rise of 17%. The particularly high rate of suicide in middle-aged men has led to recommendations to focus on and consider the prevention needs of this high risk group, particularly as they are often not in contact with services.

The study aims to examine the characteristics of middle-aged men who die by suicide, determine how frequently suicide is preceded by factors more often associated with suicide by men than by women, examine the role of support services and make recommendations to strengthen suicide prevention for middle-aged men. This will be a UK wide, multi-agency study. We will combine available data from official bodies: coroner inquest hearings/police sudden death reports, criminal justice reports, safeguarding adult reviews, NCISH data and Serious Incident reports. Study findings will be published as a report on the NCISH website with associated infographics and short videos of the key messages. Additional outputs may include peer-reviewed academic papers.

1819-0276 Cara Richardson
Application to Access the ScotSID Database

Suicide kills at least 800,000 people each year globally and it is the leading cause of death in young and middle-aged men in most Western countries including in the UK. What is more, 75% of all UK suicides are men. Although there have been many advances in our understanding of suicide risk, there are many gaps in our knowledge and our ability to reach the most vulnerable men is limited. There is general recognition that we need to move beyond solely psychiatric explanations of suicide risk, to focus on more complex approaches, which integrate a large number of risk factors. To this end, O'Connor1 has developed the Integrated Motivational-Volitional model of suicidal behaviour (IMV), a theoretical model of suicidal behaviour. This model is now recognised as one of the predominant frameworks to understand suicide risk.

Despite the fact that suicide deaths are most often among men, especially among those who are most disadvantaged, relatively little research has focused specifically on men. Guided by the IMV model, this project aims to use the ScotSID database to enhance understanding of various aspects of men and women's lives prior to death by suicide, such as patterns of presentation to health care services, which can guide prevention and intervention services.

The analysis of the existing ScotSID dataset will advance our understanding of suicide risk and the findings will inform Scottish Government's National Suicide Prevention Action Plan. This project will target Action 7 of the National Suicide Prevention Action Plan, to "consider how risk of suicide is elevated for groups within the broader general population and identify specific action to address this". The findings of the project will be shared with key members of the suicide prevention leadership group, who are supportive of this project.

1819-0282 Dr Annemarie Docherty
Critically ill patients with co-existing cardiovascular disease: short and long term consequences of critical illness

Novel clinical trial design is needed to reduce the burden of research on patients, reduce costs, and improve efficiency. High quality routine healthcare data can help identify at risk groups and quantify important outcomes. This work is framed around critically ill patients with cardiovascular disease (CVD), following on from my PhD. Patients with CVD have a vulnerable heart muscle at risk of damage due to lack of oxygen. Interventions to increase oxygen delivery may benefit these patients. I will describe critically ill patients with CVD using data routinely collected in all Scottish hospitals for the first time. I will explore patterns of multimorbidity and heathcare trajectories in these patients, as well as healthcare usage. I will identify rates of cardiovascular events and mortality, and identify groups where the cardiovascular risk is greatest, and therefore where cardiovascular interventions are most likely to be beneficial. I will validate my findings in the equivalent national dataset in England.

1819-0293 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:

- In hospital management of out of hospital cardiac arrests (Attachment D - Protocol)
- Dysphagia in Parkinson’s Disease (Attachment L - Protocol)

We are applying for approval to use our standard retrospective case review 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 dataflow diagram is shown in Attachment E.

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.

1819-0306 Dr Claire Niedzwiedz

Prescribing for common mental health disorders amongst people diagnosed with cancer: data linkage study of the Scottish population

Cancer often has a significant impact on mental health. Anxiety and depression in people with cancer are both common. Poor mental health may negatively affect cancer treatment and recovery, as well as quality of life and survival. However, the mental health needs of people with cancer are often given little attention during and after treatment. This is important because at least 4% of the Scottish population are currently living with cancer, with the prevalence expected to rise. Research into the rates of treatment for anxiety and depression (e.g. antidepressants) in people with cancer is lacking. Our aim is to explore the prescribing patterns of medication for anxiety and depression amongst long-term cancer survivors and among people with a recent diagnosis of cancer. We will explore whether people with cancer are more likely to receive a prescription for common mental disorders compared to the general Scottish population and investigate the factors that may increase the likelihood of receiving a prescription, such as age, gender and socioeconomic deprivation, as well as clinical factors such as the type, stage and treatment of cancer. Whether prescribed medications for common mental disorders among people with cancer impact on important outcomes such as survival will also be investigated. This research has potential to benefit clinical practice, patients and the general public, via improved recognition of the link between cancer and common mental disorders, identification of high-risk time points for intervention and clarity on the mental health needs of those who survive cancer.

1819-0310 Karen Crawford

Best Services Trial (BeST?)

The Best Services Trial is a randomised, controlled trial (RCT) comparing social work interventions for children under 5 who enter care on account of abuse or neglect. RCTs in social work are unusual and the participants, very vulnerable. For these reasons, there must be scrutiny of the safety of participants.

This proposal aims to monitor safety of over 300 child participants in Scotland and the mortality of their birth parents. The safety monitoring is based on appraisal of the children’s deaths (if any), hospitalisations, and attendances at accident and emergency, including reasons for these attendances and/ or admissions.

To be clear, this application requests electronic health data not for the trial itself, but to monitor the safety of the participants in the trial. Trial outcome data is being gathered separately.

2019/20 Applications approved by HSC-PBPP

1819-0314 Professor Malcolm G Dunlop

Colorectal Cancer Genetic Susceptibility Programme

This particular application is seeking renewal of permissions for the current record linkage through the NHSCR under SR178. We are currently conducting detailed genetic analysis from blood and tissue samples from individuals who have developed bowel cancer or at heightened risk of developing such due to genetic predisposition. This will in the long term help us develop new treatments, help predict who will be susceptible to cancer, and so be able to prevent disease progression. This additional outcome data from NHSCR has been supporting our research aims in identify the genetic architecture of colorectal cancer.

1819-0315 Professor Helen Colhoun

SDRN Type 1 Bioresource Data Linkage

Type 1 diabetes mellitus (DM), Latent Autoimmune Diabetes of Adulthood (LADA) and Maturity Onset Diabetes in the Young (MODY), affect over 25,000 people in Scotland. These conditions continue to exert a toll on morbidity and mortality with ongoing high rates of cardiovascular disease (CBD), renal disease, retinopathy and many other sequelae. Research into and, ultimately, the prevention of the disease and its complications has been hampered by the small size of the existing cohorts of type 1 DM patients that have been studied (typically hundreds of patients when thousands are needed). With funding from CSO and Diabetes UK, we have created a biobank of blood, urine and DNA samples, with associated study data from type 1 diabetes adults in Scotland. The purpose of the biobank is to create a resource for research investigation the causes, pathogenesis and preventability of type 1 diabetes and MODY in addition to the complications of diabetes. In order to make this a rich resource for research, detailed incidence data on complications of diabetes and other relevant data such as drug exposures are needed. Therefore, we wish to link the study data to SMR and GRO death datasets and other datasets detailed below at regular intervals.

1819-0321 Dr Amanda Cross

Multicentre randomised controlled trial of ‘once only’ flexible sigmoidoscopy in prevention of colorectal cancer morbidity and mortality. Short Title: The UK Flexible Sigmoidoscopy Screening Trial (UKFSST)

Colorectal cancer (CRC), also known as bowel cancer, is a common malignancy that is very treatable when diagnosed at an early stage. The use of flexible sigmoidoscopy (FS) as a screening tool can not only identify cancers at an earlier stage but can also remove precursor lesions potentially leading to long-term protection. When this project began in 1994, there was no evidence demonstrating the benefit of FS screening and this project aimed to address this knowledge gap.

In this trial, an experimental group of patients had a single FS examination at around age 60 when they entered the study, whereas the control group received no screening (in line with the care guidelines at that time).

We have already demonstrated a significant benefit to participants who received a single FS screen compared to those who did not in preventing the development of CRC and reducing the number of deaths from CRC after seventeen years of follow-up1. Now, we propose to continue follow-up of the trial participants over a period of up to twenty-five years to provide data on the long-term benefits of this procedure, and to address other important questions surrounding FS screening.

This research will build on existing knowledge on the impact of FS and will provide evidence to the National Bowel Cancer Screening Programme (BCSP) in England on the long-term effectiveness of a single FS examination on the reduction in new cases and deaths from CRC over a period of up to twenty-five years.

1. Atkin W, Wooldrage K, Parkin DM, Kralj-Hans I, MacRae E, Shah U, Duffy S, Cross AJ et al., 2017, Long-term effects of once-only flexible sigmoidoscopy screening after 17 years of follow-up: the UK Flexible Sigmoidoscopy Screening randomised controlled trial, LANCET, Vol: 389, Pages: 1299-1311, ISSN: 0140-6736

1819-0323 Dr Peter Gallacher

Incidence and outcomes of acute coronary syndrome in dialysis and renal transplant patients: a national, longitudinal data-linkage study

Kidney disease is common and is a risk factor for heart disease. The risk of suffering from heart disease, in the form of heart attacks (for which the medical term is ‘acute coronary syndrome’ [ACS]) or strokes, increases as renal function worsens. Those with end-stage renal failure receiving dialysis or with a kidney transplant are at the greatest risk.

Over the past three decades, patients without kidney disease have benefited from advances in the diagnosis and treatment of heart disease, which have led to improved patient outcomes. It is unclear whether the same improvements have also occurred in dialysis and transplant patients. It is not uncommon for patients with kidney disease to be deprived of potentially life-saving treatments and medications when they present with heart disease as doctors feel there is not enough research and evidence to suggest that these would be beneficial in these patients.

In this proposal, I will explore what impact new therapies have had on the rates of ACS and strokes and subsequent survival in dialysis and transplant patients over the past three decades. I will compare these trends with those in the entire Scottish population to determine the extent of any differences seen in the rates during the past 30 years.

This is the first study of its kind and my results will help doctors tailor the use of treatments for heart disease in patients with end-stage renal failure. Therefore, this real world information has the great potential to directly improve care for patients with kidney disease in Scotland and beyond.

1819-0328 Laura McIver

Rheumatology Quality Registry Pilot

The project will pilot a quality registry model to facilitate symptom tracking, self-management, with shared-decision making during clinical interventions and recording of outcome measures to support co-production of care. Although in place in other health care systems (e.g. Sweden, USA), a co-produced system of this nature does not exist in Scotland.

We will do this by developing a version of the Swedish Rheumatology Quality (SRQ) Registry, in collaboration with clinicians and patients, to test in two clinics. The pilot will inform care pathways by collating patient and clinical data and provide a controlled space to test treatment modifications.

Please see the attached diagram of how our registry will work.

1819-0332 Dr Zoë Burton

PErioperAtive CHildhood ObesitY (PEACHY)

The incidence of childhood obesity is at epidemic levels and increasing in the UK. Obese adults are considered a high-risk group of patients for general anaesthesia with published national guidelines on the best practice management.

The proportion of children presenting for a procedure under general anaesthesia in the UK who are overweight or obese is currently unknown. Obese children are perceived to be at greater risk of complications from general anaesthesia. Previous non-UK studies suggest they take longer to recover from anaesthesia, require more medications to combat nausea and vomiting and are at greater risk of complications that may threaten their airway and breathing.

This study involves reviewing the anaesthetic care record and patient notes to collect information relating to general anaesthesia and basic demographic data in children aged 2-16 years presenting for a procedure under general anaesthesia.

The aims of this study are to establish the prevalence of obesity in the paediatric surgical population (i.e. the proportion of children attending UK hospitals for procedures under general anaesthesia who are overweight or obese) and to ascertain whether obese children are at increased risk compared to their healthy weight counterparts.

This information will be used with the goal of reducing avoidable harm both at national and local level in the future. It will raise awareness of the prevalence of obesity in UK children having surgery, highlighting the additional risks involved for these children. Future harm reduction strategies may include pre-operative education of children and parents regarding childhood obesity, and increased input from clinicians in the pre-operative period in terms of optimisation of these children prior to surgery.

2019/20 Applications approved by HSC-PBPP

1819-0333 Sally Stewart
ECONI Phase 4 Modelling Project End

This is a request for anonymised linked Scottish data held by NHS HPS and ISD to support a modelling project being undertaken by a team at Glasgow Caledonian University (GCU) which will assess the cost effectiveness of strategies for screening hospital patients to identify if they are carrying antibiotic resistant Carbapenemase Producing Enterobacteriaceae (CPE). The cost effectiveness work will use a standard methodology and the parameters requested will be included within a Markov Model.

CPE data are currently held within HPS as part of a national surveillance program, and are published as aggregate data within the SONAAR report Health Protection Scotland. Scottish One Health Antimicrobial Use and Antimicrobial Resistance Report 2016. Health Protection Scotland, 2017 Carbapenamase numbers by enzyme and organism 2003-2017 (2017 data until end of June)

We only require aggregate data and this should not include patient identifiers. In order to calculate these numbers a randomly generated anonymous patient identifier will be required to identify patients who have multiple samples taken, this will be undertaken by the PHI analyst. There is no requirement for the GCU team to have access to patient identifiable data.

1819-0336 Dr Timothy Cheetham
Symptomatic glucocorticoid induced adrenal suppression in the United Kingdom and Ireland

We are seeking approval for a British Paediatric Surveillance Unit (BPSU) facilitated study. The BPSU facilitates surveillance of rare health conditions affecting children across the UK and Republic of Ireland. The unit 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 a Principal Investigator. We are studying patients who have developed adrenal suppression (AS) following Glucocorticoid (GC) medicine. Natural GC, made by the adrenal glands that sit above the kidney, keep the body working normally and help it deal with the stress of trauma and infections. GC medication is frequently used to treat diseases in young people. GC medication can be applied to the skin, inhaled or swallowed as part of the treatment of many conditions such as eczema, asthma or arthritis. If the body absorbs large amounts of GC medication, then this can stop the person making natural GC. This inability to produce natural GC is called adrenal suppression and is a particular concern at the time of infection when extra ‘natural’ GC would normally be produced by the body. If additional GC is not administered at such times in patients with AS then they can become very unwell. This is referred to as an adrenal crisis and can be fatal. We intend to look at how common it is for young people to present unwell at hospital because of AS.

2019/20 Applications approved by HSC-PBPP

1819-0340 George Ramsay

Characterising cause of mortality trends of patients admitted to Emergency General Surgery in Scotland

General Surgery is a mixture of different surgical specialties. Approximately half of admissions present in an unscheduled manner and have conditions such as appendicitis, diverticulitis and blocked bowel as a result of cancer.

Emergency General Surgery (EGS) is not as commonly researched as other specialties such as breast, upper gastrointestinal or colorectal surgery. As such, little is known about the outcomes of these patients. Our group has recently shown that EGS patient have an extremely high mortality rate after their discharge from hospital but within one year of its occurrence. Up to one third of people aged over 75 admitted to EGS services across Scotland will die within one year of this admission. Whilst this is extremely high, it is unclear if there are any patterns in the cause of death. Scotland has some of the best health records in the world. The Information Services Division of NHS Scotland has nationally stored, locally coded data on all hospital admissions and all causes of death. We propose to look at the last 25 years of EGS data and ask the question: of what do EGS patient die once discharged from hospital? If there are any links or patterns that can be deduced, changes to current clinical practice could be developed.

1819-0345 Ann Banfield

ISCHEMIA-Extend: Long Term Follow Up of ISCHEMIA Trial Participants

The Ischemia Trial is a clinical trial that compares two standard treatments for patients with ischemia (reduced blood flow because of narrowed arteries) of the heart to learn which one is better and safer. The treatments are:

- Treatment with medicines and lifestyle changes alone, with a plan to use cardiac procedures only if they are needed, or
- Treatment with invasive cardiac procedures (cardiac catheterization), and then stent placement or bypass surgery along with medicines and lifestyle changes.

This trial is an international trial which started in the UK in 2012. Recruitment ended in December 2017, and patients have been followed up in clinic since then. This clinical follow up period ended on 30th June 2019.

By extending the follow up period of the ISCHEMIA patients via digital methods, we will gain additional information on how long-term all-cause mortality is affected by how patients have been treated in their 2 randomised groups. The trial participants, who are known to have coronary artery disease, were randomised to either interventional treatment such as surgery or stents, or to tablet treatment, as described above. The data will be used for research purposes only and is intended to assist the study goal to provide evidence to improve cardiovascular healthcare practices for the public across the globe. The study results will be publicly available through publication in peer reviewed journals and conference presentations. Subjects will not be contacted directly about the study results.

2019/20 Applications approved by HSC-PBPP

1819-0349 Nicola Starkey
Child Adolescent and Psychological Therapy National Dataset

Currently there are gaps in the information required locally and nationally for both child and adolescent mental health services (CAMHS) and psychological therapies services (PT) across Scotland. There is a need to improve our understanding of patient flows and waiting times in these highly pressured services in order to improve patient experience and deliver more responsive and timely services. We (ISD) need to provide better intelligence to support the Health Boards in NHS Scotland to deliver the national target on CAMHS and psychological therapies waiting times, as part of the wider Mental Health Access Improvement Support Team (MHAIST) project with the focus being on timely and patient centred services, avoidance of harm to patients arising from long waiting times, referral rejections, and reducing variation across services by learning from good practice.

At present, ISD receives aggregate returns on a monthly basis from CAMHS and psychological therapies services, providing information on the number of people waiting and duration of waiting time, the number seen, and the number of people who did not attend for their appointment (DNA). These returns do not provide information on reasons for referral or rejection of referral, detail of symptoms, clinical problems, treatments, outcomes or clinical pathways. This limits the ability of clinicians within the Health Boards to use the data for meaningful service improvement in terms of waiting times; ensuring patients are seen by the most appropriate professional, risk management and other quality measure. This newly developed patient-level dataset will provide data in these areas and overall, the impact of improved CAMHS and PT data will aid understanding of patient pathways at population and individual level in order to support optimisation of services in support of better health outcomes and reduced inequalities across CAMHS and PT services in Scotland.

1819-0357 Dr Shamez Ladhani
Characteristics of Children with Pneumococcal Meningitis in the United Kingdom and Republic of Ireland

The bacterium *Streptococcus pneumoniae* (also known as the pneumococcus) is a major cause of meningitis (inflammation of the lining of the brain) globally. It causes significant disability and death. In industrialised countries such as the UK, up to a third of survivors of pneumococcal meningitis may develop disabilities such as deafness, blindness, epilepsy and cerebral palsy.

There are almost 100 different strains of the pneumococcus. The UK and Ireland introduced a vaccine against the seven most common strains (PCV7) in their immunisation programmes in 2006 and 2008, respectively, and this vaccine was then replaced with one that protected against 13 strains (PCV13) in 2010. Both vaccines have led to rapid and sustained reductions in serious pneumococcal infections in children and adult as well, because of indirect (herd) protection. The overall reduction in pneumococcal disease, however, has been associated with a small and steady increase in disease due to strains that are not covered by the current vaccines. Currently nearly all invasive pneumococcal infections in children are caused by strains not covered by the existing vaccine.

Our study intends to measure how many children develop meningitis caused by pneumococcus, the strains of pneumococcus, the clinical severity, treatment given and outcomes one year later. This will provide important information for doctors treating children with meningitis, for public health specialists who monitor infectious disease and for those who are responsible for overseeing the vaccine programme.

1819-0358 Professor Maggie Cruickshank
Thermocoagulation of CIN

Current treatment for cervical intraepithelial neoplasia (CIN) is by local ablation (also known as thermocoagulation or cold coagulation) or excision of the transformation zone of the cervix (TZ).

There is currently a lack of long-term data on the effectiveness of treatment by thermocoagulation on women who have been treated for cervical abnormalities.

This study will use routinely collected data from Scotland to help fill this evidence gap. There are two relevant national data-sets: NCCIAS (National Colposcopy Clinical Information and Audit System; containing colposcopy records, including colposcopy results, treatment and histology) and SCCRS (Scottish Cervical Call Recall System, containing cervical screening data, including dates of tests and the results of these tests). Data from both data-sets contain the Community Health Index (CHI) number and so can be linked.

Women who have had treatment for histologically confirmed CIN from 1 January 2005 to 31 December 2014 will be identified from national colposcopy records. Within the Safe-Haven (NHS Research Scotland North (DaSH)), this will be linked to any subsequent colposcopy episodes and subsequent screening data.

On the basis of the subsequent colposcopy and screening data, women will be classified as being disease free during follow-up, or having a histologically confirmed CIN diagnosis during follow-up after treatment. The proportion of women who had their initial treatment by thermocoagulation who have histologically confirmed CIN during follow-up will be compared to the proportion of women who had their initial treatment by excisional treatment who have histologically confirmed CIN during follow-up.

1920-0001 Dr Jessica Butler
Mapping the healthcare journeys of people with fibromyalgia

Fibromyalgia is a common condition causing widespread chronic pain and profound fatigue. Diagnosis is difficult and people can wait up to ten years for a diagnosis, after many GP consultations and referrals to different specialists.

Most people with fibromyalgia are not receiving timely access to treatments, and there is little evidence on how to organise health services for them. Patients feel dissatisfied with current services, believing that no-one is willing to take responsibility for their care.

With this work we aim to understand what happens to fibromyalgia patients during their health care journey. We will collect 500 fibromyalgia patients’ health care records from attendance at: clinics, hospitals, A&E, and GP out of hours, as well as prescribing. We will link these to two previous surveys these patients completed on their physical and mental symptoms, impairment, quality of life, and medical costs.

We will use this information to map the medical journeys of people with fibromyalgia. This will include how many consultations they have had, referrals to different specialist services, any hospital admissions, when these occurred, what their diagnoses were, and what treatments were given. We will identify common pathways of care for people with fibromyalgia and describe whether those are associated with better or worse health or satisfaction.

We will also measure the costs to patients and the NHS of caring for people with fibromyalgia using the current pathways, and will be used to design new, more efficient models of care that better suit peoples' needs.

1920-0004 Susan McVie
Violence and underlying vulnerability

Despite a remarkable reduction in violent crime in recent years, it is still a key policy priority in Scotland. Emergency services deal with high volumes of violent incidents and an increasing number of calls involve some aspect of underlying vulnerability. For example, in 2017/18, Police Scotland dealt with almost 100,000 crimes or offences involving violence, a high proportion of which involved people in crisis. In addition, the Scottish Ambulance Service has seen a 4% year-on-year increase in 999 calls, primarily from people with underlying vulnerability. Policy makers are keen to understand more about how aspects of vulnerability impact on violent crime, especially as this is a primary driver for policies like the 'public health approach to reducing violence' and 'adverse childhood experiences' informed approaches to policing.

Nevertheless, there is very little underpinning evidence about the extent to which violent crime in Scotland is related to underlying vulnerability caused by drugs, alcohol or mental health issues. Little is known about the pattern of calls for service from people who experience violence or the extent to which this involves both the police and the ambulance service. And little is known about the longer term outcomes of those who experience violence, such as their risk of premature death.

The proposed research seeks to address these questions by linking Ambulance Call-out and Hospital Admissions data which identify violence-related incidents with data on drug misuse, alcohol and mental health conditions, and death records. This research will support the development of violence prevention policies in Scotland.

1920-0005 Dr Sarah Martin
Scottish Health Survey child boost eligible sample

Each year, interviewers for the Scottish Health Survey visit an extra 4500 addresses to ask parents and children under 16 questions about their health and wellbeing. This is to ensure that enough children contribute to the survey so that meaningful statistics can be published about their experiences to inform health policy in Scotland.

These addresses are randomly selected, and it turns out that more than 3500 of the 4500 are not eligible to take part in the survey because there are no children living at the selected address. This is a great waste of everyone's time and effort, and a disproportionately expensive way to identify eligible households with children.

We propose instead that the list of selected addresses gets checked against the addresses in the Community Health Index (CHI) record, and that addresses where children are registered are marked on this list before the interviewers set out. This would reduce the address list from 4500 to around 900, saving a lot of wasted travel time to ineligible addresses and avoid disrupting residents there.

1920-0028 Carolyn Wilson
Family Nurse Partnership (FNP)

Individual, social and economic circumstances faced by many young mothers present a challenge to a successful start in life for children and may interrupt the mother's longer term economic stability [Hall & Hall 2007]. Children of teenage mothers are more likely to have lower birth weight, not be breastfed, be at greater risk of accidents and early death, do worse educationally, have more emotional and behavioural problems, and become teenage parents themselves [Botting et al. 1998]. Intervention early in the lives of families with young mothers might enhance life chances for mother and child. The Family Nurse Partnership (FNP) was developed in the US as an intensive preventative home visiting intervention delivered by specially recruited and trained nurses [Olds 2002], and was formally adapted for use under license in the UK. FNP offers young women aged 19 and under and vulnerable women under 25 who are expecting their first child, home-visiting support from early pregnancy until their child's second birthday. Potential clients are identified at maternity booking. Maternity staff contact FNP teams who offer participation and enrol the client if appropriate. This application puts gathering, checking, analysing, reporting and learning from information provided by FNP participants and staff on a modern, secure database. This means that it will be easier for staff to enter data and for staff and participants to see whether the programme is doing what it is supposed to, where clients are doing well and for clients and staff to agree priorities for further improvement.

1920-0046 Danny McGee
SNBTS Transfusion Team Audit Programme

A key objective of the SNBTS Transfusion Team is to improve clinical transfusion practice. Well-conducted audit is widely recognised as a tool for driving health care quality improvement.

This project will continue to deliver a rolling programme of national audits of clinical transfusion practice in Scotland under the robust mechanism already in place. The programme aims to deliver 1-2 audits per year focussing on safe, effective and appropriate clinical transfusion practice.

Each audit is managed by the SNBTS Transfusion Team audit group, under the same governance, data collection, data protection and security, confidentiality and project management arrangements. Results are fed back to stakeholders and appropriate clinical communities and findings published in peer reviewed publications where possible.

2019/20 Applications approved by HSC-PBPP

1920-0057 Fabia Cientanni

Understanding Uptake, Adherence, and Outcome in cCBT Services: Evidence from Socioeconomic, Clinical, and Healthcare-Belief Perspectives

Computerised Cognitive Behavioural Therapy (cCBT) offers a way to provide psychological treatment quickly and widely by allowing patients to complete a course of therapy in their own home. However, one of the criticisms of cCBT is that it is claimed to have low numbers of people starting treatment (poor uptake) and high numbers of people dropping out of treatment (poor adherence). The theory of health locus of control (HLoC) may be able to help us understand why this might be so. HLoC proposes that we all have beliefs about the degree of control we have over our health outcomes, from having perceived firm control, to having perceived little control over what happens with our health. HLoC might therefore be important in determining whether people start and complete cCBT. Peoples' attitudes towards using the internet as a medium of treatment may also be important in determining uptake and adherence. People might be more likely to engage with cCBT if they believe it is valuable or appropriate for meeting their needs. By assessing attitudes toward eHealth, we hope to learn more about peoples' views towards using the internet as a means of treatment.

The proposed study aims to test whether HLoC and attitudes towards eHealth are able predict uptake, adherence and outcome (clinical improvements) in those receiving cCBT.

1920-0058 Dr Alice Jackson

The epidemiology of peripartum cardiomyopathy in a Western European country: An analysis of the Scottish population from 1986-2017 (Children)

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. There are a number of studies on women with PPCM from around the world (although none from the UK and only 2 from Europe). However, there is very little research into babies born to these women. Currently only a handful of small studies exist describing very early outcomes for newborn babies (i.e. in the first 28 days of life) and provide minimal and inconclusive data. Whether the health of a child born to a woman with PPCM is affected in the longer-term is entirely unknown. In this study, we want to answer the following important research questions:

- Do children born to women with PPCM have higher rates of morbidity and mortality than children born to healthy mothers?
- What are the short and long term outcomes for children born to women with PPCM?

Using the unique resource available in Scotland – the Information Services Division of the NHS – we will analyse linked data on all PPCM children from 1986-2017, which will allow us to answer this question. For the purposes of this application, children born to women with PPCM will be termed PPCM children.

1920-0066 Dr Alice Jackson

The epidemiology of peripartum cardiomyopathy in a Western European country: An analysis of the Scottish population from 1986-2017 (CHI no for mother)

We have already received approval for the study 1617-0359, which aims to investigate the pattern of peripartum cardiomyopathy (PPCM) in Scotland from 1986-2017. 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.

Using the unique resource available in Scotland – the Information Services Division of the NHS – we will analyse routinely collected data on all women in Scotland admitted to hospital with PPCM from 1986-2017 (PBPP approved). This application related to a second part of the study, in which we will undertake review of patient records (those women with PPCM or possible cases of PPCM) in order to:

1. Validate (confirm) the diagnosis. This allows us check the accuracy of the diagnosis, which is often not straight forward. This way we can ensure that the study encompasses ‘true’ PPCM and is of most value to patients and doctors.
2. Obtain more detailed information on important features of the condition, such as heart function at the time of diagnosis measured by heart scans (e.g. echocardiography). This will allow us to describe the condition in more detail than we would be able to using only routinely collected data. For example, we will be able to investigate how many women fully recover heart function – a crucial question with this particular condition.

Possible cases of PPCM are defined as women with a code for heart failure or cardiomyopathy around the time of pregnancy with no history of cardiac disease prior to the diagnosis.

1920-0068 David McDonald

Standardised Pathways of Care

The aim of this proposal is to support the implementation and continuous improvement in care provided by standardising the pathways that patients receive before, during and after undergoing major surgical operations.

Clinical teams from across Scotland have reviewed the latest evidence and through consensus, developed a national pathway for that particular surgical cohort and now through a Scottish Government initiative are implementing the pathway. The proposed data collection will continue to aid each team to understand in greater detail and in a timely manner, what is their current pathway and how does it differ to the agreed national pathway.

The data set for each pathway of care collects information on the patients' characteristics (e.g. age), the processes of care (e.g. time in surgery,) and the outcomes of the surgery (e.g. readmission rates). This allows clinicians at a local level a greater understanding of the type of patients they see for this operation and how they are doing in providing the agreed care plan. Furthermore, through the sharing of aggregated data for key components of the pathway, local teams will be able to compare their practise with all units in Scotland. Through this sharing of practice and outcomes, teams will come together on a quarterly basis to review the data from across Scotland and work to further improve the care provided.

Through implementing evidence-based interventions, it has been shown that this will reduce both the physical and mental stress to patients; improve patient outcomes and equity of treatment across NHS Scotland.

1920-0080 Dr Anoop Shah

Population trends and outcomes following hospitalisation with cardiovascular disease

Cardiovascular diseases are common and account for a large number of deaths and hospitalisations in Scotland annually. Despite significant reductions in mortality from cardiovascular diseases over the past few decades, the burden remains very substantial with significant rises in treatment and hospitalisations in recent years.

There has been significant changes in the way cardiovascular disease is diagnosed and treated over the past 5-10 years. The widespread implementation of more sensitive diagnostic tests such as high-sensitivity cardiac troponin and computed tomography imaging has transformed the way cardiovascular disease is diagnosed. In addition, there has been many new medications and procedures introduced into routine clinical practice such as newer antiplatelet medications, heart failure medications and transcatheter aortic valve implantation.

We wish to evaluate the impact of these important interventions on the population trends in incidence and outcome of cardiovascular disease in Scotland. We will perform this study by linking information on medicine prescribing, cardiovascular procedures, hospitalisations and causes death. Results from this study will provide important insights into the opportunities and priorities for research, prevention and public health policies.

1920-0093 Lorraine Donaldson

Scottish Intensive Care Society Audit Group Application for linkage within NSS

Data from critical care units in Scotland is held by the Scottish Intensive Care Audit Group (SICSAG), part of the Information Services Division, National Services Scotland. This PBPP application is to request approval for regular linkage of SICSAG data to other datasets also held by the Information Services Division, National Services Scotland. The other datasets of interest are; 'General Acute Inpatient and Day Case - Scottish Morbidity Record (SMR01)' and 'National Records of Scotland (NRS) - Deaths Data'. The purpose of the linkage is to enhance the SICSAG dataset by;

- populating missing hospital outcomes on the SICSAG dataset with hospital outcomes held in SMR01,
- access the co-morbidities recorded in SMR01,

- access SMR01 admission dates, to examine hospital readmissions,
- use of date of death from NRS to access long-term outcomes.

The benefit in doing this linkage is by making use of data already recorded in other datasets rather than having to request critical care staff to duplicate work and collect the same data again. It will allow for more detailed analysis of the critical care patient population in Scotland by making use of datasets held within National Services Scotland.

1920-0099 Dr Liam Mullen
RIPCORD 2

RIPCORD 2 is an open-label, prospective, dual-arm, multi-centre, randomised controlled trial across 17 PCI (percutaneous coronary intervention) centres in the UK. It is comparing the routine use of pressure wire to standard angiographic assessment in patients treated for stable coronary artery disease or non-ST elevation myocardial infarction. 1100 patients were randomised 1:1 to either conventional angiography alone or routine pressure wire assessment - in all main coronary vessels. There are two separate primary outcome measures. The primary quality of life outcome measure will be patient reported quality of life at one year using the EQ-5D-5L Health questionnaire. The primary health economic outcome measure is a comparison of health care costs, observed over a 12 month followup period. The case record form captures key elements of resource utilisation during the index procedure and up to the confirmation of the initial management strategy. Subsequent costs for each patient will then be calculated for hospitalisation events, reported by the UK electronic health records. We will capture details of all subsequent hospitalisation events including: all unplanned/acute admissions, elective admissions involving an overnight stay, elective procedures, operations and investigations.

This will include any episode that overlaps the start or end date for follow up. A standardised UK cost model will be applied for reported diagnostic and procedural codes. The primary analysis will assess observed total costs and compare the mean (or median) total costs incurred in the two groups. Secondary outcome measures include the incidence of clinical events e.g. death, stroke or myocardial infarction as defined by codes from electronic health records.

We are therefore seeking 12 month data from electronic health records for all 1100 patients as the primary means of trial follow up. Simultaneous applications for Hospital Episode Statistics data in England and Wales are being made.

1920-0101 Dr Lucy Plumb
A prospective surveillance study of conservatively managed children with end-stage kidney disease in the United Kingdom and Republic of Ireland

We are seeking approval for a new BPSU-supported study.

Kidney Disease is a major health problem for children, their families and the NHS. Progression to end-stage kidney disease (ESKD) means renal replacement therapy (RRT) such as dialysis or kidney transplantation is considered. While RRT offers a chance of survival, it isn’t a cure and treatment can be burdensome and technically challenging. In some cases, it’s in the child’s best interests not to pursue long-term RRT and instead opt for conservative care: active support of the child's kidney condition without RRT. In the UK, we don’t know how many children this affects, who it affects or reasons for choosing conservative care.

Our aim is to identify children reaching ESKD for whom a decision is made not to start long-term RRT. It is a rare disease surveillance study performed through the BPSU. Paediatricians across the UK and Ireland will be asked to notify the BPSU of children who meet the study definition. They will be invited to complete a questionnaire about the child and their care. Another brief questionnaire will be sent 12-months later to ask about the child's outcome after starting conservative treatment.

This study will increase our knowledge of childhood ESKD. It will be the first to describe conservatively managed children, factors important to families and medical teams when deciding upon conservative care and the multi-professional support received by families. This study will help us understand where access to care and support for children with kidney failure can be improved.

1920-0104 Richmond Davies

NSS Public Health & Intelligence Data Quality and Terminology Services Caldicott approval for rolling access to patient level data for auditing and improving quality of clinical coding and data recording.

NHS National Services Scotland (NSS) has legal powers to produce National and Official statistics. It also has obligations to ensure that its statistics are based on accurate data and it must demonstrate that it takes active steps to evidence the quality of the data behind its published statistics. The data, which are coded to international standards, are supplied by NHS Boards to NSS and these are the basis of the national datasets held in NSS which are analysed to produce national statistics.

To evidence data quality, a team of QA assesors and clinical coding tutors in NSS’s Public Health & Intelligence (PHI) check the quality of samples of the data held in NSS against the equivalent data held by the local data suppliers. PHI produces national reports and bespoke detailed local reports which are used by local Boards to drive improvement in the accurate recording and coding of local data. PHI also provides free clinical coding training and advice to hospital clinical coders to help them improve the accuracy of their recording and coding.

The aim of this proposal is to seek renewal of approval from National Caldicott Guardians through the Public Benefit and Privacy Panel (PBPP) for the small team of authorised and well trained specialist PHI DQA auditors and clinical coding tutors for continued and open ended access to local Board data which are used to facilitate the auditing of national data held by NSS and the continued provision of training and advice to local hospital clinical coders.

1920-0125 Ronan McCabe

The health impact of Scotland’s Baby Box scheme

The ‘early years’ of life are critical to health and development. The Scottish Government has recently set out an agenda to improve these critical years and has introduced several policies to this effect. Amongst these is Scotland’s Baby Box scheme (BB), introduced on 15th August 2017. The stated goals of the BB are to decrease deprivation and improve health.

The BB provides all Scottish mothers with a box containing items deemed essential to the first year of life (e.g. blankets, clothing, and an ear thermometer). It also includes information regarding healthy parental behaviours such as safe sleeping, breastfeeding, and preventing exposure to second-hand smoke; the box itself can be used as a safe sleeping place.

This study aims to explore the health impacts of the BB for both mothers and infants. It will look at certain health-related outcomes following the introduction of the BB and determine if there is evidence of a noticeable change. These health-related outcomes will include breastfeeding, safe sleeping and parental smoking behaviour; other outcomes of interest include infant immunisation uptake, maternal mental health prescriptions, and hospital admissions. The study will also explore whether the BB improved outcomes in different sub-groups of the population such as single parents or those living in disadvantaged communities. This study will help us understand whether investments in the BB and similar policies are important for improving health and reducing health inequalities.

1920-0127 Professor Frank Sullivan
ECLS Data Sharing Project

The ECLS study investigated the effectiveness of the EarlyCDT-Lung test and subsequent X-Ray and CT scanning in potentially identifying those at high risk of lung cancer before the presentation of symptoms. The ECLS study was funded by the Scottish Government and Oncimmune Limited. Oncimmune Limited developed the use of autoantibody assays, including EarlyCDT-Lung, in the early detection of solid tumours. The ECLS study was co-sponsored by the University of Dundee and NHS Tayside. The East OF Scotland Research Ethics Committee REC1 reviewed and approved the ECLS study, REC number 13/ES/0024.

The EarlyCDT-Lung test is an early detection test designed to assist lung cancer risk assessment and detection in the earliest stages of the disease. The ECLS trial was a randomised controlled trial of 12,000 participants at high risk of developing lung cancer, recruited through NHS Tayside, NHS Great Glasgow and Clyde and NHS Lanarkshire. Participants were randomised 1:1 to either the EarlyCDT-Lung test or standard practice. For those participants randomised the blood test, a positive blood test was followed by an initial X ray and subsequent CT scan every 6 months for 24 months.

Data was collected from ECLS participants at base line and throughout the study using a range of methods. The primary outcome data was provided by eDRIS and included in the complete ECLS data set, analysed by the ECLS collaboration. Data was securely stored in a number of systems during the running of the ECLS study and then collated by HIC into the ECLS datasets which were subsequently made available for analysis by the ECLS collaboration via the HIC Safe Haven. One of the data sets was provided by eDRIS under the initial application ref: eDRIS-1516-0030.

We now wish to make the complete, anonymous ECLS data sets, including the NSS data, held under the custody of the ECLS Data and Sample Access Committee available for future research. The ECLS data sets are defined in the ECLS eDRIS datasets v1 25-11-2019 (attached) with the associated ECLS dataset Directory v1 25-11-2019 (attached). Applications for data will be submitted to the Access Committee for initial approval and if successful, HIC will release the requested data via the HIC Safe Haven, subject to HICs SOPs. Approvals for data is the responsibility of the ECLS Data and Samples Access Committee – see Process Flowchart and ECLS Data and Sample Access Committee Terms of

Reference, attached. If data linkage to non-ECLS datasets held by HIC is requested by the applicant, this must be stated in the Data and Sample Access Request Form. The Committee will decide on access to the ECLS datasets but access to non-ECLS datasets will be managed as per HICs SOPs.

1920-0128 Dr David Walsh

Understanding the health benefits of active commuting in a Scottish context

To assess the health benefits, and resulting policy implications, of active commuting in Scotland, using the Scottish Longitudinal Study (a 5% sample of the Scottish Census) linked to morbidity and mortality records.

There is a considerable amount of research evidence of the health benefits (and associated cost savings) of active commuting (principally walking and cycling). This has included a recent, large-scale, UK study which demonstrated an association between cycling commuting and notably lower risks of all-cause and cause-specific mortality, while controlling for the effects of a broad range of behavioural and biological risk factors1. Although the latter UK study had a number of strengths – not least its ability to control for a broad range of potentially important confounders – it was also associated with a number of important weaknesses: a limited follow-up period, a narrow age range of participants, and the established lack of representativeness of the data source . The aims of this new study are: first, to address some of those limitations (e.g. in terms of incorporating a much longer follow-up period, using a broader age group, and also examining different outcomes); and second, and perhaps most importantly, to produce new evidence based on a specifically Scottish context – using a large representative Scottish sample – with which to make specific recommendations aimed at Scottish Government policy-makers.

1 Celis-Morales C. A., Lyall D. M., Welsh P. et al. Association between active commuting and incident cardiovascular disease, cancer, and mortality: prospective cohort study. BMJ. 2017; 357: j1456

1920-0131 Professor Jennifer J Kurinczuk

MBRRACE-UK – Delivering the UK Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP)

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

To carry out this work MBRRACE-UK collects information across the UK about:

- all mothers who die during pregnancy or up to 12 months after giving birth (surveillance and confidential enquiries);
- some mothers who experience particular, very serious illness in pregnancy (confidential enquiries);

- all mothers whose pregnancy results in the baby being stillborn (surveillance);
- all mothers and babies when the baby dies in the first few weeks after birth (surveillance);
- samples of mothers and babies where the baby is stillborn, dies in the first few weeks after birth or is very seriously ill in the period after birth (confidential enquiries).

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

1920-0144 Dr Michael Fleming

Investigating the relationship between health and educational outcomes in children

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

We previously demonstrated associations between gestational age/low birth weight and increased risk of special educational need and followed this up by demonstrating that schoolchildren receiving medication for chronic conditions such as diabetes, asthma, epilepsy, attention deficit hyperactivity disorder, depression, and skin disorders have poorer educational and health outcomes compared to their peers.

We aim to build on previous work by studying the impact of a range of factors (chronic conditions, early life factors, neonatal and childhood morbidity and maternal/obstetric factors) on: subsequent health (hospital admissions, prescribing for chronic conditions [including those referenced above], and deaths); educational outcomes (school absences, school exclusions, special educational need [including autism and intellectual disability], academic attainment, and leaver destination [employed, further education, unemployed etc.]).

Specific research objectives are to investigate how the following are associated with subsequent educational and health outcomes:

1. Childhood chronic conditions (e.g. diabetes, asthma, epilepsy, ADHD, depression, skin disorders, autism, and learning disability)
2. Neurodevelopmental multi-morbidity (for example co-existing ADHD, depression, autism, learning disability, or epilepsy)
3. Early life morbidity (e.g. hospitalisation) and other early life/lifestyle/development factors
4. Maternal and obstetric factors

1920-0207 Dr Stephen Knight

ELF 2 – Defining the Denominator

The aim of this study is to better understand the decision making by doctors and associated patients outcomes for older (65 years and above) hospitalised patients who do not receive emergency surgery due to frailty, concurrent illness or other rationale. Any hospital in the United Kingdom can take part as long as they perform eligible surgical procedures on a routine basis. We will achieve this aim by auditing frailty and disease state to quality standards outlined by the National Emergency Laparotomy Audit (NELA). Most complications occur in the first 90 days of surgery – so we will focus on this time frame, with an additional follow-up point of 1 year to determine longer term outcome for this patient population.

We will include all older patients (=> 65 years old) who are reviewed by a surgical team in the study period at each participating hospital. The study is proposed to run from Monday 2nd March 2020 to Sunday 14th June 2020 (with the last 90-day follow-up period ending on 13th September 2020 and 1-year follow-up ending on 14th June 2021). Data will be collected on all patients reviewed by the surgical team during the time-period with follow-up to 90-days after their operation. This will include all older patients (=> 65 years old) who have an abdominal condition which usually requires emergency abdominal surgery (excluding trauma, vascular, urology and gynaecology causes) to correct via an open abdominal operation (laparotomy).