Public Benefit and Privacy Panel Approved Applications 2017-2018

As at 31 March 2018

Application Reference	Applicant	Title of Study	Decision	Level of Approval
1516-0232	Jayne Scotland	Data analysis for the National Managed Clinical Network (NMCN) for Children with Exceptional Healthcare Needs (CEN)	Approved	Tier 1
1617-0243	Dr Sarah Mitchell	The National Lifecurve Survey	Approved	Tier 1
1516-0509	Dr Gary McLean	Antihypertensives as Repurposed Treatments for Mood Disorders: Scottish National linkage and UK Biobank investigation. ("ARTforM" study)	Approved	Tier 1
1617-0312	Dr Simon Crawley	Evaluation of Anaesthetic Facemasks to Inform the Clinical Advisory Panel for National Procurement Exercise NP178 (2016)	Approved	Tier 1
1617-0369	Dr Stephen Pavis	Preparing NSS data for efficient research dataset creation: a pilot project	Approved	Tier 1
1617-0296	Dr Mirijam Allik	The health of Looked After Children in Scotland	Approved	Tier 2 Out of Committee
1617-0179	Dr Caroline Jackson	Assessing the impact of major mental illness on the outcomes and complications of cardiovascular disease and diabetes: a national data linkage project	Approved	Tier 1
1617-0244	Lisa Iversen	The Royal College of General Practitioners' Oral Contraception Study	Approved	Tier 1
1516-0196	Kathryn Fitzpatrick	Short and longer-term outcomes for women and their children according to intended mode of delivery after previous caesarean section	Approved	Tier 1
1516-0461	Dr Gillian Hawkins	Comparing incidence of gastrointestinal infection in areas of high private water supplies and high failure rates with the rest of the population	Approved	Tier 1
1617-0181	Dr Peter Murchie	NASCAR+: Exploring associations between geography, treatment, follow-up care and survival of cancer patients in Northeast Scotland	Approved	Tier 1
1617-0246	Lisa Clark	A Phase II Efficacy Study of Intracerebral CTX0E03 DP in Patients with Stable Paresis of the Arm Following an Ischaemic Stroke	Approved	Tier 1
1516-0578	Daniel Levin	Fourth Follow-Up of SHHEC cohort	Approved	Tier 1
1516-0608	Dr Iris Egner	Renal disease in patients with the TSC2/PKD1 contiguous gene deletion".	Approved	Tier 1

1516-0582	Dr Sarah Goodbrand	The impact on female fertility of severe ulcerative colitis and its medical and surgical treatment in Lothian	Approved with conditions	Tier 1
1617-0304	David Henderson	Using linked data to understand the relationships between Multimorbidity and the use of Health and Social Care	Approved with conditions	Tier 1
1617-0309	Richard Hunter	AHP Operational Measures Data – Phase 2	Approved	Tier 1
1718-0012	Dr Peter Murchie	Understanding the interplay of geography and demographic characteristics in the diagnosis of eight common cancers: The NASCAR-CENSUS project	Approved with Conditions	Tier 1
1617-0189	Dr Mairead Black	Offspring renal calculi following elective caesarean	Approved	Tier 1
1516-0264	Dr George Mells	UK-PBC Genetics Study	Approved	Tier 2 Out of Committee
1617-0162	Professor Michel Coleman	CONCORD -3 study, an international study on cancer survival	Approved	Tier 1
1718-0017	Dr Matthew Henry Iveson	Childhood cognitive function and use of long-term care across the life course: Linking the Scottish Mental Survey 1947 to healthcare and administrative data.	Approved with conditions	Tier 1
1718-0010	Dr Matthew Henry Iveson	Childhood cognitive function and later-life recovery: Linking the Scottish Mental Survey 1947 to healthcare and administrative data.	Approved with conditions	Tier 1
1617-0311	Dr Lynne Forrest	Migration to Scottish New Towns and the impact on premature mortality in Glasgow: analysis of 1947 Scottish Mental Survey data	Approved	Tier 1
1516-0573	Dr Laura Pidgeon	A health informatics approach to the assessment of prescribing and clinical outcomes in bipolar disorder: national Scottish data linkage study	Approved	Tier 1
1617-0329	Sally Stewart	Evaluation of Cost of Nosocomial Infection (ECONI) Phase 2 and 3	Approved	Tier 1
1516-0504	Shuna Colville	Scottish Motor Neurone Disease Audit, Research and Trials	Approved	Tier 1
1718-0022	Dr William Atkinson	SR8 - Mortality Study of Employees at UKAEA Dounreay	Approved with conditions	Tier 1
1617-0255	Dr Peter Joshi	A study of the outlook for lifespan, health-span and population size in Scotland 2020-2035, based on observed disease and mortality trends 1990-2015.	Approved with conditions	Tier 2 Out of Committee
1516-0522	Dr Lucy Stirland	Associations between polypharmacy and mental health outcomes in older adults: an epidemiological approach	Approved	Tier 1

1718-0050	Greig Stanners	Linking Flexible Sigmoidoscopy Study data with Faecal Immunochemical Test study data, and Scottish Bowel Screening Programme data.	Approved	Tier 1
1516-0281	Dr Deborah Kinnear	Poor oral health in adults with intellectual disabilities.	Approved	Tier 1
1617-0227	Suneetha Ramani Moonesinghe	Perioperative Quality Improvement Programme (PQIP)	Approved with conditions	Tier 1
1617-0332	Dr Callum Kaye	Outcomes of patients admitted with Haematological Malignancies in Scottish ICUs	Approved	Tier 1
1617-0204	Kate Stewart	New statistical tools to model environmental influences on antibiotic resistance in people	Approved	Tier 1
1617-0052	Dr Deborah Kinnear	Predictors of mental ill health in mothers caring for a son or daughter with intellectual disabilities	Approve with Conditions	Tier 1
1718-0053	Lesley Watson	Cancer Survival Analysis	Approved	Tier 1
1617-0328	Shengyuan Zhao	Epidemiology of Carbapenamase producing organisms (CPOs) in Scotland	Approved	Tier 1
1617-0178	Francis Appiagyei	Anonymised GP practice patient data and secondary care data linkage in Scotland for the At-Risk Registers Integrated into primary care to Stop Asthma crises in the UK (ARRISA-UK) Study	Approved	Tier 2 Out of Committee
1516-0114	Dr Vittal Katikireddi	Understanding the health and employment support needs of the Scottish working age population	Approved with Conditions	Tier 2 Out of Committee
1718-0044	Professor Nick Bailey	Wider impact of benefit sanctions on health	Approved with Conditions	Tier 2 Out of Committee
1617-0321	Emma Milburn	Scottish Health and Care Experience Survey	Approved	Tier 2 Out of Committee
1617-0318	Nicola McGuire	Investigating the relationships between environmental factors and participation on outcomes for individuals with complex mental health needs.	Approve with Conditions	Tier 1
1718-0027	Dr Rohit Sinha	Predictors of survival in patients with TIPSS for refractory ascites	Approved	Tier 1
1617-0327	Professor Harry Campbell	RESCEU data linkage	Approved	Tier 1
1617-0150	Diane Havard	TARDIS trial MR 1259	Approved	Tier 1
1617-0289	Kathy McGregor	Linkage Unscheduled Care Datamart (UCD) to Prescribing Data contained in the Prescribing Information System (PIS)	Approved	Tier 1
1617-0197	Dr Tom Clemens	Environmental Determinants of Fertility Success	Approved with	Tier 1

			conditions	
1617-0023	Dr Stuart McIntyre	Evaluating the enhanced recovery pilot in Obstetrics, and the related analysis of Caesarean Section variation in Scotland	Approved	Tier 1
1718-0030	Dr Christine Campbell	Second primary cancers: a case note review and interview study to understand pathways to diagnosis and patient and provider experiences	Approved	Tier 1
1617-0374	Dr Úna McMenamin	Medications with hormonal effects and outcomes in patients with breast and prostate cancer: A Scottish cohort study	Approved	Tier 1
1718-0136	Stephen Riddell	NHS Information Services Division/Alan Turing Institute Data Study Group Collaboration – SPARRA Algorithm Development	Approved	Tier 1
1718-0085	Cheryl Denny	Scottish Routes from Diagnosis: Development of a Cancer Survivorship Outcome Framework	Approved	Tier 1
1617-0330	Dr Stamatine Iliodromiti	Association of birthweight and perinatal indicators with perinatal, childhood and maternal outcomes: a population based linkage study	Approved	Tier 1
1718-0004	Hazel Dodds	Development of (electronic data collection system for the Scottish Trauma Audit Group (eSTAG))	Approved	Tier 1
1718-0040	Dr Cheryl Gibbons	Point Prevalence Survey of Healthcare-Associated Infections and Antimicrobial Use in Scottish Long-Term Care Facilities (HALT)	Approved	Tier 1
1617-0275	Linsey Galbraith	Estimating the Prevalence of Problem Drug Use (among individuals aged 15-64) in Scotland in 2015/16	Approved	Tier 1
1617-0348	Professor Zosia Miedzybrodzka	Evaluating a new protocol for primary-care initiated identification and management of patients with familial hypercholesterolemia: observational study and cost-effectiveness analysis.	Approved	Tier 1
1718-0179	Linda Kerr	NHS Scotland Shared Services Radiology Programme	Approved with Conditions	Tier 1
1718-0100	Dr Peter Adlard	SR48 - Human Pituitary Growth Hormone Follow-Up Study	Approved	Tier1
1718-0056	Dr Unoma Okudo	Transfer for Treatment Direction/ Transfers Out of Prison in 2016	Approved	Tier 1
1516-0483	Dr Bruce Mason	Supporting people with palliative and end-of-life care needs “out of hours”: a mixed-methods study of needs, demand and experiences to inform person-centred service developments	Approved	Tier 1
1617-0206	Hugh Paterson	A comparison of the management of acute diverticulitis between Scotland and Switzerland	Approved	Tier 1

1617-0067	Professor Sharon Cameron	BRIDGE-IT	Approved	Tier 1
1516-0553	Dr Margo Chase-Topping	The phylogenomics of human and cattle Escherichia coli (E. coli) O157 and the strain genotypes associated with super shedding and human disease	Approved	Tier 1
1516-0577	Daniel Levin	SHARP Survey Follow-up Study	Approved with Conditions	Tier 2 Out of Committee
1718-0158	William Malcolm	Identification of risk factors for antimicrobial resistance in patients with suspected sepsis	Approved	Tier 1
1617-0147	Professor Helen Colhoun	Extending our understanding of the impact of diabetes in Scotland: A project to support continuing Scottish diabetes data linkage	Approved with Conditions	Tier 1
1617-0360	Stephen Knight	Consent process for patients across Scotland	Approved with Conditions	Tier 1
1718-0186	Amelia Rudd	Establishing the incidence of Tako-tsubo Cardiomyopathy in Scotland – the STARR study (Scottish Tako-tsubo Network/Registry) – Phase 1	Approved with Conditions	Tier 1
1617-0338	Professor Colin Palmer	SHARE- Central data transfer to SHARE in Health Informatics Centre (HIC) within FARR Dundee. (FD)	Approved with conditions	Tier 2 Full Committee
1718-0141	Dr Elizabeth Murphy	Scottish Society for Rheumatology Web Based Audit	Approved with Conditions	Tier 1
1617-0265	Robin Flaig	UK Biobank prospective cohort – longitudinal follow-up through linkage to health-related records in Scotland	Approved with Conditions	Tier 2 Full Committee
1718-0020	Dr Martin McCoy	Distress Brief Interventions (DBI) Programme Data Collection	Approved with Conditions	Tier 1
1718-0121	Dr Sarah Maclean	Frailty and outcomes in the Intensive Care Unit	Approved with Conditions	Tier 1
1718-0184	Dr Rachel Knowles	Surveillance of severe microcephaly in the UK and Ireland (SSM-UKI)	Approved with Conditions	Tier 1
1516-0110	Dr Claudia Zabke	The British Society for Rheumatology Biologics Registers in Ankylosing Spondylitis (BSRBR-AS) data linkage Scotland	Approved	Tier 1
1718-0132	Dr Sarah Murray	Preterm perinatal mortality in twins compared to singletons: a population study	Approved	Tier 2 Out of Committee

1718-0118	Emma Milburn	Inpatient Experience Survey	Approved with Conditions	Tier 2 Out of Committee
1718-0208	Dr Frank Popham	Selective schooling and long-term health: a data linkage study	Approved	Tier 1
1718-0106	Claire Lawrie	Audit of current practise in primary care for investigation of women presenting with symptoms, which may be due to ovarian cancer against the Scottish cancer referral guidelines	Approved	Tier 1
1617-0362	Peter Croan	VS Warehouse	Approved	Tier 1
1718-0101	Maria Aresu	Airwave Health Monitoring Study (MR837)	Approved with Conditions	Tier 1
1718-0205	Dr Zoe Harclerode	PAediatric unPlanned dAY case Admissions (PAPAYA)	Approved	Tier 1
1718-0162	Diane Havard	Prevention Of Decline in Cognition After Stroke Trial (PODCAST)	Approved	Tier 1
1516-0625	Damian Mole	Identifying risk factors for progression to multiple organ failure amongst individuals with acute pancreatitis	Approved	Tier 1
1718-0221	Allan Mcleod	Linking Scottish Infected Blood data (PSD) to Hep C data (HPS)	Approved with Conditions	Tier 1
1617-0011	Dr Diane Lindsay	Genomic sequencing and epidemiology of Legionella pneumophila in Scotland	Approved	Tier 1
1718-0057	Dr Jonine Figueroa	Temporal trends of molecular portraits of breast cancer in Scotland	Approved	Tier 1
1617-0257	Dr William Whiteley	Long term follow of Asymptomatic Carotid Surgery Trial (ACST-1)	Approved	Tier 1
1617-0347	Alessia Morris	Persons at Risk Database (PARD)	Approved with Conditions	Tier 1
1718-0194	Dr Carl Counsell	Parkinsonism Incidence in North-East Scotland (PINE) study	Approved	Tier 1
1718-0107	Karyn Robertson	Transfer of the hosting of the Photosys Database from NHS Tayside to NHS NSS and upgrading of the operating system	Approved with Conditions Application withdrawn after approval	Tier 1
1718-0096	Dr Ore-oluwa Erikitola	Surveillance of persistent cystoid macula oedema following uncomplicated cataract surgery in Scotland: Incidence and management	Approved with Conditions	Tier 1
1718-0048	Professor Wendy Atkin	Frequency of follow-up for patients with low-, intermediate- and high-risk colorectal adenomas.	Approved with Conditions	Tier 1

1516-0567	Professor James Wilson	Record Linkage in the Viking Health Study - Shetland	Approved	Tier 1
1718-0254	Dr David McDonald	Emergency Surgery Pathways	Approved with Conditions	Tier 1
1718-0188	Praveena Symeonoglou	Scottish Dental Needs Assessment Programme Oral Health and Dental Services Needs Assessment for Older Adults (45 and over)	Approved	Tier 1
1718-0201	Tracey Curtis	National Invasive Cancer Audit	Approved	Tier 1
1718-0245	Dr Diane Swallow	Improving diagnostic and care pathways in progressive supranuclear palsy (PSP) and corticobasel degeneration (CBD)	Approved	Tier 2 Out of Committee
1718-0120	Dr William Stewart	FIELD: Football's Influence on Lifelong health and Dementia risk	Approved	Tier 2 Out of Committee
1718-0180	Kathy McGregor	Linkage Unscheduled Care Datamart (UCD) to Social Care data contained in the Social Care datamart	Approved	Tier 1
1718-0275	Heather Clark	The Aberdeen Children of the 1950s study	Approved	Tier 1
1718-0261	Ross Dolan	The relationship between body composition, tumour activity, functional activity and survival in patients with advanced cancer	Approved	Tier 1
1718-0206	Dr Mirko Moro	Life Unleaded: Investigating the effects of public interventions to reduce water lead pollution on infants and children's health	Approved	Tier 1
1617-0307	Professor Bruce Guthrie	Unscheduled care use in NHS Scotland	Approved	Tier 1
1516-0584	Kirsty Dunn	Predictors of mental ill-health and its determinants in fathers caring for a son or daughter with intellectual disabilities: secondary data analysis and data linkage of administrative and health records in Scotland	Approved with Conditions	Tier 1
1718-0264	Eleanor Lumley	Complex lower limb trauma: Understanding the outcomes and health services resource use post-reconstruction.	Approved with Conditions	Tier 1
1516-0560	Professor Ian Kunkler	Radiotype DX: Molecular signatures of radiosensitivity and ipsilateral breast tumour recurrence in breast cancer	Approved	Full Committee
1617-0049	Dr Karen Semple	Using linked data to follow up longer term outcomes of POPPY trial participants	Approved	Full Committee

1718-0002	Dr Alistair Ewen	A retrospective review of short term outcomes of the Triathlon total knee system	Approved with Conditions	Tier 1
1718-0088	Dr Emily Tweed	Morbidity and mortality among people experiencing severe and multiple disadvantage: a retrospective cohort study using cross-sectoral data linkage	Approved with Conditions	Tier 2 Out of Committee
1718-0267	Anne-Marine Lenzotti	S-AVANT. Follow-up to the AVANT study up to 8 and 10 years (median follow-up) in patients with colon carcinoma	Approved with Conditions	Tier 1
1718-0215	Fiona Russell	Scottish Cancer Registry and Intelligence Service (SCRIS): Developing the National Reporting of Systemic Anti-Cancer Therapy/ChemoCare data	Approved with Conditions	Tier 1
1718-0300	Dr Deborah Kinnear	Older parent carers health and its reciprocal effect on their ageing offspring with intellectual disabilities: a record linkage study	Approved	Tier1
1718-0262	Dr Kathryn Johnson	Surveillance of Foetal alcohol syndrome in the United Kingdom and Republic of Ireland (SFAS-UKI)	Approved	Tier 1
1718-0160	Professor James Roy Robertson	Edinburgh Drug Cohort Study	Approved	Tier 1
1718-0202	Professor Glen Bramley	Profile of Severe and Multiple Disadvantage in Scotland – analysis of Scottish Drugs Misuse Database	Approved	Tier 2 Out of Committee
1718-0277	Dr Kieran Docherty	Trends in the incidence, morbidity and mortality of heart failure associated with myocardial infarction in Scotland between 1986 and 2016.	Approved	Tier 1
1718-0097	Jillian Moses	Radiotherapy Dataset Project	Approved	Tier 1
1718-0076	Richard Colquhoun	National Neonatal Research Database	Approved with Conditions	Tier 2 Out of Committee
1617-0295	Dr Andrew Wong	MR1 – Health and Development Study	Approved with Conditions	Tier 2 Out of Committee
1718-0225	Roz Pollock	Maternity Care Survey	Approved with Conditions	Tier 2 Out of Committee
1718-0271	Dr Colin Tilley	Pilot new platform for workforce planning	Approved with Conditions	Tier 1
1718-0279	Dr Markus Gehrsitz	Education and Health – Is there really no Causal Relationship?	Approved	Tier 1

1718-0098	Alison Roe	Inclusion of Scotland onto the Breast and Cosmetic Implant Registry (BCIR)	Approved with Conditions	Tier 1
1718-0298	Nicola Starkey	CAHMS Rejected/Redirected Referrals Audit	Approved	Tier 1
1718-0212	Professor Matthew Bown	The United Kingdom Aneurysm Growth Study	Approved	Tier 1
1718-0270	Lucy Lennon	SMR104 – British Regional Heart Study	Approved	Tier 1
1718-0286	Fiona Mitchell	Meeting the health needs of looked after children in Scotland: an exploratory study	Approved with Conditions	Tier 2 Out of Committee
1718-0249	Professor Jennifer Kurinczuk	National Perinatal Mortality Review Tool (PMRT)	Approved	Tier 1
1718-0307	Lee Barnsdale	National Naloxone Programme Monitoring	Approved	Tier 1
1718-0336	Genevieve Cezard	Ethnic differences in trajectory of health and health decline in Scotland	Approved	Tier 1
1617-0247	Dr Joanne Given	Metformin for diabetes in pregnancy – an analysis of health outcomes in Scotland as part of a UK wide study	Approved	Tier 1

Lay summaries of approved applications

Version 1 of the PBPP application form did not include a lay summary, so for these applications a lay summary is not available.

1516-0110 Zabke The British Society for Rheumatology Biologics Registers in Ankylosing Spondylitis (BSRBR-AS) data linkage Scotland

he British Society for Rheumatology (BSR) is currently funding researchers at the University of Aberdeen to co-ordinate the BSRBR-AS study. BSRBR-AS stands for British Society for Rheumatology Biologics Register in Ankylosing Spondylitis. The study has set out to examine:

- The effectiveness and safety of biologic therapies in the management of axial Spondyloarthritis (axSpA) (including Ankylosing Spondylitis (AS));
- The development and progression of the condition in individuals (natural history of the condition);
- The impact of the condition on the individual, for instance on quality of life and work, and on the society;
- Use and cost-effectiveness of pharmacological therapies for axSpA;
- The occurrence of additional conditions associated with axSpA (co-morbidities) and their influence on disease progression; and
- Genetics of the condition.

We are recruiting axSpA patients (including AS patients) through local rheumatology centres. Patients are eligible to participate when they are starting a new biologic therapy or when they are not starting such therapy and never had any such therapy before. We are collecting data from patients' routine rheumatology clinic visits, patients' questionnaires and national databases. Sometimes the data we receive from our participating rheumatology departments is incomplete. Linking to data held by national databases allows us to get additional information for instance about hospital stays, visits to other (not rheumatology) hospital departments, or if patients develop cancer or another serious condition or dies. With this additional information we will be able to construct a more complete picture of the condition and the safety of biologic treatment. We will also be able to work out the costs associated with axial Spondyloarthritis.

1516-0114 Dr Vittal Katikireddi

Understanding the health and employment support needs of the Scottish working age population

No lay summary

1516-0196 Kathryn Fitzpatrick

Short and longer-term outcomes for women and their children according to intended mode of delivery after previous caesarean section

No lay summary

1516-0232 Jayne Scotland

Data analysis for the National Managed Clinical Network (NMCN) for Children with Exceptional Healthcare Needs (CEN)

No lay summary

1516-0264 Dr George Mells

UK-PBC Genetics Study

No lay summary

1516-0281 Dr Deborah Kinnear

Poor oral health in adults with intellectual disabilities.

No lay summary

1516-0461 Dr Gillian Hawkins

Comparing incidence of gastrointestinal infection in areas of high private water supplies and high failure rates with the rest of the population

No lay summary

1516-0483 Dr Bruce Mason

Supporting people with palliative and end-of-life care needs “out of hours”: a mixed-methods study of needs, demand and experiences to inform person-centred service developments

Improving palliative care outside of working hours (OOH), is the top UK priority for palliative care.[1] A 2013 government report stated that OOH should be integral to a complex system of 24/7 care along with generalist palliative care provided “in hours.”[2] The 2015 Ritchie Report on OOH care in Scotland identified people with palliative and end-of-life care needs (PEoLC) as needing better care.[3] A systematic review for the report highlights the need to understand decision-making by patients and carers during the OOH period. We know that many people with PEoLC needs are still not identified for a palliative approach before they die.[4] Understanding how all people with PEoLC needs use and are served by OOH care is a prerequisite for future service developments both in-hours and OOH.

Scotland is starting a radical redesign of OOH services. There is a pressing need for a robust evidence to inform these developments provided by population level analyses of current OOH service use allied with an in-depth analysis of how people access and perceive OOH services.

1516-0504 Shuna Colville

Scottish Motor Neurone Disease Audit, Research and Trials

No lay summary

1516-0509 Dr Gary McLean

Antihypertensives as Repurposed Treatments for Mood Disorders: Scottish National linkage and UK Biobank investigation. (“ARTforM” study)

No lay summary

1516-0522 Dr Lucy Stirland

Associations between polypharmacy and mental health outcomes in older adults: an epidemiological approach

No lay summary

1516-0553 Dr Margo Chase-Topping

The phylogenomics of human and cattle Escherichia coli (E. coli) O157 and the strain genotypes associated with super shedding and human disease

EHEC (also known as STEC or VTEC) O157 is the main serogroup of Escherichia coli associated with serious human disease in the UK. EHEC O157 strains can induce serious illness in humans as a consequence of the activity of Shiga toxins. Infections can be fatal or exert long-term morbidity. Currently, Health Protection Scotland (HPS) conducts active, population-based enhanced surveillance in close collaboration with the Scottish E. coli O157/VTEC Reference laboratory (SERL) and NHS Board Health Protection Teams. Over the 17 year period 1998-2015, an annual mean (95% confidence limits) of 221 (203-239) culture-positive cases was reported to HPS, with a mean annual incidence rate of 4.3 (3.9-4.7) cases per 100,000 population. Rates of human EHEC O157 infection in Scotland are generally higher than in most other United Kingdom, European and North American countries. These rates have not changed significantly since 1998. Over 40% of cases in Scotland require hospitalization, and almost 10% develop severe renal complications (predominantly children). This proposal aims to build on the findings and expertise of two research consortia that have conducted research into the epidemiology and biology of EHEC in Scotland over the last decade.

Ruminants are the host reservoir for most EHEC strains. In a 2008 publication we proposed a specific mechanism for the link between human infection and livestock carriage of E. coli O157 which involved a subset of shedding animals known as super-shedders. Super-shedders are individuals who, for a period, yield more infectious organisms (here E. coli O157) than typical individuals of the same host species. Shedding high concentrations of E. coli O157 has been proposed as a major contributor to cattle-to-cattle transmission and possibly cattle-to-human transmission. The biology and epidemiology of super-shedding is better understood for E. coli O157 than for any other system with a significant contribution from research centred in Scotland. The central tenet of this proposal is that different EHEC O157 strains are not equally likely to cause super-shedder infections. EHEC O157 strain epidemiology has predominately relied on phage typing, with PT21/28 strains shown to be the phage type (PT) more commonly identified in more serious human disease. To further advance our knowledge we need to understand strain differences at the sequence level and to determine the relationship with excretion level, zoonotic capacity and severity of human disease.

In May 2013 the Food Standards Agency (FSA/FSS) announced a call for proposals regarding research on E. coli O157 shedding. An EHEC consortium (see Additional file 1) involving many government and academic organisations in Scotland, England and Wales responded with a successful proposal – FSA project FS101055 or the 'super-shedders study' (see additional file 2) – The objective of the proposal that is relevant to this application is to determine the phylogenomics of human and cattle EHEC O157 and the strain genotypes associated with super-shedding and human disease.

Linkage of HPS enhanced surveillance data and SMR01 clinical data to human clinical E. coli O157 isolate sequences is critical to meeting this objective. Full details on the study protocol can be found in additional file 3.

1516-0560 Professor Ian Kunkler
Radiotype DX: Molecular signatures of radiosensitivity and ipsilateral breast tumour recurrence in breast cancer

No lay summary

1516-0567 Professor James Wilson
Record Linkage in the Viking Health Study – Shetland

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

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

Genetic analysis has been done on DNA extracted from blood samples provided by over 2,000 participants with ancestry from Shetland. Together with data from studies run by the investigators in Orkney, Croatia and mainland Scotland, this provides statistical power to identify new rare genetic variants associated with disease. The addition of linkage to NHS "routine" data as requested in this application will considerably enhance and extend these analyses. Future updates to the NHS data over the next five years will also allow the health of the participants to be tracked over time, adding new clinical measures and providing information on treatment and health outcomes.

1516-0573 Dr Laura Pidgeon

A health informatics approach to the assessment of prescribing and clinical outcomes in bipolar disorder: national Scottish data linkage study

No lay summary

1516-0577 Daniel Levin

SHARP Survey Follow-up Study

No lay summary

1516-0578 Daniel Levin

Fourth Follow-Up of SHHEC cohort

No lay summary

1516-0582 Dr Sarah Goodbrand

The impact on female fertility of severe ulcerative colitis and its medical and surgical treatment in Lothian

No lay summary

1516-0584 Kirsty Dunn

Predictors of mental ill-health and its determinants in fathers caring for a son or daughter with intellectual disabilities: secondary data analysis and data linkage of administrative and health records in Scotland

Of the approximately 26,000 people with intellectual disabilities in Scotland, an estimated 11,000 (42%) of these live with a parent carer (Scotland Census 2011). While attitudes within Scotland are changing, it is still often assumed that mothers are the sole care givers for their children. Yet more fathers than ever are now taking an active caregiving role (Dillenburger et al, 2009). Despite this shift in traditional gender roles, very little research has been conducted on fathers who care for their son or daughter with intellectual disabilities.

While caregiving can be very rewarding, many parent carers have reported that they experience poor mental health (Hastings and Taunt, 2002). This study aims to investigate the mental health of fathers who care for their son or daughter with intellectual disabilities, and the factors which impact their mental health. The Scotland Census 2011 provides a unique opportunity to learn more about father carers as it included a question asking if anyone with intellectual disabilities lived in the household. From the census we can also identify which of these individuals are cared for solely by their father or by their father alongside another carer, and which of these fathers reported mental health problems.

With this information, important and overdue questions on mental ill-health can be addressed which will subsequently identify what services are required to ensure appropriate support mechanisms are put in place to better support the needs of father carers. Increasing our understanding of the mental health of father carers of a son or daughter with intellectual disabilities will also provide the evidence to inform policy makers in order to make change.

1516-0608 Dr Iris Egner

Renal disease in patients with the TSC2/PKD1 contiguous gene deletion".

No lay summary

1516-0625 Damian Mole

Identifying risk factors for progression to multiple organ failure amongst individuals with acute pancreatitis

This study is the 5-year and 10-year actual minimum follow up on the acute pancreatitis (AP) linked cohort from study XRBL1231 – Identifying risk factors for progression to multiple organ failure amongst individuals with AP.

This study is seeking to assess what has happened to the cohort since the original study (XRBL1231) took place. Refer to 3.1.07 for the specific questions to be investigated.

The original study (PAC 06/13) investigated factors are associated with developing severe acute pancreatitis (SAP). It specifically evaluated whether factors existing in the health record prior to an acute episode of acute pancreatitis predicted the requirement for critical care admissions and outcome from an episode of AP. In that study, predictors of SAP were pre-existing angina or hypertension, hypocalcaemia and age 30–39 years, if type 2 diabetes mellitus was present. The risk of sAP was lower in patients with multiple previous episodes of AP. In a separate study of a historical cohort of patients with AP (Skouras et al HPB 2014), we documented a negative lasting effect of SAP on overall survival. The present study will confirm or refute that finding and add detail to the new comorbidities and cause of death, analysed in the context of pre-existing health and details of the acute AP episode.

1617-0011 Dr Diane Lindsay

Genomic sequencing and epidemiology of Legionella pneumophila in Scotland

The increase in the use of industrial water systems such as water cooling towers, in addition to other sources such as commercial shower units, hot tubs and birthing pools has resulted in an increase in frequency of legionellosis infections over the last 40 years. However, our understanding of the biology of episodes of legionellosis and particularly Legionnaires disease (LD) outbreaks is very limited. A rapid response to LD outbreaks is critical to minimise further cases, requiring the identification of suspected water reservoirs, sampling, culturing and molecular diagnostic efforts to identify and control the source. The current project will lead to an enhanced understanding of the extent of genetic and phenotypic diversity within patient and environmental samples which will be of direct relevance to source attribution, clinical outcomes and the identification of lineages that are more frequently associated with human infections.

In addition, the adoption of a culture-free metagenomic analysis of suspected source material may lead to improved outbreak investigations which can attribute clinical isolates with an environmental source. This would greatly facilitate the control of outbreaks and inform future control measures. An understanding of the diversity of L. pneumophila populations within cooling towers will also inform future designs of more effective ways for managing legionella colonisation of high risk devices.

1617-0023 Dr Suart McIntyre

Evaluating the enhanced recovery pilot in Obstetrics, and the related analysis of Caesarean Section variation in Scotland

No lay summary

1617-0049 Dr Karen Semple

Using linked data to follow up longer term outcomes of POPPY trial participants

No lay summary

1617-0052 Dr Deborah Kinnear

Predictors of mental ill health in mothers caring for a son or daughter with intellectual disabilities

No lay summary

1617-0067 Professor Sharon Cameron

BRIDGE-IT

The ‘Bridge -it’ study is designed to tell us whether pharmacists should give a supply of the progestogen only pill (POP) along with emergency contraception (EC) to women as temporary contraception until they can get to a clinic. The POP is very safe with no serious risks. We have previously undertaken a smaller similar study that showed that women who got the POP were likely to use it and more likely to be using contraception 6 weeks later than those who just got EC.

‘Bridge-it’ will take place in several parts of the UK. Women 16 and over who attend a participating pharmacy for EC will be invited to participate. During the study, some pharmacies will give EC as usual, but others will also give POP with the offer of rapid access to the local sexual and reproductive health (SRH) service. Women in the study will be surveyed at 4 and 12 months about contraceptive use, and about any pregnancies they may have had. For women who got the POP we will ask if they used it and/ or attended the SRH. Since we want to know if the POP prevents unintended pregnancies, we will check how many women in the study had an induced abortion (termination of pregnancy) within one year. This involves checking existing NHS databases with women’s permission. We will also interview women, pharmacists and SRH staff about how providing the POP / rapid access might work in everyday practice.

1617-0147 Professor Helen Colhoun

Extending our understanding of the impact of diabetes in Scotland: A project to support continuing Scottish diabetes data linkage

Scotland is one of richest sources of research on the understanding of how diabetes affects health based on electronic health care record linkage. Over past 10 years the SDRN Epidemiology group has had permission to access and link the SCI-Diabetes dataset to other healthcare data sources, such as deaths, hospital admissions and cancer registrations, in order to conduct wide-ranging analyses across a number of domains with more than 30 papers published many of which have policy relevance (see SM06 for publications and section 3.1.08 below for further details). Here we wish to continue this work as detailed in the attached proposal (SM07) including for example projects aimed at informing our understanding of cardiovascular disease (CVD) risk, pharmacoepidemiology and drug safety, and recommending how frequently screening intervals for eye disease in people with diabetes should be done (see SM07 for full details).

1617-0150 Diane Havard

TARDIS trial MR 1259

No lay summary

1617-0162 Professor Michel Coleman

CONCORD -3 study, an international study on cancer survival

No lay summary

1617-0178 Francis Appiagyei

Anonymised GP practice patient data and secondary care data linkage in Scotland for the At-Risk Registers Integrated into primary care to Stop Asthma crises in the UK (ARRISA-UK) Study

No lay summary

1617-0179 Dr Caroline Jackson

Assessing the impact of major mental illness on the outcomes and complications of cardiovascular disease and diabetes: a national data linkage project

No lay summary

1617-0181 Dr Peter Murchie

NASCAR+: Exploring associations between geography, treatment, follow-up care and survival of cancer patients in Northeast Scotland

No lay summary

1617-0189 Dr Mairead Black

Offspring renal calculi following elective caesarean

No lay summary

1617-0197 Dr Tom Clemens

Environmental Determinants of Fertility Success

No lay summary

1617-0204 Kate Stewart

New statistical tools to model environmental influences on antibiotic resistance in people

No lay summary

1617-0206 Hugh Paterson

A comparison of the management of acute diverticulitis between Scotland and Switzerland

Acute colonic diverticulitis (AD) is a common reason for emergency hospital admission in Western countries and recent data suggest that the diagnosis is increasing. Although a small number of patients require immediate surgery for control of severe infection, many patients can be treated successfully with antibiotics. Most patients will have no further episodes, but a small number have repeated attacks (sometimes years later) and eventually require major surgery to remove the affected part of the colon. In Scottish NHS practice, surgeons usually try to avoid surgery unless there is no alternative (usually for specific complications of AD, e.g. peritonitis, bowel obstruction, fistula, severe/persistent pain) as the operation is major, carries the potential for life-threatening complications and may result in a permanent colostomy.

However, in Western Europe and the USA, the surgical attitude is more aggressive. Despite recent professional association guidance emphasising conservative management (e.g. American Society for Colorectal Surgery guidelines), elective surgery following emergency presentation with acute diverticulitis is approximately ten-fold more frequent than in Scotland, based on an unproven assumption that this will prevent future episodes or complications of diverticulitis. This difference is not explained by international differences in rates of emergency hospital admission, disease severity, comorbidity or lifestyle. It is possible that the difference in attitude reflects the fee-per-item organisation of health services in non-UK countries.

We wish to compare Scottish and Swiss national data to examine the differences in surgical management of AD in the two healthcare systems and the impact on outcomes such as mortality, major operations, total hospital admissions and stoma rates.

1617-0227 Dr Suneetha Ramani Moonesinghe
Perioperative Quality Improvement Programme (PQIP)

No lay summary

1617-0243 Dr Sarah Mitchell
The National Lifecurve Survey

No lay summary

1617-0244 Dr Lisa Iversen
The Royal College of General Practitioners' Oral Contraception Study

No lay summary

1617-0246 Lisa Clark
A Phase II Efficacy Study of Intracerebral CTX0E03 DP in Patients with Stable Paresis of the Arm Following an Ischaemic Stroke

No lay summary

1617-0247 Dr Joanne Given
Metformin for diabetes in pregnancy – an analysis of health outcomes in Scotland as part of a UK wide study

Gestational diabetes, diabetes which develops during pregnancy, and type 2 diabetes are increasingly common affecting up to 18% of pregnancies. This is important as diabetes during pregnancy increases the risk to both the mother and the baby.

Traditionally insulin has been considered the 'gold standard' for the treatment of diabetes in pregnancy. However, the 2015 National Institute of Health and Care Excellence Diabetes in Pregnancy Guideline recommends metformin, an oral blood glucose lowering drug, for those with gestational diabetes. In those with type 2 diabetes the guideline states that metformin may be used when the likely benefits outweigh the potential for harm.

The routine use of metformin in gestational diabetes is controversial. Metformin has been shown to cross the placenta and we do not know if it has long term effects on children who were exposed in the womb. With increasing numbers of women in the UK taking metformin during their pregnancy more research is needed to determine its potential harms or benefits.

1617-0255 Dr Peter Joshi

A study of the outlook for lifespan, health-span and population size in Scotland 2020-2035, based on observed disease and mortality trends 1990-2015.

No lay summary

1617-0257 Dr William Whiteley

Long term follow of Asymptomatic Carotid Surgery Trial (ACST-1)

People with narrowing of their carotid artery (a large blood vessel in the neck) are at a higher risk of ischaemic stroke in the long-term, and there is a suggestion that they are also at a higher risk of dementia. We know that an operation to remove narrowing of the carotid artery (‘carotid endarterectomy’) reduces the risk of stroke, but we do not know whether it reduces the risk of dementia. ACST-1 was a large, publicly-funded, international, randomised trial that randomly allocated participants with narrowing of the carotid artery to carotid endarterectomy or no endarterectomy. The trial showed endarterectomy reduced the risk of stroke at 5 and 10 years after the operation by a small amount.

Small reductions in the risk of stroke might lead to larger reductions in the risk of dementia in the long term. We plan to investigate this question by analysing long-term data of approximately 22 years duration from NHS and Swedish electronic records on the participants for dementia, stroke and death. If we showed that endarterectomy for carotid stenosis without symptoms reduced the risk of dementia, this would be influential, because this treatment is not widely used in the NHS as surgery reduces the risk of stroke by only a small amount. A reduction in the risk of dementia would alter the risks and benefits of surgery, and provide better information to patients and clinicians.

1617-0265 Robin Flaig

UK Biobank prospective cohort – longitudinal follow-up through linkage to health-related records in Scotland

No lay summary.

1617-0275 Linsey Galbraith

Estimating the Prevalence of Problem Drug Use (among individuals aged 15-64) in Scotland in 2015/16

This proposal will result in the production of estimates of the national and local prevalence of problem drug use for those aged 15 to 64 in Scotland between April 2015 and March 2016. Local prevalence estimates will be produced for local authorities in Scotland, ADPs (Alcohol and Drug Partnerships) and NHS Boards.

This is the third time that ISD have been commissioned by the Scottish Government to undertake a study of this nature, having conducted the previous two national drug prevalence studies in 2009/10 and 2012/13. Earlier studies dating back to 2000 were undertaken by Glasgow University.

The results from the 2012/13 study were published on the ISD website on 28th October 2014. http://www.isdscotland.org/Health-Topics/Drugs-and-Alcohol-Misuse/Publications/index.asp

For the 2015/16 study, the definition of problem drugs has been expanded to include additional drugs. Estimates will still be produced for the original Scottish definition of Problem Drug Use (PDU) to maintain the time trend. Data sources for the study will also be as used in previous studies.

As much of the problem drug using population is hidden, prevalence figures can only ever be estimates, combining data about the known population (for example, those in contact with treatment services) and an estimate of the unknown population.

For the 2015/16 study, we will also compare different statistical methods for estimating PDU prevalence.

1617-0289 Kathy McGregor
Linkage Unscheduled Care Datamart (UCD) to Prescribing Data contained in the Prescribing Information System (PIS)

As individuals in Scotland make contact with Unscheduled Care Services, data about who they are, where they have come from, what is wrong with them and what happens to them are collected, mainly to inform their care. This provides a good picture of the potential unscheduled care journeys that an individual may travel through. The aim of the project is to link Unscheduled Care Datamart (UCD) to prescribing data contained in the Prescribing Information System (PIS). Effective prescribing has the potential to have an impact on contact with unscheduled care services and patient care. The linkage will allow this to be quantified as well as exploring areas where effective prescribing can lead to a reduction in contacts with unscheduled care services.

1617-0295 Dr Andrew Wong
MR1 – Health and Development Study

The MRC National Survey of Health and Development (NSHD) is the oldest and longest running of the British birth cohort studies. From an initial maternity survey of 13,687 (82%) of all births recorded in England, Scotland and Wales during one week of March, 1946, a socially stratified sample of 5,362 singleton babies born to married parents was selected for follow-up. The NSHD study team is housed within the MRC Unit for Lifelong Health and Ageing (LHA) at University College London.

The LHA wishes to link NSHD study members to Hospital Activity Statistics (SMR01) data in order to improve the quality of information on hospital admissions and health outcomes for research purposes. (A parallel application for equivalent data in England and Wales (Hospital Episode Statistics) is in the approvals process.) Currently, the study obtains self-reported hospital admission data at each follow-up which are then confirmed through contact with each hospital.

The Unit has a 5 year MRC core funded programme of research based on the NSHD with the objective to investigate risk and protective factors from across the life course that influence the ageing process. This core funding has been in place since 1962 and is renewed every five years after scientific review. Together with equivalent data from England and Wales, the data from SMR01 will be used to improve the identification of acute events such as those caused by cardiovascular disease (CVD). For example, the Unit will assess how life course risk factor trajectories of body size, resting heart rate, blood pressure, socio-economic position and health related behaviours, accumulate and interact to influence incidence of CVD, thus potentially identifying possibilities for earlier prevention. As the cohort is entering older age, hospital care becomes increasingly frequent and study members are thus less likely to report hospital admissions over a number of years accurately. It is therefore important to capture this information in other ways. New research within LHA on health service use is being developed which will utilise these data and investigate life course predictors of health care utilisation.

The NSHD has informed UK health care, education and social policy for 70 years and is the oldest and longest running of the British birth cohort studies. Today, with study members in their early seventies, the NSHD offers a unique opportunity to explore the long-term biological and social processes of ageing and how ageing is affected by factors acting across the whole of life.

1617-0296 Dr Mirijam Allik
The health of Looked After Children in Scotland

No lay summary.

1617-0304 David Henderson
Using linked data to understand the relationships between Multimorbidity and the use of Health and Social Care

No lay summary

1617-0307 Professor Bruce Guthrie
Unscheduled care use in NHS Scotland

Unscheduled care use is when people access emergency or urgent care, which includes calling an ambulance, contacting NHS24 or the GP out-of-hours service, attending A&E or being admitted to hospital as an emergency. Unscheduled care use of all kinds is steadily increasing, with many services under considerable pressure as a result. Understanding trends in and patterns of unscheduled care use is therefore of great importance to health policymakers, clinicians, managers and patients. Pressures on unscheduled care use at least partly reflect that the Scottish population is aging and partly that access to routine daytime general practice has worsened because of difficulties recruiting and retaining staff. As a result, NHS Scotland is carrying out pilot projects of new models of care (‘primary care transformation’) with the intention of improving quality of care including patient satisfaction and unscheduled care use. There are two elements to the proposed work.

In the first, we will examine patterns of use of unscheduled care including how this varies between different groups of patients, and how it varies between general practices. For variation between patients using unscheduled care we are interested in patterns of use. Two examples of what we mean by patterns are: whether some patients preferentially use GP out of hours or A&E or the ambulance service as their first point of contact; whether there are common patterns of linked episodes in a 24 hour period such as NHS24 -> Scottish Ambulance Service -> A&E -> emergency hospital admission. For variation between practices, we will measure rates of use of unscheduled care in every practice and examine whether there are characteristics of practices (eg how big they are, whether they are urban or rural) which are associated with higher or lower rates. Scotland is unique in the UK in having data for all unscheduled care, which creates opportunities to better understand unscheduled care use and how it is changing. This is important because it is a very pressured part of the NHS, but some of the increasing pressure on unscheduled care reflects pressure on daytime general practice which is reflected in falling patient satisfaction with being able to book appointments for example. Better understanding how the whole system works is therefore very important.

In the second element, we will compare groups of practices implementing particular new models of care to groups of matched similar practices working as normal. The matching will make sure that the two groups are similar before the new model of care starts. We will then examine whether the new model of care has any impact on unscheduled care use, satisfaction with daytime general practice, and quality of long term condition care (eg measures of blood pressure control, rates of flu immunisation). This is important because new models of daytime general practice are urgently needed in the face of steadily rising workload and increasing difficulty in recruitment and retention. Evaluating which of these new models leads to better outcomes is therefore very important.

1617-0309 Richard Hunter
AHP Operational Measures Data – Phase 2

No lay summary

1617-0311 Dr Lynne Forrest
Migration to Scottish New Towns and the impact on premature mortality in Glasgow: analysis of 1947 Scottish Mental Survey data

No lay summary

1617-0312 Dr Simon Crawley
Evaluation of Anaesthetic Facemasks to Inform the Clinical Advisory Panel for National Procurement Exercise NP178 (2016)

No lay summary.

1617-0318 Nicola McGuire
Investigating the relationships between environmental factors and participation on outcomes for individuals with complex mental health needs.

No lay summary.

1617-0321 Emma Milburn
Scottish Health and Care Experience Survey

No lay summary.

1617-0327 Professor Harry Campbell

RESCEU data linkage

Human respiratory syncytial virus (RSV) causes severe disease in the very young, elderly and in high risk groups. Previous studies have estimated that worldwide, RSV was associated with 34 million cases of acute lower respiratory tract infection (ALRI), 3.4 million ALRI hospitalisations and 55,000 to 199,000 deaths in children <5 years in 2005. Most published data on RSV disease burden in the elderly (aged >65 years) are from the United States and from hospital settings. The knowledge gaps have an impact on Europe’s ability to make evidence-based decisions nationally regarding new vaccines. Several candidate RSV vaccines are in advanced stages of clinical development by pharma companies who are partners in RESCEU.

This study within the larger RESCEU project, focuses on assessing the healthcare burden of RSV in at least six EU countries (Denmark, Netherlands, Finland, UK / Scotland, Italy, France and Norway. It will also estimate the association between RSV and subsequent childhood illnesses such as wheeze, asthma, pneumonia and whooping cough and the resulting economic costs.

Population

The study population will include individuals with a hospital admission for a range of respiratory diseases (including cardio-respiratory disease in adults), or being prescribed specified antibiotics for bronchiolitis/ALRI, or deaths due to bronchiolitis. Data will be collected for a period of at least 15 years from 2001 – 2016, or the latest date with complete data.

Comparator/Control

For comparison, a control cohort will be identified of children hospitalised for accidents or urinary tract infections, which are non-seasonal events. The association with subsequent episodes of asthma/wheeze or pneumococcal disease will be assessed as a comparison to the cohort of children who had bronchiolitis.

Outcome

The study will provide the first estimates of RSV disease burden in Scotland (and the partner EU countries). Estimates will be calculated in:

- all age groups
- young children
- adults with chronic medical conditions (such as COPD, heart failure, Asthma, Diabetes, immunosuppression)
- older adults (>65 years)
- selected other high risk groups of children (such as premature babies, Downs, congenital heart disease, cystic fibrosis, broncho-pulmonary dysplasia)

In young children, we will measure the association between RSV infection and subsequent episodes of asthma/wheeze/lower respiratory tract infections or pneumococcal disease during childhood. We will also provide data (anonymous summary data) to assess the economic costs of RSV illnesses to health services, systems and patients.

The study results will provide the knowledge base to allow evidence-based decision-making on the future use of the new vaccines currently in development. The research output will be of practical benefit at the national level, and will make a substantial contribution to international research.

1617-0328 Shengyuan Zhao

Epidemiology of Carbapenamase producing organisms (CPOs) in Scotland

As β-lactam antibiotics, carbapenems provide enhanced Gram-negative coverage as compared with other β-lactams and stability against extended-spectrum β-lactamases (ESBLs). Accordingly, carbapenems are often used as last resort antibiotics for treatment of multi-drug resistant (MDR) infections caused by Gram-negative bacilli (GNB). Carbapenemase producing is the main mechanism of carbapenem resistance. The rates of carbapenemase producing organisms (CPOs) have been gradually increasing worldwide over the last 10 years, leaving few effective therapeutic options available to MDR infections. In 2017, The World Health Organization developed a global priority pathogens list (global PPL) of antibiotic-resistant bacteria and carbapenem-resistant Acinetobacter baumannii/Pseudomonas aeruginosa/Enterobacteriaceae were listed as the top three pathogens of critical priority. Increases in carbapenemase producers among GNB can be attributed to multiple potential risk factors. Notably, antibiotic exposure has been reported as a factor independently associated with CPOs acquisition in healthcare facilities worldwide. Nevertheless, risk factors for CROs acquisition have not been completely characterized and conflict results are reported in various studies owing to the great heterogeneity between these studies conducting in different countries.

In Scotland, the first carbapenemase was identified in an Enterobacter cloacae complex blood culture isolate in 2003, carrying KPC-4. Afterwards, more and more CPOs were reported from nearly all parts of Scotland, showing a worrying upward trend. Additionally, there has been a 9.3% increase in carbapenem usage in Scottish acute hospitals since 2012. The epidemiology of Scottish CPO isolates, however, remains unclear. To date, no relevant data is available to the public in terms of morbidity and mortality rates, prescribing rates of clinically routine used antibiotics and risk factors for acquisition of CPOs in Scotland.

This study aims to provide an indepth epidemiological analysis of CPOs in Scotland hence to provide a comprehensive understanding of characteristics underlying factors and related morbidity and mortality associated with CPOs. Insights based on these findings will further the development of effective and appropriate prevention and infection control strategies, thus curbing future emergence and spread of carbapenem resistance in Scotland. We intend to conduct a retrospective study of epidemiology of CPOs (as listed in Appendix II) among inpatients in Scotland between 2003 and 2016. This study will involve descriptive analysis of the temporal and spatial patterns of all CPOs cases in terms of morbidity and mortality and association between antibiotic prescription and morbidity from 2003 to 2016 as well as a matched case-control study to identify risk factors associated with CPOs acquisition among inpatients between 2010 and 2016.

1617-0329 Sally Stewart

Evaluation of Cost of Nosocomial Infection (ECONI) Phase 2 and 3

No lay summary.

1617-0330 Dr Stamatina Iliodromiti

Association of birthweight and perinatal indicators with perinatal, childhood and maternal outcomes: a population based linkage study

Babies that are too small or too large near their due date have a greater risk of stillbirth, dying within the first year of life and hospital admission as they grow older compared with average weight babies. Their mothers are also at increased risk of metabolic and cardiovascular disease, with pregnancy outcomes now recognised as an early hallmark of individuals at risk. However, there is no agreement on how we define what a small or large baby is or whether current definitions can accurately predict a baby's risk of death or disease or abnormal development.

Currently, babies whose birthweight is in the lowest 10% and highest 10% of a reference chart of birthweights are defined as being too small and too large, respectively. Current antenatal care tries to identify these babies and intervene by inducing labour to prevent death or other risks. But it is not clear that these levels of 10% are the best for identifying which babies are at risk of dying. Indeed, we have shown in a study of nearly 1 million pregnancies that the risk of death and poor health at birth is best identified by defining small as the lowest 25% and large as the highest 15% of birthweights at each gestational age. However, it is important to validate our findings in a separate contemporary cohort before we suggest changing antenatal care. Furthermore it is critically important to define whether these new thresholds are associated with long-term outcomes including cause specific morbidity, impaired childhood development, special educational needs and educational attainment.

The charts that are used as references for deciding if a baby's weight is in the lowest or highest percent have always taken account of how long their mother has been pregnant (gestational age) and whether the baby is a girl or boy. Some charts (customised charts) also take account of mother's weight and height, her ethnicity and how many previous children she has had. By linking and accessing updated and novel multiple population datasets, as we propose here, we will be able to properly compare full customised charts (taking account of mother's ethnicity and weight along with other characteristics) with non-customised charts to be able to decide which are the maternal characteristics that should be taken into account to best predict infant and childhood outcomes.

We have previously shown that mothers of small babies have a greater risk of heart attacks and stroke later in life, with mothers of large babies at increased risk of diabetes. We are now interested in answering the question whether by using the updated birthweight thresholds we can identify mothers at future risk of disease better and whether customisation makes the associations stronger or weaker. Lastly there is now conflicting evidence on the contribution of anaesthesia during pregnancy on long-term childhood outcomes, and we wish to examine the contribution of anaesthesia during pregnancy on maternal and offspring outcomes.

1617-0332 Dr Callum Kaye

Outcomes of patients admitted with Haematological Malignancies in Scottish ICUs

No lay summary

1617-0338 Professor Colin Palmer

SHARE- Central data transfer to SHARE in Health Informatics Centre(HIC) within FARR Dundee. (FD)

No lay summary.

1617-0347 Alessia Morris
Persons at Risk Database (PARD)

PARD is a Scottish Government and NSS led project to enable Local Authorities (LA) to rapidly identify locations where people are at risk during an emergency. This will allow LA's to prioritise interventions to save life and minimise harm to the most vulnerable members of society.

Current systems for doing this take many days and are frequently ineffective. There is a legal duty placed on the LA to have an effective system to do this by the Civil Contingencies Act 2004. The Act also places the respons0ibility to share information and cooperate in an emergency on both the LA and the NSS.

PARD can only be used in emergencies which are also strictly defined within the Act. PARD provides considerable public benefit in using existing health and social care datasets to rapidly identify the vulnerable affected by the 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.

Permission is sought in principle from the Public Benefit and Privacy Panel for PARD with further relevant supporting documents provided by individual LAs as they satisfy and comply with the terms of the template ISA (10617-0347-PARD-4) before participating in it. Each participating LA is required to cleanse their dataset to enable them, in an emergency as defined by the Civil Contingencies Act, to interrogate social work datasets and specific information provided by NSS to assist in identifying vulnerable persons.

PARD uses 3 indicators of vulnerability from NSS datasets and currently 7, although this can be expanded, from the Local Authority datasets. Only the minimal personal data of name, DoB, address, CHI, and "yes" or "no" to the vulnerability criteria is displayed by the system.

This application covers the access to the NHS NSS dataset and is being made collectively on behalf of all LAs with the LA completing and complying with the ISP to access NHS Scotland originated data. Each LA will have to satisfy the requirements of the ISA and also provide details of their data managers and IG trai0ning.

In précis, a participating LA cleanses their social work datasets and these are geo tagged with a UPRN (Unique Property Reference Number). Social Work Department client data remains within the LAs own servers.

NHS NSS Health Data is geo tagged by algorithm with a UPRN. Data with positive return on any of the 3 indicators of vulnerability is stored in separate LA folders within NSS for access by authorised members of staff from that LA in an emergency or for system testing. LAs can only access data for their geographical area.

The SPARRA dataset used includes markers where patients have specifically asked that their data is not used. Those pat0ients wishes will be respected and their data will not be used in PARD.

A campaign to raise public awareness of the system as recommended by the Office of the Information Commissioner will be undertaken and coordinated on a national basis.

1617-0348 Professor Zosia Miedzybrodzka
Evaluating a new protocol for primary-care initiated identification and management of patients with familial hypercholesterolemia: observational study and cost-effectiveness analysis.

Familial Hypercholesterolemia (FH) is the commonest autosomal dominant disorder with at least 1 in 500 individuals (0.2%) affected. Left untreated, individuals with FH have a higher risk of coronary heart disease (CHD) and 100-fold increased mortality. CHD in people with FH can be very effectively prevented by high intensity lipid lowering treatment, which results in a 48% reduction in CHD mortality. Moreover, 50% of their first degree relatives will have the condition and thus will also benefit from intervention.

The Scottish audit of familial hypercholesterolemia was established by Prof Miedzybrodzka and her team. It links the data from Scottish national service for FH genetic testing with local and national routine data to evaluate the performance of the Scottish FH service. Here we seek to extend this study in three ways:

1. To use the existing cohort and data for research into FH Screening and clinical care.
2. To update the existing dataset and their matched controls (including addition of new cases and their matched controls accrued from last data linkage) by performing a new linkage of the same data fields.
3. To use Scottish data as part of a UK based HTA funding to identify the most cost-effective and acceptable protocol for FH cascade testing based on best current evidence.

Although guidelines recommend a nationwide, family-based follow-up system for identifying individuals affected by FH, currently this is very limited. Further, in practice, very rarely do specialist clinics contact relatives of the affected index case out-of-area. Regional variations also exist, for instance, the Welsh cascade testing service uses a combination of direct and indirect contact tracing, whilst contact is only offered indirectly through affected index case. As aspects 1 & 2 comprise a minor amendment to the existing permissions, we will focus on aspect 3 in the following documentation.

1617-0360 Stephen Knight
Consent process for patients across Scotland

The 2015 Supreme Court ruling in the case of Montgomery v Lanarkshire Health Board1 signified a change in the law on informed consent. There was previous reliance in Scotland on the Hunter and Hanley case from 1955 (The “Bolam Test of 1957 being similarly applicable in England and Wales) which judged a doctor’s actions to be reasonable if they could be supported by a reasonable body of medical opinion.

Montgomery moved away from this approach and emphasised the need for doctors to ensure that a patient of sound mind was aware of the risks inherent in treatment and of reasonable alternatives. There was a clear move away from a paternalistic approach with a fresh emphasis on collaborative decision-making and the concept of patient autonomy.

The Royal College of Surgeons of England (RCSEng) have highlighted that Hospitals and medical staff will leave themselves vulnerable to criticism and possible litigation if they fail to ensure that their approach to the consent process is in line with the principles highlighted in the Montgomery ruling. Furthermore NHS boards need to consider the resources, especially time, given to the consent process.

To our knowledge there is yet to be a published study looking at the current standard of consent for surgical procedures at either a local, regional or national level following the Montgomery ruling in 2015. Furthermore, quantitative data regarding clinician's knowledge and impact on practice of the ruling is currently lacking.

1617-0362 Peter Croan
VS Warehouse

This is NOT a research study. It is a development of (and improvement to) routine clinical service, which already takes place within NHSS.

Currently, all four NHS genetics laboratories that make up the Scottish Genetics Consortium (SGC - Grampian, Tayside, Lothian, GG&C) carry out next-generation sequencing (NGS) on affected/at-risk patients with either inherited or somatic disease with genetic involvement. The data analysis for NGS is a considerable challenge for two reasons: firstly, the amount of data that is generated by NGS is vast and therefore creates an analysis bottle-neck which is highly labour-intensive in the absence of a specialist software solution; and secondly, the clinical utility of the generated data can only be maximised where all related information is shared amongst the laboratories to aid interpretation. It is an acknowledged fact throughout the genetics, molecular pathology and haemato-oncology disciplines that NGS offers unrivalled benefits to patient management/treatment and indeed has become a routine test for many clinical contexts. However, NGS requires both specialist software for the subsequent data analysis to be fea0sible within the NHS and also the data must be shared to maximise the interpretation power within it. A further driver for this particular project is that genetics services in Scotland are commissioned as a national service and therefore the four SGC laboratories that deliver this service are funded by the National Services Division (NSD) where one of the core aims to offer an equitable service across the whole of Scotland.

NGS technology has enabled laboratories to carry out much wider genetic analysis of affected/at-risk patients than was previously possible, allowing the identification of variants that significantly improve the management/treatment of affected patients. However, NGS technology challenges the current NHS infrastructure in a number of ways. The hugely increased data generated by NGS means that there is now a huge analysis burden on laboratories, where this time-consuming analysis is often carried out in parallel where disease remits are shared or overlap. It can take laboratory scientists several hours to investigate0 and interpret a single 'novel' variant. Without sensible co-ordination and collaboration, the same analysis could take place in more than one laboratory, thus duplicating the already onerous analysis.

1617-0369 Dr Stephen Pavis
Preparing NSS data for efficient research dataset creation: a pilot project

No lay summary

1617-0374 Dr Úna McMenamin Medications with hormonal effects and outcomes in patients with breast and prostate cancer: A Scottish cohort study

Due to enhanced detection methods, the number of breast and prostate cancer survivors has dramatically increased in the past few decades. Hormone therapies (including tamoxifen or aromatase inhibitors in breast cancer and androgen deprivation therapy in prostate cancer) are commonly used in the treatment of these cancers to reduce the risk of cancer recurrence, however, their influence on risk of second cancers and other adverse events is relatively unknown. This study will investigate the effect of hormone therapies used in the treatment of breast and prostate cancer patients on the development of second cancers, for example; contralateral breast cancer (i.e. cancer in the other breast), colorectal cancer, oesophageal cancer, stomach cancer, lung cancer and bladder cancer. Separate aims of this study will investigate the influence of hormone therapy medications on risk of other adverse events such as heart disease, stroke, diabetes, bone fractures, lung disease, depression etc. Other commonly used medications which influence sex hormone levels (for example digoxin, 5-alpha-reductase inhibitors, spironolactone, levothyroxine, phosphodiesterase type 5 inhibitors) will also be investigated with respect to these outcomes.

The Scottish Cancer Registry will provide robust information on primary cancer diagnoses (as well as second cancers), cancer prognostic and treatment data. The substantial follow-up time within the Cancer Registry will enable investigation into the longer-term impact of hormone medication use on clinical outcomes in breast and prostate cancer patients. The detailed drug prescription data from the Prescribing Information System will provide important information relating to the type, dose and duration of drug use. Information on adverse events will be retrieved from linkage to both Outpatient and Inpatient hospital records. Moreover, linkage to the Scottish Renal Registry will provide important supplementary clinical information for certain outcomes (e.g. renal replacement therapy in analysis of acute kidney injury). Further linkage to Accident & Emergency dataset and the Mental Health Inpatient and Day Case dataset will ensure complete capture of other adverse event outcomes e.g. bone fractures and depression, respectively.

This study will provide a unique opportunity to assess the harms and benefits associated with hormone modulating medications in a ‘real world’ clinical setting. Specifically, this investigation will help determine if hormone modulating medications are implicated in the development of other cancers and will shed light on potential (non-cancer) adverse events that may be associated with the use of these medications. The increased duration of exposure to hormone therapies in breast and prostate cancer populations due to increased survival warrants further investigation into the longer-term clinical impact of these medications.

1718-0002 Dr Alistair Ewen

A retrospective review of short term outcomes of the Triathlon total knee system

Joint replacements have become a common and successful procedure performed to relieve pain and enhance mobility in patients with advanced osteoarthritis. Around 8,000 primary knee replacements take place in Scotland annually, with nearly 2,000 of these performed at our institution. Our Orthopaedic department has been using the Stryker Triathlon knee replacement implants since late 2010 and has carried out over 1000 cases using these implants alone. The focus on outcomes of total knee replacements has moved from only survival to patient reported outcome measures (PROMs). It is therefore important to know how implants are performing not only in terms of clinical outcomes but also PROMs. There is also an increasing recognition of the importance of the level of function gained by patients and functional outcome is now considered to be a crucial component for measuring the success of a knee replacement. It is widely accepted that at around one year post-operation, patients will have regained most of their function and that good function at this point is indicative of good longer term outcomes. Hence it is important that functional outcomes at one year are assessed, but also whether any post-operative complications have arisen during the first year.

1718-0004 Hazel Dodds

Development of (electronic data collection system for the Scottish Trauma Audit Group (eSTAG))

Major trauma describes serious and often multiple injuries where there is a strong possibility of death or disability and is the most common cause of death in young people in the UK. The Scottish Trauma Audit Group (STAG), Public Health Intelligence (PHI), NHS National Services Scotland (NHS NSS) initially audited the management of seriously injured patients in Scotland from 1992 - 2002 and recommenced this audit in 2011. The STAG now includes patients aged over 13 years, in 18 hospitals with an Emergency Department (ED) in Scotland. The aim of the audit is to improve the care and outcomes of patients with serious injuries through measuring compliance against standards of care to support local quality improvement. Monthly reports are provided to participating hospitals and an annual national report is also published on the STAG website www.stag.scot.nhs.uk.

In 2013 a Quality Framework for Major Trauma Services provided a report to the National Planning Forum (NPF) Major Trauma Sub Group outlining possible ways to enhance existing major trauma services (for all ages) in Scotland. They recommended the introduction of a Major Trauma Network in Scotland. Work to achieve this objective is well under way with a Scottish Trauma Network (STN) expected to be established from 2017. The NPF have also made a series of recommendations for future trauma data collection provided by the STAG.

The existing Scottish Trauma Audit is a paper based system that was developed in 1992. It is a time consuming and labour intensive system that must be rationalised to seek maximum efficiencies. The audit currently collects data from 18 hospitals (around 3000 cases per year) increasing to 30 hospitals with the launch of the STN. The existing system is populated by Local Audit Coordinators (LACs) based in NHS Boards and managed centrally via the Scottish Healthcare Audits (SHA) of PHI at NHS NSS.

This proposal is to develop an electronic data collection system (eSTAG) to facilitate collection of data from the 30 hospitals in Scotland dealing with patients who have suffered serious injury as detailed below. This will increase the efficiency and data quality of the trauma audit data collection, and allow for national reporting of specified Key Performance Indicators (KPIs) for the Scottish Trauma Network, as recommended by the NPF sub-group, the Major Trauma Oversight Group (MTOG).

Potential impacts of not undertaking development include:

- Reduced capacity for local/ national reporting against agreed national KPIs for the STN;
- Inability to respond efficiently and timeously to future information needs of the Scottish Government and NHS Boards across Scotland. In particular the requirement from the Scottish Government to measure the effectiveness of the newly established STN to be implemented from 2017;
- Continued data quality and validation issues; and
- Continued antiquated time consuming data collection practices.

1718-0010 Dr Matthew Henry Iveson

Childhood cognitive function and later-life recovery: Linking the Scottish Mental Survey 1947 to healthcare and administrative data.

No lay summary.

1718-0012 Dr Peter Murchie

Understanding the interplay of geography and demographic characteristics in the diagnosis of eight common cancers: The NASCAR-CENSUS project

No lay summary.

1718-0017 Dr Matthew Henry Iveso0n

Childhood cognitive function and use of long-term care across the life course: Linking the Scottish Mental Survey 1947 to healthcare and administrative data.

No lay summary.

1718-0020 Dr Martin McCoy

Distress Brief Interventions (DBI) Programme Data Collection

Distress Brief Interventions (DBIs) are an innovative way of supporting people in distress. The DBI approach emerged from the Scottish Government's work on the Suicide Prevention and Mental Health strategies. The DBI approach is initially being piloted over 53-months (November 2016 to March 2021) in four sites across Scotland: 1. Penumbr0a in Aberdeen, 2. Support in Mind in Inverness, 3. Scottish Borders Joint Mental Health Service 4. North & South Lanarkshire.

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

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

1718-0022 Dr William Atkinson
SR8 - Mortality Study of Employees at UKAEA Dounreay

No lay summary.

1718-0027 Dr Rohit Sinha
Predictors of survival in patients with TIPSS for refractory ascites

Patients with liver cirrhosis, as a consequence of their disease progression may develop ascites (fluid in the abdomen) which may require regular drainage. TIPSS (transjugular transhepatic porto-sytemic shunt) can be performed as a day case procedure to alleviate the problem of fluid accumulation in the abdomen. As per current standard of practise, such patients are selected based on scoring system known as MELD (model of end-stage liver disease) which acts as a prognostic marker and appropriateness for TIPS. This model was designed almost 2 decades ago. There is an unmet need to refine the scoring system based on additional and newly identified predictors of improved survival. This will not only to complement but better the existing model allowing better selection of patients with improved odds for the procedure.

Study Design: Retrospective review of TIPSS database (maintained by the Hepatology nurse for clinical care) at RIE, NHS Lothian. Suitable patients will be identified and medical records will be reviewed to populate desired parameters (clinical and investigative information performed as a part of their routine clinical care). Subsequent analysis of collected parameters (blood tests) will be performed to identify any predictors or improved survival. A mathematical algorithm will then be constructed based on the newly identified parameters to predict improved survival in this group of patients.

This algorithm's power to predict survival will be tested against similar patient group created from other centres (2 centres in Scotland and one centre in England).

Funds from endowment will used for professional statistician in assistance for writing a predictive mathematical algorithm.

1718-0030 Dr Christine Campbell
Second primary cancers: a case note review and interview study to understand pathways to diagnosis and patient and provider experiences

No lay summary.

1718-0040 Dr Cheryl Gibbons

Point Prevalence Survey of Healthcare-Associated Infections and Antimicrobial Use in Scottish Long-Term Care Facilities (HALT)

Long-term care facilities (LTCFs) are an important source of healthcare-associated infections (HCAI). HCAI contribute to the morbidity and mortality of this ageing and at-risk population. Knowing the overall burden of disease, as well as understanding more about who gets infected, when and why, can contribute to a reduction in the spread of infections and result in improved resident safety in care home settings. Additionally, antimicrobial resistance (AMR) is an issue of growing concern nationally and internationally and an important step to address this is to gather data on antimicrobial usage. It is therefore important to have a clear picture of whom and for what diagnoses residents are receiving antimicrobial treatment and prophylaxis to ensure that prescribing in Scottish care facilities is appropriate.

Point prevalence surveys (PPS) are useful for gathering this type of information. In 2010, Scotland participated in the first PPS of European LTCFs (HALT project, 2010) which collated data from 722 LTCFs across 25 European countries. Scotland surveyed a total of 4870 residents from 83 Scottish care homes.

Coordinated by Health Protection Scotland (HPS), Scotland proposes to conduct a further PPS of LTCFs in 2017, from which, the current prevalences and epidemiology of HCAI and antimicrobial use in the Scottish setting will be estimated and described. This will provide up-to-date intelligence for evidence-based policy making. This is part of the European Centre for Disease Prevention and Control’s (ECDC) third European-wide ‘Healthcare-associated infections and antimicrobial use in Scottish long-term care facilities’ project (known as the HALT-3 project).

LTCFs have been sent an introductory letter from the HALT team at HPS via the Care Inspectorate informing them of the survey and inviting them to participate. Participation is voluntary. The HALT team at HPS will provide training for LTCF staff to enable them to collect information using survey questionnaires and following standard definitions. There are three questionnaires for recording information on infection prevention and control (IPC) structure and processes, staff and training, and resident information including details of HCAI and antimicrobials received. Data collection will be carried out in October 2017 by trained LTCF staff. Completed survey questionnaires will be returned to HPS for data entry, verification and analysis. Local (for each participating LTCF) summary reports and a national report will be written to describe the results.

In addition, a single “gold standard” team from HPS will carry out a gold standard validation (GSV) study in a small number of LTCFs (2-3 facilities). This will involve the GSV team carrying out data collection in a LTCF in parallel on the same day as the local, in-house data collection team. This is to identify which data items were accurately recorded by the local data collectors when compared to the GSV. These results will be combined with similar data from other European data by ECDC to give a European estimate of sensitivity and specificity. Furthermore, an international visit by the ECDC accredited validation team will also take place to assess the knowledge and understanding of the GSV team.

1718-0044 Professor Nick Bailey

Wider impact of benefit sanctions on health

No lay summary

1718-0048 Professor Wendy Atkin

Frequency of follow-up for patients with low-, intermediate- and high-risk colorectal adenomas.

We are proposing to extend the remit of the original study which evaluated the ‘frequency of follow-up for patients with intermediate-risk adenomas’. Using the same retrospective cohort database, we now propose to review the frequency of follow-up for the low- and high-risk adenoma groups in addition to the intermediate-risk group.

Findings from our Intermediate Adenoma study to investigate colorectal cancer (CRC) incidence during six years of follow-up among individuals classed as having intermediate-risk adenomas have shown that adequate CRC protection can be achieved with less than the currently recommended surveillance[1, 2]. We identified a subgroup (up to 50% of intermediate-risk patients) in which CRC risk is so low that further surveillance after the first follow-up is not warranted. The study also justified using CRC risk as a more valid measure than advanced adenomas of the need for regular colonoscopy surveillance.

We now propose to use the cleaned and coded retrospective cohort database of 253,798 patients, which includes 30,259 individuals with colorectal adenomas, to examine CRC incidence in those individuals classed as having low-risk or high-risk adenomas as well as update the analyses previously performed on the intermediate-risk group. We will review the implications of these findings to the current (2002) United Kingdom adenoma surveillance guidelines[3], with colleagues at the University of Oxford conducting a health economics analysis using CRC staging data to estimate the cost implications of these alternative surveillance strategies.

1. Atkin WS, Wooldrage K, Brenner A, Martin J, Shah U, Perera S, Lucas F, Brown JP, Kralj-Hans I, Greliak P, Pack K, Wood J, Thomson A, Veitch A, Duffy SW, Cross AJ. Adenoma surveillance and colorectal cancer incidence: a retrospective, multicentre, cohort study. Lancet Oncol 2017. Published Online April 27, 2017 http://dx.doi.org/10.1016/ S1470-2045(17)30187-0
2. Atkin WS, Brenner A, Martin J, Wooldrage K, Shah U, Lucas F, et al. The clinical effectiveness of different surveillance strategies to prevent colorectal cancer in people with intermediate-grade colorectal adenomas: a retrospective cohort analysis, and psychological and economic evaluations. Health Technology Assessment, 2017 volume 21, number 25.
3. Atkin WS, Saunders BP. Surveillance guidelines after removal of colorectal adenomatous polyps. Gut. 2002;51:V6-V9.

1718-0050 Greig Stanners

Linking Flexible Sigmoidoscopy Study data with Faecal Immunochemical Test study data, and Scottish Bowel Screening Programme data.

No lay summary.

1718-0053 Lesley Watson

Cancer Survival Analysis

This proposal is seeking approval to enable each of the three Scottish Cancer Regional Networks to provide QPI data (i.e. cancer audit data), on behalf of their Boards (See note 1) to the Information

Services Division (ISD) of NHS Scotland for the purposes of enabling ISD to carry out national survival analysis using QPI data.

ISD already carry out survival analysis on behalf of all NHS Scotland boards, to fulfil the mandated requirement (in line with CEL 06 (2012)) to publish survival analysis alongside cancer Quality Performance Indicator (QPI) data. ISD currently make use of 'Cancer Registration' data for the purposes of survival analysis. The long time intention has been to replace Cancer Registration data with QPI data once the QPI data was sufficiently mature (collection of QPI data only began in February 2012). The Regional Cancer Networks now have access to five years worth of QPI data for some tumour groups and there is an appetite to make use of this rich, now mature data source to provide more clinically focussed Survival Analysis (for example looking at outcomes for different treatment modalities and surgical approach). Utilising QPI data will enable ISD to (e.g.) assess within the Survival Analysis, the impact of cancer QPIs on patient outcome, identify variance between regions and explore the reasons for variance with clinicians/NHS Boards in much more detail.

The QPI data to be provided to ISD will be patient identifiable as ISD will require to link this data with GRO and SMR01 data to enable the Survival Analysis to be carried out. The resultant Survival Analysis reports are published and are non-patient identifiable. (An example of a current Bladder report can be found under 'Survival' here: http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Bladder/).

QPI data is recorded for all patients with cancer in Scotland (bar Lothian) within the eCASE database, in a standardised and structured way. QPI data in Lothian Health Board is held within their TRAK system/ database, in a standardised and structured way.

Note 1: The Scottish Cancer Regional Networks are responsible for overseeing data governance, analysis and reporting of cancer Quality Performance Indicators (QPI) on behalf the Health Boards within their region. The QPI data is stored in eCASE for all Boards in Scotland (bar Lothian).
WoSCAN Health Boards: GG&C, FV, A&A, Lanarkshire
SCAN Health Boards: Lothian, D&G, Fife, Borders
NOSCAN Health Boards: Grampian, Highland, Tayside, Shetland, Western Isles, Orkney, Shetland

1718-0056 Dr Unoma Okudo
Transfer for Treatment Direction/ Transfers Out of Prison in 2016

This project sets out to investigate transfers of inmates from prisons in Scotland to hospitals on account of poor mental health. Prisoners are transferred to hospital for ongoing provision of care and treatment when the prison environment is deemed inappropriate to carry this out. There are provisions under the Mental Health Care and Treatment Scotland 2003 Act for these transferred to be carried out. The project will provide information on how this legislation is used regionally and nationally, to highlight any issues with the way the law is implemented in order to inform policy makers and service providers of any improvements that require to be made. The project will also specifically focus on the issue of transfer times from prison. It is hoped that any problems identified in this area would lead to systemic changes that would ensure the prompt transfer of prisoners in need of urgent care within hospital environments. It is often reported that the availability of beds in hospital is an issue that leads to significant delays in transfer. However, there is currently no evidence to support these reports. This project seeks to investigate this matter.

The project was commenced in January 2017 whilst I had a post as a Speciality Registrar working at the Mental Welfare Commission. Its design is most in keeping with a service evaluation project and all information on patients/prisoner will be fully anonymised. The Mental Welfare Commission regularly produce monitoring reports that look at different provisions under the Mental Health Act and how they are being implemented across Scotland. This will be similar, except that I will be looking at a further aim, as detailed below.

From the Mental Welfare Commission, I have been able to access all the transfers out of prison in 2016. I have also been able to get the characteristics of most of the prisoners including age, gender, index offence. I have information on the prisons they were transferred from and hospitals they were transferred too. The information that I now require is that of times of referral for transfer out of prison and when the prisoners were eventually transferred out to hospitals. This information will be recorded in Vision (and Docman) and will allow me to get data on delays in transfer out of prison.

1718-0057 Dr Jonine Figueroa
Temporal trends of molecular portraits of breast cancer in Scotland

Breast cancer is a heterogeneous disease comprised of multiple different subtypes defined by their molecular genetic or expression profiles, which differ in their aetiology, incidence, treatment and mortality. Oestrogen receptor (ER) represents an important target for responsiveness to anti-oestrogen therapy and aetiologic differences by risk factors (e.g. age, screen detection and deprivation index, SIMD). In Scotland, ER data were collected on breast cancers from 1997-present[1], which is unique in the UK, since Wales does not hold any data on ER, Northern Ireland holds data from around 2008, and England holds data from about 2009. In the US[2] and Denmark[3], secular data show increasing ER-positive incidence and declines in ER-negative incidence, and using preliminary data from the cancer registry (SMR06) shows similar divergent incidence trends in Scotland (Figure 1). However, whether incidence and mortality trends, when stratified by ER, differ by different subgroups of the population are unknown (e.g. by socioeconomic status; age-group; and whether screen-detected).

Molecular profiling data that can be derived from tumour tissues, using a variety of methodologies [e.g. immunohistochemistry (IHC), mRNA expression, copy number changes, and DNA sequencing], if linked with important demographic and clinical data, may provide a comprehensive picture of temporal trends in breast cancer's incidence and mortality across the population. Molecular studies of breast cancer such as TCGA, PAM50 and METABRIC have shown many more new markers that are predictive of treatment and mark aetiologic differences, beyond ER, which are not captured in the SMR06 cancer registry or other clinical databases [4-8]. Hence, using collections of archived formalin-fixed paraffin embedded (FFPE) tumour tissues linked to SMR06 and other electronic medical record datasets would provide a better understanding of whether the trends in the incidence or mortality of different molecular subtypes of breast cancer have changed over time and whether these changes are similar across the entire population of women in Scotland. Understanding such trends would assist planning of breast clinical services as well as inform stratified medicine and public health prevention programs.

Oestrogen receptor (ER) expression in breast tumours is a key marker of aetiology and treatment differences. Preliminary data from over 73,000 cases in Scotland, show the incidence of ER-positive breast cancers rising and ER-negative breast cancers declining from 1997-2014. The underlying reasons for these divergent trends are lacking, as are answers on whether important subgroups of the population differ in these incidence or mortality trends (e.g. age, socio-economic status, and screening). Further, recent advances in 'omics technologies have changed breast cancer treatment decisions beyond ER, identifying subgroups of cases that might benefit from different chemotherapy, radiotherapy and hormonal treatment regimens. Using the electronic medical record datasets of Scotland we seek to develop a high-dimensional 'omics dataset through a proof-of-principle study using 1600 Lothian Bioresource stored tissues from two five-year periods. This proposal will quantify at the population level how many women might benefit from new 'omics defined molecular subtypes of breast cancer, with the goal of defining the populations that might most benefit from prevention, screening or treatment interventions in the UK and abroad.

1718-0076 Richard Colquhoun
National Neonatal Research Database

This application is to continue to receive data from Scottish neonatal units into the National Neonatal Research Database (NNRD), a national resource.

The NNRD was created in 2007. Data has flowed to the NNRD from English neonatal units since 2007 and from Scottish and Welsh neonatal units from 2014. Data are received from all English, Welsh, Scottish and the Isle of Mann neonatal units (currently 187 in total).

The NNRD holds operational clinical information captured in the course of care and makes this available for multiple purposes including audit, health services evaluations and research. Data in the NNRD comprise the Neonatal Data Set (SCCI1595) and consist of demographic details, daily records of interventions and treatments throughout the neonatal inpatient stay, information on diagnoses and outcomes, and follow-up health status at age two years. At present, there are data on approximately 8500,000 babies and 8 million days of care in the NNRD.

The Neonatal Data Analysis Unit has been given permission to use and store information in the NNRD for defined purposes in accordance with the following regulations: Research Ethics Committee approval (Reference 16/LO/1093) and Confidentiality Advisory Group approval (Reference: ECC 8-05(f) 2010).

1718-0085 Cheryl Denny
Scottish Routes from Diagnosis: Development of a Cancer Survivorship Outcome Framework

Scottish Routes from Diagnosis (SRfD) is a planned programme of research which seeks to link and analyse routinely collected data in a retrospective analysis, to quantitatively describe the survivorship of cancer patients in Scotland. It is a key objective of the current Macmillan-ISD partnership project, Scottish Cancer Pathways, and is an adapted framework based on the English Routes from Diagnosis.

In this first phase of work, cancer registry data for patients diagnosed with four of the most common cancers in Scotland (making up over half of all cancers diagnosed per year (http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/)) will be linked to secondary care, unscheduled care, prescribing and mortality information in order to:

- Map patient pathway experiences – what happens to distinct groups of patients from diagnosis to death
- Describe survivorship morbidity and health outcomes, i.e. survival, incidence, cancer and non-cancer related co-morbidities, and mortality
- Identify relationships and further our understanding of how patient characteristics influence the diversity of outcomes within and between cancer sites

The cohorts of cancers included in this research are the four most common cancers: lung, breast, colorectal and prostate cancer.

Given that there are almost 220,000 people living with and after cancer in Scotland, and this number predicted to rise to 360,000 by 2030†, the development of robust research and data analysis is crucial to better understanding the impact this will have on Scotland's cancer population and the services and support they need.

† Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Projections scenario 1). Macmillan analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated 2.5 million in 2015 in the UK. The share of this total in Scotland is taken from Maddams J., Thames Cancer Registry, personal communication. See also Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009. 101: 541-547.

1718-0088 Dr Emily Tweed

Morbidity and mortality among people experiencing severe and multiple disadvantage: a retrospective cohort study using cross-sectoral data linkage

Analysis of this dataset will answer key research questions identified by the affected population, healthcare professionals, and policymakers, as follows:

1. How common is SMD in Scotland, and what are the most common combinations of experiences? What are the demographic characteristics of people affected by SMD?
2. What is the association between SMD and risk of the following outcomes:
    - Ambulance call-outs
    - A&E attendance
    - Hospital admission
    - Death
3. How do the associations observed in question (2) vary with other characteristics known to influence health, such as age, gender, area deprivation, and urban/rural status?
4. What are the costs of A&E and hospital care associated with SMD in Scotland?

Linkage of routinely collected data is a particularly valuable technique for studying the experiences of people with adverse social circumstances, who are often not recruited to or retained in traditional cohort studies. Scotland's world-leading track record in data linkage makes it an ideal place to undertake this research.

Our analysis will provide the first comprehensive picture of what conditions cause ill-health and death among people with SMD. Our results will therefore help inform how health and social services for people with SMD are designed and delivered: for instance, they may identify a need for greater integration across homelessness, criminal justice, addictions care, and mental health services. Our results will also inform decisions about resource allocation: for instance, quantifying current levels of spending on unscheduled health care for this population will help policymakers understand whether preventative interventions (such as Housing First) are likely to provide good value for money.

1718-0096 Dr Ore-oluwa Erikitola

Surveillance of persistent cystoid macula oedema following uncomplicated cataract surgery in Scotland: Incidence and management

This study will be undertaken in association with the British Ophthalmological Surveillance Unit (BOSU). The principal aims of BOSU are to involve ophthalmologists in the surveillance of rare eye conditions of public health importance, and in research into uncommon eye disorders. At any one time BOSU surveys several different conditions, with each condition surveyed for a specified period. This will be an epidemiological study and cases will be identified through the BOSU reporting system. The BOSU is a unit run by the Royal College of Ophthalmologists to assist with the epidemiological study of rare ocular disorders.

The unit operates an active surveillance scheme in the UK through which independent research groups in ophthalmology and related fields can ascertain cases on a nationwide basis. The surveillance scheme involves all consultant or associate specialist ophthalmologists with clinical autonomy in the UK. At the end of every month they receive a report card. Included with the card are case definitions of all conditions currently the subject of surveillance. Respondents indicate either how many cases of each disorder they have seen or confirm that they have no new cases to report. This is done by placing a tick in the appropriate box on the card. The surveillance unit receives no information at all concerning the patient. Individual investigators are notified which ophthalmologists have reported a positive case by the BOSU. The investigator then contacts the reporting ophthalmologist directly using a questionnaire to collect information about the reported case.

The research work will be carried out at one site (Gartnavel General Hospital). Local collaborators are only required to fill out a data collection proforma seeking clinical information available from the hospital notes of patients who have persistent cystoid macula oedema following uncomplicated cataract surgery. They do not need to carry out any procedures mentioned in point 4.25 of the Standard Operating Procedures for ethic committees in the United Kingdom which require a principal investigator to be appointed at each site.

The reporting ophthalmologists will complete the data collection proformas without any additional consultation with the patient. All the information requested will be available directly from the case notes of the patient. For informed consent to be obtained, the reporting ophthalmologist would be required to call the patient for an additional consultation for no purpose other than obtaining consent. If the reporting ophthalmologist fails to recall the patient or the patient fails to attend the additional appointment, information about that patient would not be included, and the completenesss of the study would be compromised. As the study aims to improve information about persistent CMO in pseudophakic patients, which is an important cause of decreased vision, it is in the interests of the public health to have as complete data as possible.

The name and address of each patient will not be recorded at any point. The only patient specific information to be recorded will be the month, year of birth and gender. All patient information will be stored solely on a password-protected file on the Greater Glasgow and Clyde Hospital server in a separate database from the main clinical details. The patient, their GP and their family will not be contacted by the investigators at any point and their care will not be affected in any way.

1718-0097 Jillian Moses
Radiotherapy Dataset Project

The radiotherapy datasets RTDS is a data standard that requires all radiotherapy departments to collect and submit standardised data monthly against a nationally defined dataset. The purpose of the standard is to collect consistent and comparable data across all Radiotherapy providers in order to provide intelligence for service planning, commissioning, clinical practice and research and the operational provision of radiotherapy services.

Public Health England PHE took over responsibility for RTDS with effect from 1 April 2016. Previously the management and delivery of RTDS lay with the National Clinical Analysis and Specialised Applications Team (NatCanSat).

Scottish Government is now seeking to implement this solution with PHE to ensure regular and consistent collection of the RTDS, to enable meaningful benchmarking of radiotherapy services and make data readily available.

The RTDS is made of 26 data items listed in the NHS data dictionary. The data items are grouped according to radiotherapy attendance, att0endance identification, radiotherapy episode, radiotherapy prescription or radiotherapy exposure. Each dataset item is listed as mandatory (technical process (e.g. submission of the data set, production of output etc.) cannot be completed without this data element being present) or required (NHS business processes cannot be delivered without this data element). The dataset includes the diagnosis as described by the International Classification of Diseases (ICD) currently on the 10th Revision 5th Edition, the anatomical treatment site described by the OPCS Classification of Interventions and Procedures(OPCS-4.8) which includes a descriptor of the radiotherapy anatomical treatment site (“Z” code) and planning and treatment technique (“X” and “Y” code).

The RTDS data items are extracted from prexisting local electronic sytems which include the oncology information system (OIS) (Aria®) and patient administation system PAS (mulitple vendor systems are in use). Data is then locally validated with violations highlighted to the provider prior to upload on the application programming interface (API) site.

Following successful upload the data is accepted by National Cancer Registration and Analysis Service (NCRAS) staff in the English National Cancer Online Registration Environment (ENCORE) System to enable processing of 32 monthly reports. These reports are published on the dedicated portal, CancerStats. CancerStats is the information and reporting portal for all feedback on datasets which are managed or supported by NCRAS.

Individual provider level data will be presented on CancerStats alongside English and Welsh NHS provider data with the option of applying a filter so Scottish data may be seen separately. CancerStats is password protected on an individual basis, available to providers via N3 connection and via registration with NCRAS only. Individual provider level data is available to allow providers to benchmark themselves against other providers.

1718-0098 Alison Roe

Inclusion of Scotland onto the Breast and Cosmetic Implant Registry (BCIR)

NHS Digital has developed a Breast and Cosmetic Implant Registry (BCIR) and was launched in October 2016. This is expected to capture the details of all breast implant procedures completed in England by both the NHS and private providers. The Department of Health directed NHS Digital to carry out this work in response to Recommendation 21 of the Keogh Review of the Regulation of Cosmetic Interventions. See link: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192028/Review_of_the_Regulation_of_Cosmetic_Interventions.pdf

The purpose of the BCIR is to record the details of any patient, who has had breast implant surgery, so that:

a) they can be traced in the event of a product recall or other safety concern relating to a specific type of implant. Should an implant recall arise, an agreed process will be followed.

b) to provide an ‘early warning system’. A later phase of the registry is to consider a facility to enter anonymised data, especially if this remains a consented registry for England. This would then help provide a denominator for the total number of implant procedures, so if there was to be a recall in the future, the registry would indicate the full scale of the recall. More data on the registry would better inform an outlier process through the identification of any trends and complications related to specific implants.

NHS Digital may publish reports on the total numbers and types of implants, procedures and outcomes. These reports will only contain aggregated information (that is, data that has been grouped or combined) so that no individual patient will be identifiable.

The registry is operational in England and was launched on 10 October 2016. This application proposes to include Scotland onto the registry.

The PBPP review of this application has identified that, given the duty to ensure patient welfare in the case of potential recall of an implant which must be shared with affected patients, that inclusion in the registry must be mandatory in Scotland. Therefore the inclusion of Scottish NHS patient information in the BCIR should proceed without further consent and processing of this data should be exercised using Data Protection Act Schedule 2.5(d) and 3(8). NHS Digital is working with the Scottish Government to establish the approvals required to enable this.

1718-0100 Dr Peter Adlard
SR48 - Human Pituitary Growth Hormone Follow-Up Study

We aim to assess the death rates and incidence of cancers of individuals treated in the UK with pituitary derived human growth hormone between 1959 and 1985. This is used to assess the public health risks to the general population. We monitor the incidence of Creutzfeldt-Jakob (CJD) disease in this population, collate data for summary statistics for health agencies, and collaborate in research with experts investigating the types and causes of CJD. We also use the derived knowledge when interacting with patients at risk of dying of CJD, for whom we provide an information service and support expertise.

1718-0101 Maria Aresu
Airwave Health Monitoring Study (MR837)

The Airwave Health Monitoring Study was established in 2003 to evaluate possible health risks associated with the use of TETRA, a digital communication system used by the police forces and other emergency services in Great Britain since 2001.

It is a long-term observational study following up the health of the police force with respect to TETRA exposure, and ability to monitor both cancer and non-cancer health outcomes. It addresses needs raised in a report by the Advisory Group on Non-Ionising Radiation (AGNIR) on the possible health effects from TETRA.

The aim of this proposal is to estimate the risk of all cancers, certain mortality outcomes and various non-fatal, non-malignant health disorders in relation to Airwave use. As well as the focus on cancer incidence, the proposal will investigate non-cancer health outcomes (including cognitive, neuropsychiatric and neuro-degenerative effects which may be linked to sickness absence and early retirements), as the mechanisms of any putative health effect related to TETRA use are unknown.

The cohort consists of police force employees from Great Britain and c. 53,000 participants are enrolled at the present.

1718-0106 Claire Lawrie

Audit of current practise in primary care for investigation of women presenting with symptoms, which may be due to ovarian cancer against the Scottish cancer referral guidelines

Scottish Referral Guidelines for Suspected Cancer (2014) recommend that an abdominal palpitation should be undertaken, CA125 (which is a protein, often found on the surface of ovarian cancer cells, and in some normal tissue. There is a blood test for CA125, and it is a marker of ovarian cancer, however blood levels may also be raised in non-cancerous conditions) blood serum level measured and urgent pelvic ultrasound scan carried out:

- In any woman over 50 years of age who has experienced new symptoms within the last 12 months that suggest irritable bowel syndrome; or
- Women (especially those over 50 years) with one or more unexplained and recurrent symptoms (most days) of:
    - Abdominal distension or persistent bloating
    - Feeling full quickly or difficulty eating
    - Loss of appetite
    - Pelvic or abdominal pain
    - Increased urinary urgency and/or frequency
    - Change in bowel habit.

In contrast, NICE Ovarian Cancer: recognition and initial management guideline 2011 recommends that CA125 blood serum level is measured first and an ultrasound scan of abdomen and pelvis is carried out if the CA125 level is > 35 IU/mL. A joint audit through both The Scottish Clinical Imaging Network (SCIN) and The Scottish Clinical Biochemistry Managed Diagnostic Network (SCBMDN) consists of two parts:

- Audit of uptake of the Scottish Cancer Referral Guidelines in primary care
- Audit of the clinical effectiveness, of including ultrasound with CA125 testing at initial investigation. This audit will be dependent on the data collected and the results of the audit of uptake of the Scottish Cancer Referral Guidelines in primary care.

CA125 will be collected from the 01/01/2015 until 31/07/2015; ultrasound data will be just prior and after those dates. Dates were chosen to ensure details of patients who had a CA125 test carried out and were subsequently diagnosed with ovarian cancer were added to the SOCRATES (or SMR06) system. And that the system is updated one of twice a year. Period of time after data collected to allow the data to be uploaded and updated. Scottish cancer referral guidelines were published in Aug 2014, so to assess the impact of the cancer referral guidelines implementation.

1718-0107 Karyn Robertson

Transfer of the hosting of the Photosys Database from NHS Tayside to NHS NSS and upgrading of the operating system

This application is for a proposal to move the Photosys national database, currently hosted within NHS Tayside on behalf of NHS Scotland, to NHS National Services Division.

The national phototherapy network (Photonet) was designated as a national managed clinical network in 2002 to address a number of issues identified through CRAG funded audits of phototherapy services in Scotland (1991/1996). The audits identified the need for a central computer system as well as the need for a follow up system to identify patients at risk of skin cancer.

Photonet was commissioned and funded by National Services Division, NHS NSS with management and administration support services provided for the network by NHS Tayside through provision of a service level agreement. Photosys, the database developed to meet the identified need for a central computer system, was developed and hosted by NHS Tayside with funding provided from NSD. All health boards input patient data to Photosys for all courses of patient treatment.

Following a decision by NHS Tayside to no longer continue to develop and host national databases, agreement was reached that the Photosys database should be transferred to NSS for hosting and support. In April 2014, responsibility for the management and administration of the Photonet network was transferred to NHS National Services Scotland from NHS Tayside as part of the establishment of a National Network Management Service. This made the transfer of the database more critical as the support is provided by staff now within NHS NSS.

For some years there has been no development and upgrading of the database and the move NHS NSS is necessary to be upgraded to a current version of the platform it is designed on. This will make the database more stable, remove some of the ‘bugs’ and allow for the progression of a number of identified change controls.

The information contained in the Photosys database allows phototherapy clinicians to access information about their patients’ previous courses of treatment enabling them to take appropriate clinical decisions about future treatment. It also enables the identification of any patients at risk of skin cancer to prompt follow up. The network uses the aggregate audit data to measure the performance of each phototherapy unit against 21 agreed evidence based standards of care. The audit data is reported back to the units annually to support local quality improvement.

1718-0118 Emma Milburn
Inpatient Experience Survey

The Scottish Care Experience Survey Programme is a suite of national surveys which aim to provide local and national information on the quality of health and care services from the perspective of those using them. The survey programme supports the three quality ambitions of the 2020 Vision – Safe, Effective and Person-centred – by providing a basis for the measurement of quality as experienced by service users across Scotland. In particular, the surveys support the person-centred quality ambition which is focused on putting people at the centre of care; ensuring that care is responsive to individual personal preferences, needs and values; and assuming that individual values guide all care decisions.

The Inpatient Experience survey is a vital component of the programme, capturing the views of users of hospital services in Scotland, at a time of significant transformational change. The survey is biennial, and sits alongside the other surveys in the programme to provide a holistic picture of patient experience across the health and care system.

The Inpatient Experience Survey will be run by the Scottish Government (SG) and NSS Public Health & Intelligence PHI(ISD) using a long standing partnership approach. A copy of the partnership agreement for this survey is attached at Annex B.

The outputs from the proposal will be a range of analyses available at different levels of geography, containing robust and comparable information about peoples experiences of the care that they've received. This analysis will be provided by PHI(ISD) via an interactive dashboard (using Tableau) which will allow local areas to interrogate the data in different ways to meet their particular needs. This will provide vital evidence locally and nationally to inform service improvement, leading to improved outcomes for patients.

This survey is administered by post. It is important that PHI(ISD) are able to access the names and addresses of people who have had an overnight stay in a hospital in Scotland, so that they are able to draw a sample of people who have used the services in question.

1718-0120 Dr William Stewart
FIELD: Football's Influence on Lifelong health and Dementia risk

There is growing public anxiety over possible increased risk of dementia in former professional footballers. In part, this is because researchers are increasingly recognising a specific form of degenerative brain disease, chronic traumatic encephalopathy (CTE), in post-mortem examinations of former footballers. These observations have led to numerous media stories reporting anecdotal evidence suggesting footballers might have higher rates of dementia than expected and calls for football heading to be banned for younger players.

However, to date, no properly designed studies looking at risk of dementia in former footballers have been conducted. Given the widespread, global popularity of football, it is therefore a priority that the question of possible high dementia risk in former footballers is addressed. In addition, it is important that any data on dementia in former footballers are interpreted in context of wider lifelong health outcomes from having played football to allow sport and public health organisations to provide balanced and safe advice on any risks or benefits of football participation.

To this end, we have brought together a team of leading researchers and experts in traumatic brain injury, public health and sport to study lifelong health outcomes in former footballers. Using a comprehensive database of former professional footballers and NHS Scotland's unique electronic health records we propose to investigate a wide range of physical and mental health outcomes, including dementia rate, in former footballers and compare these to appropriate age, sex and deprivation matched controls.

1718-0121 Dr Sarah Maclean
Frailty and outcomes in the Intensive Care Unit

Frailty is "a condition characterised by loss of biological reserve and vulnerability to poor resolution of homeostasis following a stressor event". Frailty increases the risk of an adverse outcome (including ICU and hospital mortality) in patients requiring Intensive Care Unit (ICU) admission. It may be influenced by "social comorbitidies" -namely obesity, smoking, intravenous drug use, excess alcohol use, and their associated medical problems. In assessing whether admission to ICU would benefit patients, we traditionally use physiologic scores e.g. APACHE to estimate the probability of survival.

Frailty is not routinely assessed, however the Clinical Frailty Scale (CFS) is a validated and easy-to-use scoring system which allows assessment of frailty. It may represent a surrogate for many difficult-to-measure aspects of a patient’s prehospital functional state. This is vital when addressing long-term outcomes including functional status and quality of life.

We have an increasingly ageing population and an increasing number of patients with chronic congenital diseases now surviving to adulthood. Even patients with a young chronological age may have advanced “physiological age”, which at present is not routinely measured. Frail patients may not withstand the insult of multi-organ failure, they may experience more delirium and require an increased length of stay, and frail survivors of ICU may be left severely dependent.

We aim to find out what the burden of frailty is in ICUs in Scotland, and how it is associated with “social comorbidities”. By carrying out this project we hope to determine whether the CFS is easy to use and whether CFS has prognostic value in terms of ICU outcome. It is likely that measurement of frailty will become a minimum standard of care in ICU in the next few years, and the results of this project would inform further discussion about whether the CFS is suitable for this.

1718-0132 Dr Sarah Murray
Preterm perinatal mortality in twins compared to singletons: a population study

This project is related to eDRIS-1516-0252 and also eDRIS-1516-0391 which all relate to short and long term outcomes according to gestational age at delivery in an attempt to determine the optimum timing of gestation at delivery in both singleton and twin pregnancies and guide antenatal care practices.

This is an extension of eDRIS-1516-0252 which looked at perinatal and neonatal mortality and morbidity in twins, the optimum timing of delivery of twins and their long-term educational outcomes based on gestation at delivery. This proposal has changed to now include a comparison of mortality and morbidity outcomes in twin and singletons particularly with regard to preterm infants. Twin pregnancies in general are monitored more closely and managed in a high-risk obstetric antenatal clinic compared to singleton pregnancies which if low risk are solely midwifery led care. Previous studies have shown that twins born preterm have a lower perinatal mortality rate compared to singletons born at the same gestation. This is against what would normally be expected given that twins are a high risk pregnancy. Given that the preterm birth rate in Scotland continues to be static it is an ongoing clinical problem with substantial cost to the UK economy. If it is shown that twins born preterm have a lower perinatal mortality rate compared to singletons born at the same gestation it may lead to a call to the relevant policy makers for increased monitoring for singleton pregnancies. I propose to carry out this study using the Scottish data and compare perinatal mortality rates of twins and singletons from 24 weeks onwards with particular focus on the preterm infants.

1718-0136 Stephen Riddell
NHS Information Services Division/Alan Turing Institute Data Study Group Collaboration – SPARRA Algorithm Development

The NHS NSS team are responsible for the ‘Scottish Patients at Risk of Readmission and Admission’ (SPARRA) model. This model predicts the risk of a patient being admitted to hospital as an emergency patient in the next twelve months. A risk score is calculated monthly for around 4.2 million patients in Scotland. Details of patients whose scores indicate they may be at greater risk are distributed to NHS Boards and GP Practices on a monthly basis. Risk scores are re-calculated during this monthly run to reflect recent data updates. GPs use SPARRA scores to stratify patients by risk of emergency admission. This aids them in the selection of patients with complex care needs for consideration of Anticipatory Care Plans/polypharmacy review. This data is used by GPs in conjunction with their own data.

The current iteration of this model was developed in 2012, and it is desirable for work to be done to improve the predictive ability of this model, but resource constraints within the Analytics and I0ntelligence team within NHS NSS have meant that this work has been postponed in order to focus on other priorities. Recalibration of this model has been identified as being desirable in order to improve the predictive ability of the model. Currently, logistical regression is used to calculate the SPARRA risk score but it would be beneficial to explore alternative methodologies.

The Alan Turing Institute is the UK's new national institute for data science, bringing together leading talents in data science research who are focussed on innovative and collaborative approaches, to create theoretical development and to generate impact by applying it to real-world problems. The Turing is running a 'Data Study Group' from Monday 4th September to Friday 8th September 2017. Data Study Groups are 1-week intensive workshops where a multidisciplinary group of around 60 high-potential researchers in data science (broadly construed) are brought together from the Turing and from the wider UK, to work on a problem or challenge in small teams 0of c15-20 led by a team Facilitator, and identify new, innovative approaches to that problem. For examples, please see: https://www.turing.ac.uk/media/blog/industry-challenges-tackled-turing-data-study-groups/ and https://www.turing.ac.uk/events/data-study-group-industrial-collaboration/

It is proposed that Data Study Group researchers at the Turing working on this specific problem are given access to a subset of the input data used in building and refreshing the SPARRA model during this week-long Study Group period. The Data Study Group will run from Monday 4th September to Friday 8th September inclusive; one or two Turing researchers named in this application will access the data up to one week before the event (ie from Friday 25th August 2017) to clean and pipeline it in preparation; and Turing researchers named in this application will have access to the data for up to one week after the event (ie until Friday 15th September 2017) to produce the event report for NHS Scotland, and to be available to answer any technical queries from NHS Scotland staff.

Any subset would be broadly reflective of the Scottish population as a whole, and it is proposed that this would incorporate patients from the following boards:

1. NHS Lanarkshire
2. NHS Dumfries and Galloway
3. NHS Tayside
4. NHS Grampian

The suggested access method is via a 'Safe Haven' – where researchers from the Turing remotely access the data and interrogate and manipulate it accordingly using statistical analysis packages. It is also proposed that one analyst from the NHS NSS team will be present on site during this week, collaborating with the Turing researchers and monitoring their work.

1718-0141 Dr Elizabeth Murphy
Scottish Society for Rheumatology Web Based Audit

This is an audit of clinical outcomes in patients with early rheumatoid arthritis. Data is entered at or soon after diagnosis with patient consent. Baseline data is recorded and outcomes at 6 and 12 months recorded and reported. Each centre has access to its own data and can see outcomes compared with other centres but does not have access to any identifiable data from other centres. There are agreed metrics for the key clinical outcomes (document 2)

1718-0158 William Malcolm

Identification of risk factors for antimicrobial resistance in patients with suspected sepsis

Sepsis is caused by bacterial infection in the bloodstream or body tissues. It is an extremely serious and common healthcare issue, resulting in more deaths per year than bowel, breast and prostate cancer combined. A crucial factor in the treatment of suspected sepsis is the early administration of appropriate antibiotics. If the patient has an infection that is resistant to the antibiotics initially used, the treatment will not be effective and the patient is at risk of rapid deterioration and poor outcomes including death until an effective antibiotic is given.

In each NHS board, there are guidelines on which antibiotic to prescribe for suspected sepsis. These guidelines are for empiric prescribing: when the organism causing the infection and its susceptibility to antibiotics are not known at the time of prescribing. The guideline antibiotic therefore might not be the most appropriate treatment if the infection is resistant to that antibiotic.

Several factors can increase the risk of resistance, such as previous use of antibiotics, having other diseases, older age, living in a care home and more hospital admissions. This project will investigate antibiotic resistance in patients with suspected sepsis, and will assess the impact of these risk factors by linking to data on hospital admissions and antibiotic prescriptions in the same patients.

A major challenge is that although there are International Classification of Diseases (ICD)-10 discharge codes for recording diagnoses of sepsis, these codes are not reliably applied and recorded in national datamarts held by NSS. In order to investigate risk factors, patients with suspected sepsis must therefore be identified from proxy measures. If a clinician suspects a patient has sepsis, they will have a blood sample tested for the presence of an infection. The results of this test (whether they were positive or negative) can therefore be used as a proxy for identifying patients with suspected sepsis (see links 1 and 2 in the above section: Links to additional supporting documents).

Blood culture test results are recorded in the national database of health system laboratory test results, the Electronic Communication of Surveillance in Scotland (ECOSS) datamart. Following an option appraisal in 2016, ECOSS was amended to receive and process all blood culture results regardless of result (previously only positive results were available). These data are now received from all but one NHS board (due to local technical issues).

We are therefore seeking an extract of all blood culture results from ECOSS in order to identify patients with suspected sepsis and thereafter to identify risk factors for antimicrobial resistance through data linkage.

In due course, we will use this evidence to develop risk prediction models to identify patients who may be at higher risk of resistance and for whom antibiotics other than those recommended in the local empirical policy are required.

1718-0160 Professor James Roy Robertson

Edinburgh Drug Cohort Study

The project is to continue a long running study of a cohort of people who have injected illegal drugs (almost all heroin users). The project recruited these individuals between 1982 and 2015 into a study of their drug use. The individuals involved were all, at the time of enrolment, patients registered with the Muirhouse Medical Group (MMG). The MMG is a NHS general practice located in North

West Edinburgh which, over the time period, has had more than the average number of people who use drugs coming for help and support. The purpose of the study is to find out what happens to these people over time.

In 1982 the wave of young people beginning to use illegal heroin by injection was a serious problems for the Practice, threatening to overwhelm the capacity to provide effective care. The vulnerability of these patients and their families was, and remains, obvious to the GPs involved with their care. A combination of audit and engagement with this new group of vulnerable people allowed a better understanding of their needs and the sense of treatment. The need for research was obvious from the beginning and, with support from various bodies such as the Scottish Home and Health department (now the Chief Scientist Office of the Scottish Government, the Medical Research Council, The Royal College of GPs and collaborators in various UK and European universities) the project has been influential on an international scale.

To maximise it’s full potential the proposal is to continue to access data from NHSCR in order to understand mortality and morbidity risks and outcomes.

The project has had the singular advantage of access to GRO (now NHSCR) data since it’s inception in 1984. These data, on the time and cause of death, have allowed a longitudinal study unprecedented in the UK and Europe and showing a distinct difference in outcome from similar long running research in the USA where those involved with drug use came from an entirely different group of people. The Edinburgh Addiction Cohort is therefore unique and, as such, is of huge contemporary importance to clinicians and policy makers.

1718-0162 Diane Havard
Prevention Of Decline in Cognition After Stroke Trial (PODCAST)

The original PODCAST study has been conducted in NHS hospitals across the UK and actively seeks out people admitted with stroke who are at risk of losing some of their ability to recognise and understand things in their everyday activities (their cognitive abilities). Its aim was to reduce the impact of stroke on these activities and abilities by 20%, by testing out new ways of maintaining a healthy blood pressure and cholesterol levels. Conclusive evidence that actively lowering blood pressure and cholesterol achieves this aim would benefit patients, carers and society and influence how stroke is treated and managed in hospital.

The purpose of this application is to request access to data, which will enable the PODCAST study team at the University of Nottingham, to compare information they collected for individuals who consented to participate in the study - with routinely collected data published by National Records Scotland.

This will ensure that when the findings are published they are as accurate as possible The patient information documents and informed consent forms expressly ask for permission to obtain follow-up data.

All published data will be anonymised and categorised by whichever treatment group the individual was allocated to. This means no one will be able to identify the data for any particular individual.

1718-0179 Linda Kerr
NHS Scotland Shared Services Radiology Programme

The Shared Services Health Portfolio Radiology Programme was commissioned by the Senior Leaders Forum, made up of Board Chairs and Chief Executive Officers, to deliver sustainable, efficient services which will ultimately improve service user experience considering a "Best for Scotland" approach. The Radiology Programme team has worked closely with stakeholders to develop a National Radiology Model. This Model was approved by the NHS Board Chief Executives on 9 August 2016.

The National Radiology Model describes a collegiate approach to Radiology Service provision supported by national clinical pathways, clinical governance and quality assurance frameworks. Workforce role utilisation will be maximised and flexibility to work across traditional Health Board Boundaries enabled. There are three underpinning requirements necessary to support the national Radiology Model. These are dependencies without which the radiology initiatives cannot be achieved:

1) National Radiology Data Requirements;
2) IT Connectivity; and
3) Maximising role utilisation and the ability to work across 'traditional' NHS Board boundaries.

Each of the above is included in this proposal and described in detail below. Where necessary the responses to each of the questions will be split to show the distinction between 1 & 2 above.

In addition, the Chief Executives assessed and approved a full business case for the Programme (in August 2017) which describes the background, intended approach and implementation plans in detail. The full document can be accessed here – http://www.sharedservices.scot.nhs.uk/health-portfolio/programmes/radiology/

1) National Radiology Data Requirements

NHS National Services Scotland (NSS) through its Public Health & Intelligence (PHI) Strategic Business Unit has been asked to take forward a project to deliver the first of these "underpinning requirements". This will be achieved through this proposal to develop a National Radiology Information & Intelligence Platform (NRIIP) consisting of:

a) A National Radiology Datamart within the NHS National Services Scotland (NSS) Corporate Data Warehouse (CDW).
    - The datamart will be populated from an agreed National Radiology Dataset.
    - The dataset is sourced from local Radiology Information Systems (RISs) and the National Picture Archiving & Communication System (PACS).
      N.B. Images stored in PACS are not included in the NRIIP.
      National PACS is maintained by NSS and data are sourced from local PACS and local RISs.
b) A set of Tableau Dashboards, accessible by NHS Boards, to allow improved access to Radiology information in support of service planning, service improvement and benchmarking with other NHS Boards.
c) A set of Tableau Dashboards including other relevant national data held in datamarts within the CDW.
d) A 'wraparound' consultancy and analytical service (similar to that developed for NSS Discovery).
e) The ability for NHS Boards to develop their own Tableau Dashboards to visualise their own data.

The NRIIP proposal will be delivered incrementally:

Stage 1 – Access to data collected in the National Radiology Dataset will be made available to NHS Boards using Tableau dashboards (the subject of this application).
Stage 2 – The dashboards will be enhanced to include other Datamarts in the CDW.
Stage 3 – The dashboards will be enhanced to include information on Cost and Workforce.

We will submit separate PBPP applications before Stage 2 and 3 commence as at this time it is not known which datamarts NHS Boards will require access to nor is it clear from where cost or workforce information will be sourced.

2) Integrated Compatible IT Systems – IT Connectivity

Although there is a national PACS, which contains radiology images, image reporting is siloed within each NHS Board within their local RIS. Individual NHS Boards have differing RISs where the image report is created and stored.

The aim of this Project is to enable the differing RISs which record and report upon patient images to interface with one another across NHS Board boundaries. This is what is meant by IT Connectivity.

In March 2017 an OJEU procurement exercise was initiated to identify an optimal solution to deliver connectivity nationally and integrate with existing systems. A preferred supplier is now at the point of being confirmed and implementation is anticipated shortly thereafter.

3) Maximising role utilisation and the ability to work across ‘traditional’ NHS Board boundaries.

The National Radiology Model describes virtual mobilisation of the workforce, using a collegiate approach, with staff working across traditional NHS boundaries on a regional and sometimes inter-regional and national basis. This way of working will need to be enabled by appropriate contractual arrangements. Therefore the Shared Services Portfolio established a Workforce Reference Group (WRG) Chaired by Anne MacPherson, Director of Human Resources in NHS Greater Glasgow & Clyde.

The WRG has developed the following:

a. A Good Practice Guide of Employment Arrangements to support cross NHS Board boundary working for the workforce;
b. A Professional Governance Pathway to meet the Codes of Conduct of the relevant professional governance bodies [e.g. General Medical Council (GMC) and Health and Care Professions Council (HCPC)] in order to support cross boundary working;
c. Explored the Terms and Conditions implications of regional and national Out of Hours Frameworks;
d. Developed common Job Descriptions and identified Agenda for Change banding for Reporting Radiographers; and
e. Links with the local Board’s workforce planning leads to identify for short, medium and long term challenges for radiology services.

The above documentation has been developed with full participation of partnership colleagues and has been approved by the Scottish Workforce and Staff Governance Committee (SWAG).

In addition, to address the issue of variation in employment practices for Reporting Radiographers, the radiology programme team established a Project Group. Members included a wide range of stakeholders representing the service, education and the professional bodies such as the RCR and the Society and College of Radiographers (SoR). The Project Group developed a National Framework for Reporting Radiographers which includes:

a) Common Job Descriptions.

b) A role outline to incorporate:
  - (i) Educational Pathways;
  - (ii) Scope of Practice for Plain Radiograph Musculo-Skeletal Reporting;
  - (iii) Productivity;
  - (iv) Governance arrangements; and
  - (v) Continuing Professional Development.

Maximisation of the Reporting Radiographer workforce will require NHS Boards to consider the remaining skill mix within radiology departments and reflect these changes in their local Workforce Plans. For example, an expansion in Assistant Practitioner role may be required. This, in turn, will require availability of the requisite educational courses to prepare Assistant Practitioners for their roles.

The above documentation has been developed with full participation of partnership colleagues.

There has been wide consultation with stakeholders in the Radiology community and externally in terms of the development of the 3 underpinning requirements which support the National Radiology Model – IT Connectivity, NRIIP and workforce optimisation.

1718-0180 Kathy McGregor

Linkage Unscheduled Care Datamart (UCD) to Social Care data contained in the Social Care datamart

As individuals in Scotland make contact with Unscheduled Care Services, data about who they are, where they have come from, what is wrong with them and what happens to them are collected, mainly to inform their care. This provides a good picture of the potential unscheduled care journeys that an individual may travel through. The aim of the project is to link Unscheduled Care Datamart (UCD) to social care data contained in the Social Care datamart. Data on social care including home care packages can have an impact on demand on unscheduled care services. The linkage will allow this to be quantified as well as exploring areas where effective social care input can lead to a reduction in contacts with unscheduled care services. It will also provide enhanced patient journeys.

1718-0184 Dr Rachel Knowles

Surveillance of severe microcephaly in the UK and Ireland (SSM-UKI)

Microcephaly describes a baby with a ‘small head’, who has experienced poor head growth before or after birth. This rare condition may be associated with abnormal brain structure or development, and with disability, although some babies will develop normally. Many different causes of microcephaly have been described, including genetic disorders, exposure during pregnancy to environmental toxins, certain drugs, infection or malnutrition.

There is uncertainty about the number of babies affected by microcephaly in the UK, and we lack information about how well we care for these children. This study will find out how many UK babies are born with microcephaly each year and how seriously this affects their health and developmental outcomes, including problems with hearing and vision. It will provide a better picture of the care and support these babies and their families currently receive. This will allow us to make sure the right services are available to meet the future needs of children and families. Importantly it will also provide us with a way to monitor changes in the frequency of microcephaly, for example due to Zika-virus infection.

1718-0186 Amelia Rudd

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

Acute stress-induced (Tako-Tsubo) cardiomyopathy presents like a heart attack and is triggered by intense emotional physical stress. Although heart arteries are unobstructed, the risk of death is similar to a heart attack. There is little understanding of this strong brain-heart interaction with harmful cardiac consequences and little knowledge about any predisposing factors. We plan to conduct a Scottish-side study to determine if patients who presented with an acute episode of Tako-tsubo or their immediate relatives carry a genetic susceptibility to developing this condition. In order to plan this study it is essential to know how many cases we can identify yearly in Scotland, which is the aim of this pilot project. This application will only relate to the identification of past (from the 1st of January 2010) and future (31st of December 2023) cases of Tako-tsubo cases by requesting the CHI numbers of all patients coded under Code 142.8, which is for “Other Cardiomyopathies” in the ICD-10 and future ICD-11 systems and the new coding system as described above, which should be implemented by NSS soon. We will also be requesting the CHI numbers of all patients coded under Code I21 in NHS Grampian (MI controls) annually.

1718-0188 Praveena Symeonoglou

Scottish Dental Needs Assessment Programme Oral Health and Dental Services Needs Assessment for Older Adults (45 and over)

The project aims to conduct population needs assessment/service evaluation of oral health and dental services for older adults of age 45 and over in all NHS Boards across Scotland, identify probable gaps in service and make recommendations. The report is based on the technique called Health Needs Assessment (HNA). This method is commonly used to evaluate health services at population level (not individual level). The three HNA approaches which are, corporate, comparative and epidemiological approaches will be used to deliver this report. Only activity data is collected.

1718-0194 Dr Carl Counsell

Parkinsonism Incidence in North-East Scotland (PINE) study

Between 2002-2004 and 2006-2009, we recruited all patients in Aberdeen with a newly diagnosed neurological disease called Parkinson’s as well as age-sex matched controls. These groups are being followed up lifelong to establish how this disease evolves over time and what impact it has on people’s lives compared to the controls. One important measure is how long people survive and so participants have consented to be linked to the death register so we know when they die.

1718-0201 Tracey Curtis

National Invasive Cancer Audit

The Scottish Cervical Screening Programme exists to prevent the development of invasive cervical cancer by detecting and treating the pre-invasive stages of the disease. The development of invasive cancer is therefore viewed as a potential failure of the programme. After a considerable reduction since 1988/1989, the incidence of new cases of cervical cancer has remained the same, or risen slightly, over the last five to seven years. This raises questions about the continued quality and effectiveness of the programme.

The National Invasive Cervical Cancer Audit dataset was developed at the request of the Scottish Government due to an inability of NHS Health Boards and the Scottish Cervical Screening Programme to produce comprehensive data about the circumstances relating to the development of invasive cervical cancer despite the presence of a screening programme. This data is needed to begin to understand the reasons for this stagnation in the effectiveness of the programme.

There was previously a form in place for NHS Health Boards to record some invasive cancer audit data. This form was developed by the screening laboratory service and was limited in extent, with no information gathered on the process of calling and recalling women, the accuracy of the histological and colposcopic confirmation of a screen-detected abnormality, or of the treatment. This form was neither consistently used nor comprehensive enough for the current screening programme, nor was the data collated at a national level. Thus, many aspects of the programme, essential for the successful prevention of invasive cervical cancer, were not subject to systematic evaluation.

The new dataset will allow scrutiny of the full patient pathway and processes of cervical screening and their effectiveness, this has never been possible due to the limitations of the old form which was laboratory/cytology focused. A copy of the old form is attached to this application.

“Screening histories of women developing invasive cancer are reviewed, and any areas in the programme which require improvement are identified and addressed” is included as an essential criteria in the Clinical Standards Board for Scotland’s clinical standards for the programme and so it is imperative the ability to do this review is in place in order for the programme to meet external quality assurance standards.

1718-0202 Professor Glen Bramley

Profile of Severe and Multiple Disadvantage in Scotland – analysis of Scottish Drugs Misuse Database

This proposal constitutes one part of a larger project, which follows on from a study published in 2015 entitled 'Hard Edges: Mapping Severe and Multiple Disadvantage in England' (Ref (1)). Building on qualitative scoping work, these studies seek to provide a statistical profile of key manifestations of ‘severe and multiple disadvantage’ (SMD), as a shorthand to signify the problems faced by adults involved in the homelessness, substance misuse and criminal justice systems, with poverty an almost universal, and mental ill-health a very common, complicating factor.

The overarching aim of this project is to build on this previous English study by developing a similar analysis of the situation of this SMD group in Scotland, recognising the many differences in data systems, policy and institutions, and thereby provide new insights and evidence to support more effective policy and service delivery to change the life course, outcomes and quality of life for people experiencing SMD while saving significant service and cost burdens on the NHS, local government, other public sector and society more broadly.

The main quantitative thrust of the study will entail drawing on a number of secondary administrative and/or survey datasets to paint a picture of the SMD population in Scotland. In particular we will seek to make robust national estimates of the numbers involved with different combinations of disadvantages, their socio-demographic profile, economic situation, and geographical distribution. We will also provide a profile of the health/quality of life and other outcomes experienced by these groups, draw out evidence on background circumstances and potential causal factors, and estimate the extent of use and cost of services

The study is using a range of secondary survey and administrative data sources to create a profile of adults experiencing combinations of homelessness, chronic offending, substance misuse, mental health problems and domestic abuse/violence. Through triangulating evidence about people in particular overlap groups in terms of these conditions, from different sources, the aim is to produce robust national estimates of the numbers involved, their socio-demographic profile, economic situation, geographical distribution, health/quality of life and other outcomes, background circumstances, and use and cost of services across NHS, local government, and other public sector bodies.

The main reasons for this approach, involving multiple administrative and survey datasets, are that people experiencing SMD are often poorly represented in mainstream household based surveys, because of non-response or not actually being present in private households, while they may be captured through usage of relevant services, although the coverage of these is also uneven.

Scoping work has identified the Scottish Drugs Misuse Database (SDMD, alias SMR25a/b) as the key administrative service-based dataset in the domain of substance (drug) misuse. This proposal is for accessing these datasets to undertake detailed analysis within the secure data lab setting provided by the ADRC in Edinburgh, Scotland. This will complement parallel analyses of other datasets providing complementary and overlapping views of the population of interest.

1718-0205 Dr Zoe Harclerode
PAediatric unPlanned dAY case Admissions (PAPAYA)

The Royal College of Anaesthetists recommend that all anaesthetic departments regularly audit the frequency of unplanned admissions after elective day case anaesthesia (1) and propose that rates should be <2% in adults (2). This standard is not specific to the paediatric populations, who undergo different operations to adults and have different co-morbid conditions. However single centre audits have shown that unplanned paediatric admission rates may approximate this figure (3,4). This however, is not a paediatric specific standard. Children undergo different operations to adults and also have different co-morbid conditions.

There is an increasing drive to manage more patients as ‘day cases’ to improve their experience, reduce pressure on inpatient beds and time spent in hospital as well as make cost savings. No data currently exists in the UK for the proportion of unplanned admissions following planned day case general anaesthesia.

The initial phase of this project was a survey of UK hospitals which demonstrated that only 21% of 63 participating centres are regularly auditing their rate of unplanned admissions.

This phase will audit the frequency of unplanned admissions in the paediatric population against the RCOA standard mentioned above. Specifically, we aim to answer the following questions:

1. What is the proportion of unplanned admissions after day case general anaesthesia in children 0-16 years for the hospitals that sign up?
2. Does the paediatric population studied comply with the audit standards set out by the Royal College of Anaesthetists?
3. What are the common reasons for unplanned admission?
4. Are there any variables related to unplanned admission, such as age, ASA grade, surgical procedure, surgical speciality, duration of surgery, visit to pre-assessment clinic, grade of primary anaesthetist and surgeon?

PATRN, a pan-UK paediatric focussed anaesthetic trainee research collaboration, supported by the APAGBI and RAFT, is uniquely placed to deliver this project.

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1718-0206 Dr Mirko Moro

Life Unleaded: Investigating the effects of public interventions to reduce water lead pollution on infants and children's health

Lead is a very toxic element that can have adverse consequences on babies and children's health, even at low concentrations. There are different sources of lead exposure. Tap water and leaded-petrol were two of the most common in the UK until mid 1990s. Lead service pipes were widely used around the world to connect homes to street water mains. Lead is dissolved from the interior of the pipe and ingested when drinking from the tap. Lead was a popular material because of its durability. In the 1970s, the majority of people – including pregnant mothers – living in Glasgow would drink water from the tap that contained 5 times the level of lead than is currently accepted. When the toxicity of lead started to be widely recognised, sometimes after campaigns by civic groups, the UK regulators set up programmes and policies to reduce and eventually phase out lead from water pipes and petrol.

This project attempts to examine how specific interventions to clean up the environment from lead influenced all pregnancy outcomes (e.g., live births, birth weight, stillbirths, miscarriage) and infant mortality by combining historical and administrative health data, with modern statistical techniques. The analysis we propose will study two water treatment programmes that successfully reduced lead content in tap water in Glasgow in 1978 and 1989.

Results from this project will provide evidence of the benefits of these interventions for Scotland. This will also inform the debate on the short and long run benefits of environmental regulation in general – and its contribution to a healthy and productive population. Finally, our estimates provide robust evidence of the toxicity of lead and can be used by policy makers, planners and civic groups living in cities and countries that still experience lead exposure to levels that are comparable (or even higher) than our sample.

1718-0208 Dr Frank Popham

Selective schooling and long-term health: a data linkage study

Education is associated with better health. However, it is still unclear whether it has a causal impact. Natural experiment studies allow better assessment of causality. Allocation to selective secondary schooling, where the length of education is longer, was often based on achieving a certain level on a test score. This allows a regression discontinuity design that makes use of the fact that those either side of the cut-off point on the test score are similar apart from the type of secondary school they are allocated to. Here we propose to use data from a 1950s Aberdeen birth cohort for whom test score, secondary school attended and later life health are available to test the impact of secondary schooling on health.

Background

Education has long been regarded as important for adult health and health inequalities [1]. Given that policy influences the amount, quality, and distribution of education, it is important to study to what degree education impacts health.

One difficulty is that controlled experimental studies for long-term outcomes like adult health are impractical, and this means we rely on observational studies. However, because background socio-economic characteristics are key drivers of education, confounding is a major issue in observational studies that is difficult to account for [2,3] and because those attending different types of school will differ it may be their background rather than schooling that affects adult health.

Natural experiments provide a way around this by controlling for confounding more through design rather than statistical control. Historically, state selective schools (grammar and senior secondary in England and Scotland, respectively) chose students based on scores from tests given at the end of primary schooling, around age 11 [5]. This opens up the possibility of a natural experiment, as those with similar test scores who fell one side or the other of the cut-off are likely to have similar range of background characteristics, but attended different schools as if randomised.

Such a situation is ideal for a regression discontinuity study. Previous research has used this method with the Aberdeen Children of the 1950s cohort to assess selective schooling's impact on economic outcomes [4, 5]. It showed that selective schooling increased the length of education, the likelihood of getting higher qualifications, and the likelihood of having a professional occupation. However, selective schooling only slightly increased income for women and did not increase income for men [4, 5].

The Aberdeen Children of the 1950s cohort is a large population with extensive early-life records of schooling and socio-demographics, and follow-up later in life. This allows evaluation of the natural experiment in schooling assignment, and here we propose to analyse the effect of this assignment on long-term health.

Rationale

This study fits closely with the remit of Administrative Data Centre-Scotland (ADRC-S) as it makes uses of a historical cohort linked to contemporary administrative data to explore a key social determinant of health. It also fits with the aims of the inequalities and policy programmes of the Medical Research Council/Chief Scientists Office Social and Public Health Sciences Unit, University of Glasgow as these have a focus on using natural experiments to understand policy driven social determinants of health and health inequalities.

1718-0212 Professor Matthew Bown
The United Kingdom Aneurysm Growth Study

The United Kingdom Aneurysm Growth Study aims to find out more about abdominal aortic aneurysms (AAA). This is a condition where the main artery in the body swells up and there is a risk of it bursting (rupture) as a result. Not all AAA require treatment however. There is only a risk of rupture if the AAA gets very large. AAA are often found when they are small when they are not dangerous but some AAA will increase in size and if this occurs the only available treatment to prevent complications is surgery. Very little is known about why some AAA grow and some do not. Also, AAAs can grow at different speeds and little is known about this either.

The aim of the UK Aneurysm Growth Study is to gather a large enough collection of information about men with AAAs to be able to find out why AAA grow. In total, the Study will include data from around 5000 men with AAAs.

The UK National Health Services offer screening for AAA to all men in the year of their 65th birthday and around 3000 men are diagnosed with AAA each year. Through these programmes, men with AAA will be recruited into this study. Men with AAAs will be sent a letter of invitation to join the study by their national NHS screening programme. If men agree to participate in the study they will be asked for their permission to allow the study team to send them research questionnaires, have blood and urine samples taken for the study and to allow the study team to have access to their medical records.

Study participants will have blood and urine samples taken on two occasions and will be asked to fill in questionnaires about their health every year for 5 years. The study team will use information provided by the men in the study to obtain information about their AAAs from their national screening programmes and also get updates on their health status from their NHS.

Through this study more detailed information about why and how aneurysms occur and grow will be found out, potentially leading to alternative ways to care for patients with AAA or even drug treatments for small aneurysms - and avoiding the need for surgery in those with AAA. The study will also enable many other diseases of older age to be studied as a by-product of recruiting many participants without AAAs and following these people over time.

1718-0215 Fiona Russell

Scottish Cancer Registry and Intelligence Service (SCRIS): Developing the National Reporting of Systemic Anti-Cancer Therapy/ChemoCare data

The Innovative Healthcare Delivery Programme (IHDP) is working to ensure that Scotland makes better use of its cancer data. NHS NSS, jointly with IHDP, has started a programme of work to deliver a Scottish Cancer Registry and Intelligence Service (SCRIS) which will include accessing and reporting Nationally against datasets not previously available centrally.

Existing Systemic Anti-Cancer Treatment (SACT) data collected by NHS Boards is to be sourced as part of the SCRIS developments to allow pan-Scotland benchmarking and comparative analysis and reporting to be undertaken. These data are collected locally in an operational system called ChemoCare.

NHS Scotland has 3 regional cancer networks; North of Scotland Cancer Network (NOSCAN), South East Scotland cancer Network (SCAN) and the West of Scotland Cancer Network (WoSCAN). Within NOSCAN there are three separate instances of the ChemoCare system managed by Grampian, Highland and Tayside NHS Boards. SCAN and WoSCAN each have a single region-wide system configured in a ‘hub and spoke’ arrangement, with the hubs located in NHS Lothian and NHS Greater Glasgow and Clyde respectively.

The major challenge is the collating of comparative data from multiple disparate data sources which, although using the same system (ChemoCare), are held on systems with different configurations and operational practices. Each of the 5 instances of ChemoCare record its data against locally managed definitions. For national reporting it is necessary to map local data to national definitions.

NSS worked on a proof of concept with SCAN and WoSCAN using anonymised patient level data, approved by their local IG contacts, and have established a reliable means of accessing and standardising these data remotely using data virtualisation (DV). An evaluation is attached (Attachment 1). The DV approach taken fell in line with the overall NSS Business Intelligence Technical Strategy and made use of DV evaluation software provided by Denodo.

This application is seeking approval to build on the proof of concept and access patient identifiable SACT data from all 3 Regional Cancer Networks using DV, initially, to build a suite of national comparative reports (Attachment 2). Access will also be required to NRS Deaths details to produce the 30-day mortality report as part of the suite of reports. These reports and data will be incorporated into a SACT data dashboard within a Cancer Intelligence Platform being developed as part of SCRIS. The SACT data dashboard will be made available to NHS Board staff. Access to the SACT data dashboard will be password protected on an individual basis, available via an N3 connection only.

1718-0221 Allan Mcleod
Linking Scottish Infected Blood data (PSD) to Hep C data (HPS

Contamination of blood for transfusion and blood products (clotting factors derived from blood to treat haemophilia and associated clotting disorders) with blood borne viruses such as hepatitis C (HCV) in the 1970s and 1980s was a significant public health issue. While heat treatment of blood products and screening of donated blood (established in 1987 and 1991, respectively) have eliminated this as a transmission route in Scotland, there remain hundreds of individuals who were infected through blood and blood products and still alive.

In 1988, the Macfarlane Trust was established to provide support to people with haemophilia who were infected with HIV as a result of NHS blood products, their families and dependants (a large proportion of the people were also infected with HCV). The Eileen Trust provided similar support for those infected with HIV through blood and blood products but excluding those with haemophilia. In 2004, the UK government established the Skipton Fund. Through this, those infected with HCV from NHS blood or blood products and still living were eligible to receive ex-gratia payments. This support depended on the severity of the recipient’s liver disease: Those infected with HCV but without advanced liver disease (stage 1) receive annual payments considerably less than those with advanced disease(stage 2)Also both groups receive one off lump sum payments. In 2011, the Caxton Foundation provided additional support to those who had received Skipton payments. This included grants, winter fuel payments, financial support during treatment, and other support.

From April 2017 the Scottish Infected Blood Support Scheme took over from the existing UK schemes in providing support for Scottish beneficiaries. This scheme is managed by National Services Scotland (NSS). The new scheme has been introduced as a result of the Scottish Financial Review commissioned by the Scottish Government. The financial review assessed the strengths and weaknesses of the previous UK-wide ex gratia payment schemes for HIV/Hepatitis C infection via NHS treatment and any unmet need which could be addressed by an improved scheme(s).

One key recommendation of the Financial Review was:
“The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review to create new criteria based on health impact, rather than focusing predominantly on liver damage.”

A short-life working group was established to take forward an evidence-based review of health impacts caused by Hepatitis C to examine whether new criteria should be established, based on broader health impacts caused by the virus. This project will inform this review.

1718-0225 Roz Pollock
Maternity Care Survey

The purpose of this application is to ask permission for NRS to access the Statutory Register of Births, to select a representative sample of mothers. Names and addresses of selected mothers will be shared with the Scottish Government (SG) so we can administer the Maternity Care survey by post using an approved contractor. The Scottish Government holds the contract for the survey administration and will be the sole Data Controller for the survey data.

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

The Maternity Care survey is a vital component of this survey programme. It will provide high quality and comprehensive information on women's experiences of maternity care in 2018, 2020 and 2022 and will repeat the surveys undertaken in 2013 and 2015. The results will provide benchmark data for NHS Boards and will inform the implementation of the recommendations in the Forward Plan for Maternity and Neonatal Care in Scotland. Understanding the experiences of women who recently gave birth and used maternity services is an essential part of providing high quality maternity care. While some aspects of NHS care quality will continue to be regularly monitored through a range of methods, many important aspects of quality can only be assessed by asking those who have recently used maternity care services to describe their experiences. Through listening to the experiences of these women, maternity service providers and policy makers can understand what works well and where and why services are falling short of the high quality care that all mothers and babies require.

In 2015, 5,025 women were invited to participate in this survey and of those, ~41% returned completed questionnaires. This high response rate indicates positive engagement and desire of these women to provide feedback on their experiences and contribute to service improvement. With most reporting very positive experiences overall, we are committed to on-going monitoring and identifying key areas for improvement.

The outputs from the proposal will be a range of analyses available at different levels of geography, containing robust and comparable information about women's experiences of the care that they've received. This analysis will be provided by the SG via an interactive dashboard (using Tableau) which will allow local areas to interrogate the data in different ways to meet their particular needs. This will provide vital evidence locally and nationally to inform service improvement, leading to improved outcomes for mothers. Info graphic survey interpretations suitable for a lay audience will be available both for future and previous projects (see Annex C (2016)).

1718-0245 Dr Diane Swallow

Improving diagnostic and care pathways in progressive supranuclear palsy (PSP) and corticobasel degeneration (CBD)

No lay summary available

1718-0249 Professor Jennifer Kurinczuk

National Perinatal Mortality Review Tool (PMRT)

The number and rate of babies who are stillborn or die soon after birth in the UK places us in the bottom third of comparative rates across Europe. To reduce our baby death rate and prevent the deaths which are avoidable we need a better understanding of why babies die during pregnancy and soon after birth.

Local reviews of care when deaths occur have the capacity to lead to a better understanding of where care could be improved to prevent future deaths and the capacity to improve the information given to parents when their baby dies This is so they have a better understanding of what happened and why, and also information about whether this has implications for future pregnancies. Evidence suggests that relatively few reviews of baby deaths are conducted and, when they are carried out, the quality is highly variable and range from excellent to extremely poor.

The MBRRACE-UK collaboration is commissioned to collect the national information about all deaths of babies during pregnancy and in the month after they are born (this is called perinatal mortality surveillance). The MBRRACE-UK/PMRT collaboration, led by MBRRACE-UK, has been commissioned to develop and support the implementation of the National Perinatal Mortality Review Tool (PMRT) on behalf of the Department of Health (England) and the Welsh and Scottish Governments. The aim of the PMRT is to provide a method of structured review for clinical staff in Health Boards undertaking review of the care provided when a baby is stillborn or dies soon after birth. It is intended to improve the quality of reviews which are carried out and thus improve the information given to parents and the learning to prevent future similar deaths.

The PMRT is wholly integrated with the MBRRACE-UK perinatal mortality surveillance data collection in order to minimise the burden on clinical staff and thus maximise its uptake; both systems are concerned with the same group of babies and have the goal of reducing the number of babies who die and thus the national perinatal mortality rate.

Local reviews should be carried out as part of standard clinical care and staff in Health Boards do not require the consent of parents before a review is undertaken although it is good practice to tell them that a review of the care they and their baby received will be undertaken. We will also encourage staff in Health Boards to seek parents’ perspective of their care and any concerns they have about the care they received. Although the PMRT is not a data collection tool per se, during the process of using the PMRT to conduct local reviews of care, identifiable information and clinical data will be collected about individual mothers and their babies. PBPP approval is sought specifically to enable this information to be held without parental consent on the MBRRACE-UK/PMRT system which is stored on the secure MBRRACE-UK servers.

1718-0254 Dr David McDonald

Emergency Surgery Pathways

This proposal is an amendment/extension to on-going data collections (1617-0082) and (1617-0294) which have proven to be a successful model for establishing standardised pathways of care within two surgical specialities nationally. Due to this success there has been strong interest from other surgical specialities who wish to adopt the same model to establish a standardised pathway of care and the Scottish Government (SG) are keen to facilitate this.

To continue this success SG intend to spread the same methodology and aims to emergency surgery specialities. This will involve developing a national pathway of care with clinical teams across Scotland along with a clinically relevant minimal dataset. As was done with the previous data collections the aim is to standardise clinical pathways of care, develop shared learning of best practice and to improve patient care across all sites. This will help to reduce and address the wide variation in pathways and outcomes currently found in emergency surgery specialities. This programme is very much aligned with the Clinical Strategy for NHS Scotland and the most recent CMO report on ‘Realistic Medicine’ and has support from the CMO office for spreading and adopting the model of care across NHS Scotland.

The initial focus will be on emergency laparotomy surgeries where at present no NHS Scotland hospital has a planned pathway of care. The intention will be to continue to spread this methodology to other surgical specialities We have found that from the recent data collections for colorectal surgery (1617-0082) and Caesarean section (1617-0294) that where a standardised pathway of care has been adopted nationally there have been a number benefits. For example, greatly reducing variation in the patient pathway and therefore providing an equitable service to patients. Boards used the national data to understand where variation exists and have addressed this by sharing best practice by way of visits to exemplar sites. Patient outcomes have improved with length of stay reducing whilst the numbers of surgeries have increased. Importantly, patient safety has not been compromised as a result of achieving this and boards review and discuss this at regular local project board meetings as well as at quarterly national meetings.

Through collection of the data across all participating sites in the previous data collections, a number of interesting and novel findings have arisen. One example of this is that when patients receive all elements of the post-operative pathway as designed they have a statistically significant reduction in hospital stay and complication rates. However as there are a number of elements of the pathway implemented simultaneously it is unclear what may be driving this improvement. Therefore, by setting up a National Publication group of clinical leads from across Scotland we aim to further investigate the findings of the data to improve patient care. This has only been possible to look at due to the large number of patients’ data being collected around NHS Scotland. It is anticipated that the formation of a Publication group would be undertaken for each speciality specific database to further understand and improve patient care across Scotland resulting in sharing of best practice and further standardisation of pathways for specific procedures.

1718-0261 Ross Dolan

The relationship between body composition, tumour activity, functional activity and survival in patients with advanced cancer

Prognostication is a core clinical skill fundamental to the clinical management of patients with advanced cancer. The recent Inflammatory Biomarkers in Prognosis in Advanced Cancer (IPAC) study was a multicentre UK based study of over 300 patients, examining the relationship between biomarkers and prognosis such as C-reactive Protein (CRP) and components of the differential white cell count in patients with advanced cancer. In addition to these markers weight loss has been used as an indicator of such nutritional decline and poor prognosis with associated reduction in functionality. While more patients who are now being diagnosed with cancer are obese it still holds true that significant loss of lean muscle mass has an associated deleterious prognostic effect. The ability to use routine CT scans to measure body composition has resulted in an explosion of interest in the ability of skeletal muscle mass to predict outcomes in patients with cancer. For example, the disproportionate loss of lean tissue has been associated with chemotherapy toxicity, increased risk of post-operative complications in operable disease and poorer cancer specific and overall survival. In patients with advanced cancer, cachectic muscle loss has been associated with marked deterioration in functionality which not only affects patient prognosis but also quality of life. One of the proposed driving forces behind this systemic activity has been tumour metabolic activity which can now be accurately assessed using PET-CT scans.

Therefore the aim of the proposed study is to examine the relationship between the systemic inflammatory response, tumour activity, body composition, functional activity and survival in patients with advanced cancer who have already been included in the recent IPAC study. This will be carried out by retrospectively and tumour activity will be assessed using PET-CT scans and image analysis. Muscle loss will be assessed using standard CT-scans and image analysis. Functional activity has been assessed using the 2min walk test/timed get up test and finally inflammation with modified Glasgow Prognostic Score/Neutrophil Lymphocyte Ratio (mGPS/NLR) and muscle quality with plain CT scans..

1718-0262 Dr Kathryn Johnson

Surveillance of Foetal alcohol syndrome in the United Kingdom and Republic of Ireland (SFAS-UKI)

Fetal Alcohol Syndrome (sometimes known as FAS) is a rare condition which occurs when the developing baby is exposed to alcohol in the womb. Alcohol can cross the placenta into an unborn baby's blood stream. The exposure of an unborn baby to alcohol can then affect the development of the brain, leading to challenges in learning and development. Alcohol can also affect the development of other parts of the unborn baby’s body, particularly the face.

The exact amount of alcohol that cause FAS is unknown but FAS can be completely prevented by avoiding the use of alcohol in pregnancy.

In addition to the specific effects on growth, brain and facial development, babies and children affected by FAS can sometimes have:

- Hearing problems
- Speech problems
- Seizures (fits)
- Liver problems
- Kidney problems
- Heart defects

In the UK and Ireland we currently know little about the exact numbers of babies and children affected by FAS and the services they require to support them throughout their childhood. The aim of the study is to answer both these questions and ultimately improve the treatment and support we can provide to babies, children and families affected by FAS.

1718-0264 Eleanor Lumley

Complex lower limb trauma: Understanding the outcomes and health services resource use post-reconstruction.

Lower limb trauma continues to be a challenge for the reconstructive surgeon and the multidisciplinary team involved. Such extremity injuries often result from high-energy trauma and may be described as complex, severe or potentially life-threatening injuries. Open fractures pose greater issues for both the surgeon and patient, with increased risk of amputation, extensive soft tissue loss, deep seated infection and need for re-intervention. The incidence of open long bone fractures is approximately 11.5 per 100,000 persons per year, the majority of which occur in the tibial diaphyseal region.

Optimal care for patients with severe lower limb trauma is centred on combined management by orthopaedic and plastic surgery – so called 'orthoplastic' teams. Therefore, early transfer to a specialist, major trauma centre is recommended. The publication of British Orthopaedic Association Standards for Trauma (BOAST) guidelines for complex, open lower limb fractures further reinforces the essential input of the plastic surgeon in the initial stages for simultaneous definitive fixation and best achievable soft tissue coverage. This improves overall surgical outcome, reducing the need for additional surgeries or the alternative, limb amputation and reductions in post-operative complications including non-union, infection and osteomyelitis.

The medium- and long-term health services resource use following definitive limb reconstruction and throughout long term follow up remains unclear. A better understanding of patients' need could help to improve the way in which care is delivered to these patients. In trauma patient populations, analysed in large prospective epidemiological studies, 80% of patients exhibited reduced quality of life, compared to that of the normal adult population, largely attributable to the persistent and significant lasting physical disability. Castilo et al. highlight the knowledge gap regarding the use and the unmet needs of physical therapy and rehabilitation services following lower extremity trauma, vital components for long term success and favourable outcomes post-reconstruction. Chronic pain is recognised as a major issue following complex extremity injuries, and there is interest in evaluating new treatments, but patterns of who develops chronic, and when, are poorly understood.

1718-0267 Anne-Marine Lenzotti

S-AVANT. Follow-up to the AVANT study up to 8 and 10 years (median follow-up) in patients with colon carcinoma

This S-AVANT study will be an extension at 8 and 10 years median follow-up of patients previously included in the AVANT trial.

The AVANT study (ROCHE Laboratory initiative - December 20, 2004 to June 8, 2007.) assessed in patients with resected stage II/III colon carcinoma whether bevacizumab provides a benefit when added for 24 weeks to the currently most effective treatment, i.e. FOLFOX-4, as well as XELOX as third arm with capecitabine as an oral fluoropyrimidine, followed by 24 weeks of bevacizumab alone.

The AVANT study aiming at demonstrating superiority of bevacizumab in combination with FOLFOX-4 or XELOX compared to FOLFOX-4, did not show prolongation of DFS at 3 year when adding bevacizumab to chemotherapy in resected stage III colon cancer.

However, more relapses and deaths due to disease progression have been observed in both bevacizumab arms. A more prolonged follow-up is necessary to assess overall survival and to evaluate long-term results and safety.

The aim of the S-AVANT study is to update data and assess long term results of the AVANT study in terms of efficacy and safety.

Participating in this trial does not involve any medical procedure, visits to site or additional treatments for participants. Participants will be identified by the screening/randomisation number assigned in the previous AVANT trial. Participant initials and date of birth will be used by the Investigator site staff (clinical care team) to allow reconciliation with the previous study, as the screening/randomisation number is not robust enough for the clinical care team to identify previous AVANT study participants with any certainty. It does not impact participants' medical care and poses no further risk to safety or privacy.

To avoid a specific visit to the site, the Investigator or qualified, designated member of the Investigator's clinical team will attempt to contact the potential participant by telephone to explain the purpose of the study, minimising the burden for participants by avoiding a visit to the study centre when they are not due for a normal clinic visit as part of their routine care. The Investigator staff will discuss the collection of data with the participants without pressure, giving them the background to the study and an explanation about why this study is being conducted. An invitation letter will be sent to the patient as a follow up to the telephone call. The Investigator will also provide the Participant Information Sheet to ensure the participant has understood the details and requirements of the study. No data will be collected from the patient notes until they have agreed to this data collection and signed the appropriate consent form. Patient dissent will be recorded in the patient notes and on a specific Patient Contact Form.

Deceased and Lost to Follow-Up Patients

Due to the nature of the disease, there may be participants from the previous AVANT study who are deceased or lost to follow-up and therefore obtaining consent would not be possible for those participants. CAG has given approval to collect and process confidential patient information without consent for this cohort in England and Wales and we are seeking the same approval in Scotland.

1718-0270 Lucy Lennon
SMR104 – British Regional Heart Study

The British Regional Heart Study (BRHS) is an observational, prospective study of the causes heart disease and stroke in British men, which aims to explain variations in disease risk. Cardiovascular disease (CVD) remains a major cause of death and disease, particularly at older ages (>70 years). The goal of the research is to find ways in which we can prevent or postpone the onset of heart disease in people in their 70s and 80s – a time of life when heart disease is particularly common. If we can prevent or delay the onset of heart disease in later life, this could help a considerable number of people to live longer without symptoms or disability resulting from heart disease – allowing older people better quality of life and greater independence.

The study, set up in 1978, recruited a cohort of 7735 middle-aged men (40-60 years) from one general practice in each of 24 British towns, participants have been flagged at NHSCR Edinburgh & Scotland since recruitment. The Scottish towns included in this study are Falkirk n= 309, Ayr n=301, Dunfermline n=352.

The BRHS is one of very few prospective population studies with in-depth information on a wide range of relevant factors (health-related behaviours, social factors, biological risk markers) in later life as well as in middle age, with detailed participant examinations at 40-59, 60-79 and 72-91 years. Continued detailed follow-up of cohort members for CVD mortality, morbidity, and disability (crucial for interpreting the results of the 60-79 year and 72-91 year examinations) and for health-related behaviours (particularly physical activity and sedentary behaviours) will allow us to investigate the causes, prediction and prevention of CVD risk in later life.

Continuing follow-up of the surviving men of the BRHS cohort for mortality and for cardiovascular morbidity and disability is requested. We seek to continue to use three established methods (mortality flagging, General Practice record reviews and questionnaires to study participants) to follow up surviving participants for all-cause mortality, cardiovascular disease and disability. The annual reviews of participants' General Practice records will provide information on (i) new major CVD diagnoses (myocardial infarction, angina, stroke, transient ischaemic attack); (ii) reports of previous investigation and invasive treatment of CHD; (iii) new cases of heart failure and atrial fibrillation,; (iv) diagnoses of peripheral arterial disease; (v) reports of deep venous thrombosis and pulmonary embolism; (vi) diagnoses of diabetes, (vii) dementia. Reports of key diagnoses (myocardial infarction, stroke) will continue to be verified in accordance with World Health Organization criteria using additional information on clinical history and investigations obtained. In the case of heart failure relevant information on clinical, radiological, echocardiographic and cardiac catheterization procedures will continue to be systematically sought from medical records. Brief participant questionnaires will be sent annually to verify new cardiovascular disease and diabetes and the development of physical disability and its causes. This continuing follow-up information will be linked to BRHS re-examinations at 60-79 years and at 72-91 years, will allow us to study the later life determinants of CVD.

1718-0271 Dr Colin Tilley
Pilot new platform for workforce planning

The aim of the National Workforce Plan is to get "the right people into the right place, at the right time, to deliver sustainable and high quality health and social care services for Scotland's people."

To support this aim, the National Workforce Plan recommended integrating statistical, demographic and labour market information on the NHS Scotland workforce to build the evidence Boards will require in future. In particular, the plan made the following three recommendations:

1. NHS Education for Scotland (NES) will provide proposals to bring together existing data sources in a new supply side "platform" by Autumn this year. This will consider the NHS Scotland workforce and how this fits wider social care and local authority needs in the context of integration.
2. NES will work alongside stakeholders to bring together relevant data sources; analyse and align them to better inform workforce planning; and work to determine the data required for effective decisions on workforce and improving analysis of future demand and supply and the "pipeline" between education and employment. This work will be delivered in Autumn 2017, while being responsive to Parts 2 and 3 of this Plan and the wider, whole system approach required for the future.
3. NES will lead development of a minimum standardised dataset with potential to use across different sectors, with agreed data collection and collation parameters. It is important that this work aligns with the rollout of e:ESS across NHS Boards, where much work has already been undertaken to ensure a consistent dataset on the NHS workforce. This will require a phased approach.

An analytical framework for workforce planning has recently been set out in two complementary papers (https://human-resources-health.biomedcentral.com/articles/10.1186/s12960-016-0155-2, https://human-resources-health.biomedcentral.com/articles/10.1186/s12960-016-0168-x) that aimed to inform the development of the WHO's global strategy on human resources for health (HRH)](http://www.who.int/hrh/resources/pub_globstrathrh-2030/en/).

The framework describes the demand for HRH as a function of the health and social care objectives of the system, the services that deliver these outcomes, the combination of inputs such as staff, facilities, technology and medicines that deliver these services, and the cost of these inputs.

The framework describes the supply of HRH as a function of three linked stages: education, registration and participation.

NES proposes to bring together existing data sources on education, registration and participation to provide a supply side platform to better inform workforce planning.

Specifically, NES proposes to transfer education, registration and participation data to the Microsoft Azure Data Lake, which securely stores data in the cloud (see attached risk assessment).

Data on education, registration and participation will allow workforce planners at local, regional and national level to develop a clearer picture of the supply of HRH.

This application seeks approval to transfer an extract of NHS Scotland workforce data to the Microsoft Azure Data Lake to support workforce planning in Scotland.

Initially only the people listed in Section 1 will have access to these data. But the intention is that local, regional and national workforce planners will have access to these in due course.

1718-0275 Heather Clark
The Aberdeen Children of the 1950s study

The Aberdeen Children of the 1950s (ACONF) research database provides a unique opportunity to advance research concerning influences on health throughout life and across generations.

The ACONF research database is made up of information collected both in a survey carried out on all primary school children in Aberdeen in 1962, and a follow up of these children as adults by questionnaire in 2001. This information includes school test and medical records, data extracted from their birth records and some information on their social circumstances. In later life, the 2001 questionnaire asked about their circumstances including health and wellbeing; lifestyle characteristics (e.g. smoking and drinking); employment and family. This data has also been linked to data describing the environment in the 1960s (i.e. from the census of the time) and to descriptive data relating to the relevant primary schools attended.

The cohort is based in Aberdeen, but the information has been used extensively by researchers investigating life course epidemiology i.e. the influences, both biological and sociological, in early life and even across generations that affect later health and wellbeing. The data has also been used collectively with other cohort information, for example to review the association between size at birth and risk of type II diabetes in later life. There is a continuing value in maintaining the cohort in the long term, for example researchers investigating cognitive ageing have already shown an interest in the cohort data.

1718-0277 Dr Kieran Docherty

Trends in the incidence, morbidity and mortality of heart failure associated with myocardial infarction in Scotland between 1986 and 2016.

Heart attacks are a common health problem in the United Kingdom (UK). In the last 30 years, the risk of dying from heart attacks has been reduced through the use of medications and interventions such as angioplasty (using balloons and stents to open up blocked or narrowed heart arteries).

Despite these advances, a proportion of people who survive heart attacks sustain damage to their heart muscle. This means that the heart does not pump blood around the body as efficiently as it should, and can, over time, lead to symptoms such as breathlessness, fluid retention and reduced exercise capacity. This is known as heart failure. The development of heart failure also increases the risk of death in the years following a heart attack.

The nature of heart attack presentations has changed over time, resulting in a difference in the characteristics of the population at risk of developing heart failure following a heart attack. Additionally, the degree of comorbidity in an increasingly elderly population who survive heart attacks may play a role in the risk of developing heart failure. The complex interplay of these factors has led to uncertainty regarding the risk of heart failure post heart attack in the modern era of widespread access to effective life-saving heart attack treatments and interventions.

There is conflicting evidence on both the rate of incidence of heart failure following heart attacks over time and its association with mortality. Given the high socio-economic impact of heart failure, we feel it important to provide evidence to help the identification of those at highest risk of heart failure post heart attack and identify those who may benefit from investigation of novel treatments to reduce the risk of heart failure and its associated morbidity and mortality.

We propose to describe the incidence and mortality trends in heart failure associated with heart attacks in Scotland between 1986 and 2016.

1718-0279 Dr Markus Gehrsitz

Education and Health – Is there really no Causal Relationship?

A positive correlation between education and health is well established in the literature. More educated people tend to be healthier. However, it is doubtful whether this is indeed a causal effect. One reason is that determinants of education are often simultaneously determining health. Take the case of inert self-control. Self-control is an asset in both gaining education and health, might be the defining factor for both, and might thus render the positive correlation between education and health spurious. In a similar vein, environmental factors such as parents' socio-economic status are confounding. For instance, more resourceful parents tend to invest more into both their children's health and their children's education. So again, a third factor - in this case parents' socio-economic status - overlaps with any direct effect of education on health, making it impossible to gauge the role educational attainment itself plays in improving health.

Correlations are, however, not a useful basis for designing public policy. If education indeed has a causal effect on health, education policies might be a better tool to promote health than additional health care spending. On the other hand, if the correlation between health and education is largely spurious, policy makers should allocate more resources towards health care and prevention. In other words, providing an answer to this research question is of major interest to policy makers who have limited resources to work with. That is the goal of this study. Moreover, my research will help inform the discussion about extending the minimum school leaving age.

The proposed study aims to estimate the causal effects of education on several health outcomes. It builds on a natural experiment that enables me to distinguish correlation from causation, namely changes in compulsory schooling laws. In the UK the minimum age at which children can leave school was raised from 15 to 16 on September 1st 1972 (and from 14 to 15 in April 1947). As a result children who were born on or shortly after September 1st 1957 could not leave school until part way through grade 10. Students born on or before August 31st 1957, on the other hand, were free to leave school as soon as they turned 15. As a result the slightly later born cohort of students obtained significantly more education than the otherwise identical cohort born just before the Sep 1st cut-off. Intuitively, the changes in compulsory schooling laws created a natural experiment by assigning students to the right of the cut-off to the treatment of an additional year of education while automatically generating a control group of students (those to the left of the cut-off) that is identical in terms of socio-economic background, etc.. This approach follows Clark and Royer (2013) who applied this methodology using Health Survey for England data.

1718-0286 Fiona Mitchell

Meeting the health needs of looked after children in Scotland: an exploratory study

Local authorities in Scotland have a responsibility to provide support for vulnerable children and young people, known as ‘looked after children’ (Scottish Government 2014). A child may become looked after for a number of reasons; including neglect, abuse, complex disabilities which require specialist care, or involvement in the youth justice system. A large proportion of these children are looked after away from home, and may be cared for by foster parents, friends or relatives (e.g. a kinship placement), or in a residential home or school. There is evidence that looked after children have higher rates of physical, emotional and behavioural health problems yet there is limited information on immediate and long-term health outcomes. This small scale project aims to examine looked after children’s use of unscheduled health care comparing those living at home with parents and those living away from home in, for example, kinship care, foster care, residential care. In order to better meet the health needs of looked after children and promote effective health interventions it is important that health information, routinely gathered on all children in Scotland, can be differentiated for looked after children. At the moment there is no robust methodology to permit this type of analysis and this hinders understanding of the needs of this vulnerable population. This project therefore also will examine the most privacy-protecting method of linking looked after children’s health data.

1718-0298 Nicola Starkey

CAHMS Rejected/Redirected Referrals Audit

Action 18 of the Scottish Government Mental Health Strategy 2017-2027 committed to carrying out an audit of Children and Adolescent Mental Health Service (CAMHS) “rejected/redirected” referrals and acting upon its findings. This action sits within the overall context of the Mental Health Strategy 2017-27 (http://www.gov.scot/Resource/0051/00516047.pdf), which sets out a raft of work to improve the experience of children and young people (CYP) using CAMHS.

There has been concern from a range of individuals and organisations about the number of rejected/redirected referrals to CAMHS Tier 2, 3 and 4 services, and about what happens to those children or young people. Currently across Scotland around one in every 1000 children and young people’s referrals are ‘rejected/redirected’ by services as on September 2017.

The Mental Health Access Improvement Support Team (MHAIST) will take forward a quantitative audit of CAMHS data in a minimum of four NHS Boards for this pilot (seven have agreed to participate). The audit may be extended to cover all Health Boards at a later date and an amended PBPP application will be submitted when required.

The MHAIST analysts, whom are based at the included pilot Health Boards, will collate the required data items from data already captured at their Health Board during February 2018 before sending it to the ISD-based core team MHAIST analysts via NHS Mail for analysis and reporting at the end of the data collection period. There will be no requirement to contact the patients or their families during the audit.

The data will be sent as either a CSV or Excel file with the data items CHI, Postcode and Sex removed and a unique study ID generated for each patient before being submitted to ISD. The file containing the study IDs and the previously removed data items will then be sent as a separate email. The two files received will be stored separately in a designated secure folder on the stats drive at ISD and will be used for analysis and reporting by the named ISD-based core team MHAIST analysts.

1718-0300 Dr Deborah Kinnear

Older parent carers health and its reciprocal effect on their ageing offspring with intellectual disabilities: a record linkage study

Scotland's Census 2011 reports that there are 26,349 (0.5%) people with intellectual disabilities (5,234 children (0.6%) and 21,115 adults (0.5%)) who reside in Scotland. Of this, 12,237 people with intellectual disabilities (an individual with an intellectual impairment and impaired social functioning which started before adulthood, with a lasting development) live with parent carers. It is estimated that 25% (n=3,000) of these individuals will have an older parent carer (60+ years)*. An increasing number of parents are continuing to care for their son or daughter with intellectual disabilities over a prolonged period of time. This is due to improvements in medical technology, health care, nutrition and the movement away from institutional to community care. Parent carers and their offspring with intellectual disabilities have a complex set of individual and joint health and care needs, which become increasingly challenging with age. While carers experience satisfaction with their caring role, small scale studies suggest stress is also common in these relationships. Those providing care over a prolonged period of time are at particular risk of poor health, and both mental and physical health are likely to deteriorate the longer the carer has been caring. People with intellectual disabilities also experience high levels of physical and mental health problems and die 20-25 years earlier than other people. Surprisingly little attention has been paid to the physical and mental health of older parent carers and the health of their ageing offspring with intellectual disabilities, including reciprocal effects of poor health, and the factors that compound or mitigate against it. The dearth of empirical evidence that explores inter-relationships between the health of older parent carers and their ageing offspring with intellectual disabilities presents a barrier to understanding the complex factors that produce differential health outcomes.

Scotland's Census 2011 is unique among the UK's 2011 Censuses in including a question on 'intellectual disability' (also known as learning disability**) and specifically differentiating this from learning difficulties such as dyslexia and dyscalculia. The Northern Ireland Census did not distinguish these conditions, and England and Wales did not include questions on either. It hence provides a unique resource to identify the health of parents caring for a son or daughter with intellectual disabilities.

1. Scotland's Census 2011: the only comprehensive consistent source of national and local data about people, their key characteristics, and housing.

1718-0307 Lee Barnsdale
National Naloxone Programme Monitoring

Information Services Division (ISD) has been requested to perform ongoing monitoring of the National Naloxone Programme which commenced in 2011 (naloxone is a drug used to prevent opioid overdose deaths).

Figures on the number and percentage of opioid-related deaths per annum with a recent prison antecedent have been included in ISD’s annual Naloxone Monitoring report (designated as official statistics) since publication of the first report (on naloxone distribution during 2011/12) in 2012.

Comparable figures on the number and percentage of opioid-related deaths per annum with a recent hospital antecedent have been included in ISD’s official statistics since naloxone distribution in 2013/14 was reported upon in 2014.

In line with the UK Official Statistics Code of Practice, ISD are seeking permission to continue producing these indicators in order that the 2016/17 and 2017/18 reports can be published in the same format as previous years (i.e. including mortality data).

1718-0336 Genevieve Cezard
Ethnic differences in trajectory of health and health decline in Scotland

This project investigates ethnic inequalities in health in Scotland. The literature review revealed a lack of a longitudinal approach to understand how ethnic health inequalities are shaped over time. Few studies have investigated the health trajectories of ethnic minorities and, to our knowledge, evidence is sparse in Europe and not available in Scotland. Furthermore most available research focuses on comparing migrants to non-migrants whereas we hypothesise that the health decline within first generation of migrants will vary by ethnic group.

The healthy migrant effect states that migrants tend to be healthier than those they leave behind in their country of origin and potentially healthier than the people they come to join in their new country of residence. As international data following people across countries is lacking, very few studies, mostly in the US, have managed to test the healthy migrant effect hypothesis (comparing health of migrants to health in country of origin) and most focus on comparing foreign-born to native-born populations within a single country. Furthermore, the longer a migrant stays in his/her country of destination, the more likely this person is to acculturate (assimilate into the native culture) and adopt the health behaviours of the local population.

This project investigates ethnic inequalities in health building on the migrant-health theories of health selection and acculturation by following people’s health over time by ethnic group. It adds to the available evidence by pushing the analysis into looking at the influence of length of residence and migrant generation, period of migrations, age groups and cohorts in addition to a range of potential risk factors for ethnic health inequalities such as socio-economic status (SES), urban/rural indicator, household and neighbourhood indicators of SES and the living environment.