2023/2024 Applications approved by HSC-PBPP to 31st March 2024

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

Application Reference	Applicant	Applicant Organisation	Title of Study	Approved/ Approved with conditions	Level of Approval	Clocked Time (days)
2223-0103 SR171	Heather Clark	University of Aberdeen	Aberdeen Children of the 1950s cohort study – transfer of NHSCR deaths and embarkations	Approved	Tier 1 Panel Meeting	19
2223-0068	Professor Jill Belch	University of Dundee/NHS Tayside	Fourth follow-up of SHHEC Cohort (renewal to 1516-0578)	Approved	Tier 1 Review	39
2122-0095	Elizabeth Thomson	University of Glasgow	Management to Optimise Outcomes in Unstable Coronary Syndromes: a developmental clinical study of management guided by coronary angiography combined with fractional flow reserve (FFR) measurement versus management guided by coronary angiography alone (standard care) in patients with non-ST elevation MI)	Approved	Tier 1 Panel Meeting	14
1920-0040	Helen Wohlgemut	University of Glasgow	The Scale and Burden of Upper Limb Trauma in Scotland	Approved with conditions	Tier 1 Panel Meeting	26
2223-0008	Dr Kirsty Dunn	University of Glasgow	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 Review	12
2122-0143	Professor Vittal Katikireddi	University of Glasgow & Public Health Scotland	Understanding the health and employment support needs of the Scottish working age population	Approved with conditions	Tier 1 Review	10
2122-0224	Dr Emma Russell	University of Glasgow	HEalth And Dementia outcomes following Traumatic Brain Injury (HEAD-TBI)	Approved with conditions	Tier 1 Review	17

2223-0179	Professor Vittal Katikireddi	University of Glasgow	Early Assessment of COVID-19 epidemiology and Vaccine/anti-viral Effectiveness (EAVE II): additional analysis of social and ethnic inequalities	Approved with conditions	Tier 1 Review	20
2122-0015	Claire Lawrie	NHS National Services Scotland	Scottish Acquired Brain Injury Network (SABIN)	Approved with conditions	Tier 1 Review	22
2223-0195	Mr Paul Bradshaw	Scottish Centre for Social Research	Perinatal and Infant Mental Health: Survey of Mothers	Approved with conditions	Tier 2 OOC	26
1617-0235	Dr Mariel Purcell	NHS Greater Glasgow and Clyde	To determine the natural history and healthcare burden of patients presenting with SCI and the demographics, diseases and management factors associated with these	Approved with conditions	Tier 1 Review	18
2122-0038	Dr Andrea Sherriff	University of Glasgow	Evaluation of the national Childsmile Programme	Approved with conditions	Tier 1 Review	21
2223-0204	Professor Andrew Smith	NHS GGC	Epidemiology of Streptococcus pyogenes in Scotland	Approved with conditions	Tier 1 Panel Meeting	11
2223-0047	Dr Mohamed Shoaeir	NHS Lothian	Improving the identification of sepsis in SICSAG data	Approved with conditions	Tier 1 Review	26
2223-0074	Euan Smith	Scottish Government	Cancer Patient Experience Survey 2023/24	Approved with conditions	Full Committee	17
1920-0148	Suzanne Breeman	University of Aberdeen	KAT (Knee Arthoplasty Trial)	Approved	Tier 1 Panel Meeting	24
2223-0189	Dr Claire Tochel	University of Edinburgh	Research using the Scottish Collaborative Optometry and Ophthalmology Network e-research (SCONe) dataset	Approved	Tier 1 Panel Meeting	19
2223-0166 HACE23	Gregor Boyd	Scottish Government	Scottish Health and Care Experience Survey	Approved with conditions	Tier 1 Review	18

2021-0164	Professor Zosia Miedzybrodzka	University of Aberdeen & NHS Grampian	Scottish Participation in UK 100,000 Genomes Initiative (continued from 1516-0377)"	Approved	Tier 1 Panel Meeting	21
2223-0155	Dr Amanj Kurdi	University of Strathclyde	UK Antimicrobial Virtual Registry (Scotland)	Approved	Tier 1 Panel Meeting	6
2223-0127	Professor Lindsay Jaacks	University of Edinburgh	Dietary Intake in Scotland's CHildren (DISH)	Approved with conditions	Tier 1 Review	32
1920-0024	Professor Steve Turner	NHS Grampian	Twenty three year follow up of the SEATON cohort	Approved	Tier 1 Panel Meeting	7
2021-0177	Dr Rebecca Barr	University of Dundee	CLEAR study	Approved with conditions	Tier 1 Review	20
2021-0089	Samuel Hall	University Hospital Southampton NHS Foundation Trust	Risk of Aneurysm Rupture Study	Approved	Tier 1 Panel Meeting	45
2223-0159	Miss Rashmi Mathew	Moorfields Eye Hospital NHS Foundation Trust	Deterioration Of Sight Caused By Delay In Review Or Treatment: Frequency and Morbidity	Approved with conditions	Tier 1 Panel Meeting	19
2122-0230	Dr Louise Marryat	University of Dundee	Maternal health, and preschool developmental, outcomes following opioid use in pregnancy	Approved with conditions	Tier 1 Panel Meeting	18
1718-0098	Alison Roe	NHS England	Inclusion of Scotland onto the Breast and Cosmetic Implant Registry (BCIR)	Approved with conditions	Tier 1 Review	20
2324-0072	Professor Colin Palmer	University of Dundee	SHARE Research Database and Biobank for cohort building and use for research	Approved	Tier 1 Review	17
2223-0217 SMR47	Dr Richard Haylock	UK Health Security Agency	National Registry for Radiation Workers (NRRW)	Approved with conditions	Tier 1 Panel Meeting	23
2223-0168	Dr Sarah Bowers	University of St. Andrews	Healthcare utilisation in the last year of life for people with multimorbidity in Scotland	Approved with conditions	Tier 1 Panel Meeting	13

2122-0053	Professor Graeme MacLennan	University of Aberdeen	THISTLE	Approved	Tier 1 Panel Meeting	9
2324-0064	Dr Tariq Ahmad	Royal Devon University Healthcare NHS Foundation Trust	CLARITY IBD	Approved with conditions	Tier 1 Review	20
1920-0071	Professor Philip Rowe	University of Strathclyde	Robotic Knee Arthroplasty	Approved with conditions	Tier 1 Review	17
2223-0216 SR264	Dr Richard Haylock	UK Health Security Agency	Nuclear Weapons Test Participants Study (NWTPS)	Approved	Tier 1 Panel Meeting	6
1819-0301	Greg Blackadder	National Records of Scotland	Updating the Scottish Longitudinal Study (SLS/CHI lookup)	Approved with conditions	Tier 1 Review	18
2021-0267	Professor Iain Moppett	University of Nottingham	SNAP 3: Frailty, Delirium and Multimorbidity	Approved with conditions	Tier 1 Review	14
2324-0029	Dr Claire Tochel	University of Edinburgh	Predicting ocular disease using the Scottish Collaborative Optometry and Ophthalmology Network e-research (SCONe) dataset	Approved	Tier 1 Panel Meeting	24
2223-0186 SMR104	Ms Lucy Lennon	UCL	SMR104- British Regional Heart Study Renewal	Approved	Tier 1 Panel Meeting	7
2223-0089	Dr Huan Wang	University of Dundee	Multivariable Lung Nodule Malignancy Prediction	Approved with conditions	Full Committee	86
2122-0119	Dr Samira Bell	University of Dundee	Understanding equity of access to best care for people with kidney failure	Approved	Tier 1 Panel Meeting	20
2223-0167	Dr Louisa Pollock	NHS Greater Glasgow & Clyde	Maternal Immunity and Infant Sars-CoV-2 Study	Approved	Tier 1 Panel Meeting	17
2223-0158	Dr Andrea Woolner	University of Aberdeen	Progesterone for Threatened Miscarriage: A prospective cohort study in Scotland – [Shortened title: PROgesterone for ThrEAtened Miscarriage, “PROTEA” Study]	Approved with conditions	Tier 1 Panel Meeting	8

2324-0146	Dr Diana Withrow	University of Oxford	Analysis of survival from blood cancer in the UK	Approved	Tier 1 Review	22
1920-0016	Claire Lawrie	NHS National Services Scotland	Audit of surgical data for patients with a difference of sex development as part of the SDSD network	Approved	Tier 1 Review	21
2122-0060	Lucy Kilburn	Institute of Cancer Research	The HER2-RADiCAL study (Response ADaptive CAre pLan) – Tailoring treatment for HER2 positive early breast cancer	Approved with conditions	Tier 1 Review	25
2324-0138	Carole Morris	PHS	Automated Feasibility Analysis (aka Cohort Discovery Tool)	Approved with conditions	Tier 1 Review	19
2223-0010	Dr Samuel Scott Ogletree	University of Edinburgh	Using secondary data to examine whether a programme of physical and social interventions in urban forests enhances community health and wellbeing: the impact of WIAT interventions on child development	Approved	Tier 1 Panel Meeting	27
2223-0150	Duncan Hill	SIPBS, Strathclyde University / NHS Lanarkshire	Evaluation of the association between physical health comorbidities and opioid dependency using Opioid Agonist Treatment as a proxy in older patients: a retrospective matched population cohort study.	Approved	Tier 1 Panel Meeting	13
2223-0182	John Kerr	University of Dundee	NHS Research Scotland Diabetes Research Register (register): Facilitating mailouts to patients with diabetes with an opportunity to join the Diabetes Register	Approved	Tier 1 Review	36
1920-0230	Dr Eliud Kibuchi	University of Glasgow	Improving Scottish Health Survey-based alcohol consumption estimates for assessing the impact of Minimum Unit Pricing (MUP)	Approved with conditions	Tier 1 Review	44
2324-0105	Prof Michel P Coleman	London School of Hygiene & Tropical Medicine	Global surveillance of cancer survival (CONCORD programme)	Approved with conditions	Tier 1 Review	30
1920-0087	Dr Gavin Simpson	NHS Fife	The development of a prognostic model incorporating patient physiology data into the Hospital Standardised Mortality Ratio predictive model to improve accuracy for predicting risk of death	Approved	Tier 1 Panel Meeting	12
2223-0200	Dr Alexander Doney	University of Dundee	Scottish AI in Neuroimaging to predict Dementia and Neurodegenerative Disease (SCANDAN)	Approved with conditions	Tier 2 OOC	61

Lay summaries for approved applications

1617-0235 Dr Mariel Purcell NHS Greater Glasgow and Clyde

To determine the natural history and healthcare burden of patients presenting with SCI and the demographics, diseases and management factors associated with these

The Queen Elizabeth National Spinal Injuries Unit (QENSIU), situated in the Queen Elizabeth University Hospital in Glasgow, is responsible for the management of all patients with traumatic spinal cord injury in Scotland. These are injuries to the spinal cord that occur due to trauma as opposed to infection or other medical causes. The unit is funded by NHS National Services Scotland. Admission numbers are around 100 annually. When a person sustains a spinal cord injury the closer the injury to the level of the brain (i.e. the higher the level of injury) the higher the demands on Health and Social Services. Care needs of people with a spinal cord injury also increase with age. Furthermore, patients are at lifelong risk of a number of medical complications, although we don't know the incidence of these complications.

In 2015, we published an article on the changes in the types of people sustaining a spinal cord injury in Scotland over the last twenty years. Of interest is the increasing number of older patients with c other illnesses and diseases sustaining a spinal cord injury SCI and increasing numbers of people with higher level injuries who will have significant care needs. Country-specific, as well as cross-country studies are desirable to inform relevant health policy for improved prevention and care. There is no recent survival or post injury data about what happens to people with a spinal cord injury from any U.K spinal cord injury Centre. We would like to know if our Scottish year on year outcome figures are improving, with the outcomes expected to inform care.

The aim of this project is to determine what happens to people with a spinal cord injury in Scotland and the associated healthcare burden, as well as improved understanding of who gets a spinal cord injury in Scotland spinal cord injury, diseases and management factors associated with these.

1718-0098 Alison Roe NHS England

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

The Breast and Cosmetic Implant Registry (BCIR) exists to capture details of all breast implant procedures carried out in both NHS and private providers.

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. it can provide an ‘early warning system’ to help inform an outlier process through the identification of any trends and complications related to specific implants, procedures or related factors e.g. site of treatment.

The PBPP review of the original application 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 worked with the Scottish Government to establish the approvals required to enable this; providers in Scotland commenced submission to the BCIR in January 2019.

Please note that the DPA articles stated above were specified by PBPP themselves, it should be for Scottish IG experts to update this on behalf of PBPP.

NHS England’s legal basis aligns to our statutory functions under the HSCA and therefore these would be:

- Article 9(2)(g) - substantial public interest, supplemented by DPA 2018 Schedule 1, Part 2, paragraph 6 - statutory and government purposes; and/or
- Article 9(2)(h) - the management of health and social care systems supplemented by DPA 2018, Schedule 1, Part 1, paragraph 2 - health or social care purposes.

1819-0301 Greg Blackadder National Records of Scotland
Updating the Scottish Longitudinal Study (SLS/CHI lookup)

The Scottish Longitudinal Study (SLS) is a joint project between National Records of Scotland & University of Edinburgh to create a research ready database which research groups can apply to use via the SLS Research Board for each individual project extract. The SLS is longitudinal and covers the census’ from 1991 onwards as well as vital events (births/deaths/marriages etc), education data and other sub datasets. The database is made up of individuals with 20 semi-random dates of birth which are followed up over time. More information can be found at: Home :: SLS - Scottish Longitudinal Study Development & Support Unit (lscs.ac.uk)

This application is requesting an update to the current linkage methodology which will be managed by NRS indexing allowing the SLS to be updated with additional flags for SLS members showing possible linkage opportunities and allowing identification of new SLS members to be added to the lookup.

1920-0016 Claire Lawrie NHS National Services Scotland
Audit of surgical data for patients with a difference of sex development as part of the SDSD network

The Scottish Differences of Sex Development Managed Clinical Network (SDSD) is looking to audit the surgical data for their patient group. Genital surgery is now less common and often subject to a

‘Freedom of Information’ request. The Scottish DSD Network is not currently able to report on genital surgery performed in Scotland. The network requested surgical data previously from ISD (now part of Public Health Scotland) and on review of this data found that the figures for surgery do not match the expected numbers or types of surgery that the surgeons represented on the network expect. In order to investigate this further, they require the CHI numbers of the patients that have received the surgery so that they can either:

- ensure that surgeries are being coded correctly and work with PHS to retrospectively amend the coding if incorrect
- look at variation in board practice to identify areas of quality improvement to the service
- measure against the approved DSD pathway

An end report containing anonymised data will be produced and will be shared with the network and published on the network website.

The network would aim to collect data for ten full calendar years (2012 to 2022) in order to get a greater view on activity.

1920-0024 Professor Steve Turner NHS Grampian
Twenty three year follow up of the SEATON cohort

The Study of Eczema and Asthma To Observe the influence of Nutrition (SEATON study) was designed to answer the question "does maternal diet during pregnancy affect asthma outcome in childhood?". Between 1997 and 1999, 2000 pregnant mothers were recruited. Follow up of the cohort was undertaken at ages 1,2,5, 10 and 15 years of age. We have shown that mum’s diet during pregnancy was linked to age at onset of asthma symptoms. We have also shown that small size from as early as ten weeks after conception is linked to increased risk for asthma.

Here we seek approval to undertake the 23 year assessment of the cohort, to see if the links we saw at ages 10 and 15 years are still present. As with the 10 and 15 year follow up, we will link the Prescribing Information System Data (PIS) held by the NHS Scotland for the study participants to identify whether they have been prescribed asthma or eczema medication in the 12 months prior to their 23rd birthday.

Birth cohort studies in the UK and world wide have found that not only is asthma linked to factors present at or before birth, but also conditions which are important to the overall health of the population such as anxiety, depression, obesity, high blood pressure and high blood cholesterol levels. In the present application we seek permission to obtain details from PIS of any medications prescribed for anxiety, depression, obesity, high blood pressure and high blood cholesterol levels. This will allow us to see if in the SEATON cohort maternal diet and early foetal size are linked to anxiety, depression, obesity, high blood pressure and high blood cholesterol levels.

1920-0040 Helen Wohlgemut University of Glasgow
The Scale and Burden of Upper Limb Trauma in Scotland

Worldwide upper limb injuries (ULI) are a leading cause of disability. ULI refers to any injury to the bones, joints, muscles, tendons, nerves, or blood vessels of the arm, forearm, wrist, hand, or fingers. It is the most common reason to go to the emergency department. Severe injuries lead to loss of employment, dependency, and a reduced quality of life. Less severe injuries require time away from employment for physiotherapy. This has implications on patients' physical and financial wellbeing. The ULI volume has financial implications to the NHS and the wider economy. Highlighting the need to provide a cost-effective service, and help people return to work and school quickly, and safely.

Patients are treated by different types of healthcare professional, and frequently must travel to receive this care. This can be difficult, frustrating, and costly in terms of travel and time. Before we make improvements, we need to know more. We don't know enough about the people affected, causes, cost, disabilities caused, and results.

Scotland routinely collects data on ULI. We can use this information to plan better services, which will cost the NHS and patients less money and time, whilst ensuring the best care. Our research group specialises in ULI care, data analysis, public health, and economics. Using these data, we plan to work out how to improve organisation of NHS care for patients with these injuries. Our research findings will be shared with healthcare professionals to improve care for people with ULI in Scotland and across the world.

1920-0071 Professor Philip Rowe University of Strathclyde
Robotic Knee Arthroplasty

We have carried out two world leading and unique Randomised Controlled Trials (RCT) of haptic, robotic knee replacement surgery (surgery in which conventional implants are used but the surgeon is guided by a robot) which showed the robotic group functioned better post-surgery. Despite showing patient benefit and clinical benefit of the robotic surgery, uptake in the UK NHS has been slow due to the increased capital cost of the robot and the implants. Uptake in the private sector is however accelerating rapidly. In our original studies we calculated Quality Adjusted Life Years (the years of life remaining for a patient following a particular treatment or intervention multiplied by a quality-of-life score giving the quality of life benefit to the patient) and conducted a simple economic evaluation which showed neutrality between additional costs between the robotic and conventional groups. However, the evaluation did not include the downstream NHS costs after surgery and therefore is not a true reflection of the cost-effectiveness of the robotic procedure. In the original analysis we showed less pain and medication use for the robotic group during their in-hospital stay. These benefits are likely to have continued post-surgery but their extent and the associated cost savings are currently unknown. We would therefore like to request permission to access NHS records to include in our analysis the participant's usage of NHS services after their operation and the associated costs. We would like to know if there is any evidence that downstream, post-surgery the robotic group needed less medication and NHS support and if so the cost savings involved for the NHS. This will assist the NHS determine if the robotic procedure is cost effective and should be more widely adopted.

1920-0087 Dr Gavin Simpson NHS Fife

The development of a prognostic model incorporating patient physiology data into the Hospital Standardised Mortality Ratio predictive model to improve accuracy for predicting risk of death

The Hospital Standard Mortality Ratio (HSMR) calculates the risk of people dying in hospital. It allows the number of people expected to die in hospital to be compared with the number who do die and is used to measure hospital safety and quality. The HSMR uses details such as a person's age, disease and serious health problems, but other information e.g. heart rate is not used.

Hospital computers now collect many details about peoples' observations or 'vital obs' - (e.g. heart rate, blood pressure, respiratory rate). These are routinely collected in the form of the 'Early Warning Score' (EWS) in hospitals.

We will add the EWS vital obs total score to the HSMR to see if they can help explain why some people die in hospital and others do not. This may help improve the accuracy of the HSMR; the HSMR is used Nationally to assess health care performance.

1920-0148 Suzanne Breeman University of Aberdeen

KAT (Knee Arthoplasty Trial)

In the late 1990s, new developments in knee replacements were identified as a priority for research within the NHS. Although they held the promise of better results, the newer forms of arthroplasty were more expensive, and information was needed on their safety and cost-effectiveness. The Knee Arthroplasty Trial (KAT) was therefore funded by the NIHR HTA programme in 1998 to examine the clinical effectiveness and cost-effectiveness of four aspects of knee replacement surgery: patella resurfacing versus no patella resurfacing; mobile bearing versus fixed bearing; polyethylene versus metal backing; and unicompartmental versus total knee replacement. In total, 116 surgeons in 32 UK centres participated in the trial. Between July 1999 to January 2003, 4070 potentially eligible participants were identified and 2352 (58%) gave their consent and were randomised.

Information on knee-related hospital readmissions and further surgery is collected directly from trial participants (postal questionnaires) at 3-months and 1-year post-randomisation and annually thereafter up to 20 years post-randomisation. Collection of outcome data on annual questionnaires is therefore ongoing with the last 20-year questionnaire due to trigger in December 2023.

In order to better evaluate these newer forms of arthroplasty, in terms of long-term safety and need for further treatment, and to achieve the overall objectives of the KAT trial, participant reported data will be supplemented with routinely collected information from Public Health Scotland and NHS Digital in England. Data has already been requested and supplied by ISD on three previous occasions and this request is to coincide with the last participants reaching 20 years of follow-up.

1920-0230 Dr Eliud Kibuchi University of Glasgow
Improving Scottish Health Survey-based alcohol consumption estimates for assessing the impact of Minimum Unit Pricing (MUP)

This research project aims to extend methodologies developed to adjust for alcohol consumption estimates obtained in Scottish Health Survey (SHeS) data. One of the ongoing challenges in alcohol research in Scotland is to accurately estimate levels and patterns of alcohol consumption using SHeS due to the issue of non-representativeness. Overall, the validity of alcohol consumption estimates obtained from surveys are often compromised by the low participation rates especially among heavy drinkers who are likely to experience alcohol related harms. So far, our research has found differences in alcohol related harm and all-cause mortality between participants in SHeS linked to hospitalisations and deaths data and the general population (unlinked hospitalisations and deaths data). We have also established that application of alcohol adjustment approaches using multiple imputation approach resulted in estimates of mean weekly alcohol consumption estimates that were up to fifth higher than those obtained using only survey weights. However, technical sophistication required in multiple imputation to improve survey reported alcohol estimates has necessitated the need to develop simpler alternatives. Therefore, the current research will focus on extending the methodologies for adjustment of alcohol consumption estimates and apply the extended methodologies to evaluate the impact of the minimum unit pricing (MUP) on alcohol consumption by sex, age, and area deprivation. This research is one of the Monitoring and Evaluating Scotland's Alcohol Strategy (MESAS) studies that will be used for evidencing the theory of change (ToC) for MUP.

2021-0089 Samuel Hall University Hospital Southampton NHS Foundation Trust
Risk of Aneurysm Rupture Study

Brain aneurysms are found in approximately 3% of people. While most cause no symptoms, some burst (rupture) and cause a type of brain haemorrhage called subarachnoid haemorrhage. 30% will die of this, and many more are left disabled. Unruptured aneurysms can be treated to prevent rupture, however, these treatments risk serious complications, including stroke and death. Deciding who to treat is based on predicting that patient’s future risk of aneurysm rupture and treating those patients with high risk. Unfortunately, how often aneurysms burst is not properly understood and our ability to predict which ones are likely to rupture is poor.

The aim of this study is to build our understanding of which aneurysm go on to rupture. This will include testing the accuracy of a currently used prediction method, known as the PHASES score, (that was developed using non-UK patients) and building a more inclusive prediction method better targeted to patients in the UK.

Patients with an unruptured brain aneurysm will be identified by neurosurgical units in Scotland, England and Wales, and baseline information about their aneurysms collected from their hospital records. These will then be searched against national databases of hospital admissions and deaths to identify which patients had a subsequent aneurysm rupture. We will then calculate the actual rupture rates to determine the accuracy of the PHASES score and see how it can be improved.

2021-0164 Professor Zosia Miedzybrodzka University of Aberdeen & NHS Grampian

Scottish Participation in UK 100,000 Genomes Initiative (continued from 1516-0377)”

The Scottish Genomes Partnership (SGP) is a partnership between NHS Scotland health board and Scottish medical schools and Genomics England, a company wholly owned by the UK Government’s Department of Health. SGP was set up to evaluate the use of the new technique of genome sequencing in Scottish healthcare to identify the genetic causes of rare, inherited conditions. Scottish families with rare conditions were invited to take part in the study during 2017-2020. They provided DNA samples and clinical data for analysis, in hope of identifying the cause of the condition in their family; and consented that their pseudonymised data would go into the Genomics England 100,000 genomes dataset (now called knowledgebase or national genomics research library) for use by researchers interested in human genetics. Results from both basic and research analyses are still being returned to some families. The research data will continue to lead to new diagnoses for participants as sequence techniques develop and new genetic conditions are discovered. There is also a great of genetic research ongoing using the data that will benefit society as a whole rather than individual patients. This world leading genomics resource set up by Genomics England is intended to remain accessible to researchers for the foreseeable future. It works like a lending library rather than a bookshop, only details of clinical features and sequence are available. Trusted researchers are given access to the data for research approved by Genomics England. If the research leads to suspicion of a new diagnosis for an individual, the finding is fed back to the families’ local NHS lab and clinic, who check the findings, verify the result and report it to the family. This process continues to lead to new diagnosis for Scottish participants.

The overall findings from this study are being used to decide if and when genome sequencing should be used as part of routine care for NHS Scotland patients.

An overview of Genomics England project and how knowledgebase data are being used in research is available at: Patients and Participants | Genomics England. Further details of how data are used is at: How your data is used | Genomics England.

An in-depth description of the data and how they are protected and how access is restricted to trusted researchers is also available at The-National-Genomic-Research-Library-V5.1.pdf (genomicsengland.co.uk) (section 9).

2021-0177 Dr Rebecca Barr University of Dundee
CLEAR study

This study has been requested by the regulators at the European Medicines Agency. Multiple sclerosis is the most common chronic neurologic disability in adult females of childbearing potential. This has prompted research into the impact of the disease on pregnancy complications and outcomes. The CLEAR Study (CLEAR is the name of the study rather than an acronym) is a Europe-wide observational pregnancy study based on routinely collected health data. The data is taken from automated healthcare databases and registers in seven European countries: Denmark, Finland, France, Germany, Norway, Sweden, and Scotland. The study focuses on women with multiple sclerosis who were exposed to oral cladribine during pregnancy and/or within 6 months before their last menstrual period or pregnancies fathered by men with multiple sclerosis treated with oral cladribine within the same period. Oral cladribine is used to treat a relapsing form of multiple sclerosis. For the Scottish group, the participants will be identified by researchers in clinical teams throughout Scotland. Data will be retrieved on pregnancies and their outcomes, and infants with major congenital anomalies during growth and development. In the selected data sources, pregnancies will be followed until the outcome of the pregnancy is known, and live births resulting from an identified pregnancy will be followed for up to one year of age. The output from the Scottish analysis will be combined with data from other European countries to answer the research question. The outcomes of this study will ensure better safety outcomes for women and their unborn infants who have been prescribed oral cladribine to treat any relapsing form of multiple sclerosis during pregnancy.

This initial application is requesting access to the minimum amount of data required to establish when sufficient patients have been exposed to cladribine for the full analysis to be undertaken: this pilot data will updated and assessed annually. This full analysis will be the subject of an updated application.

2021-0267 Professor Iain Moppett University of Nottingham
SNAP 3: Frailty, Delirium and Multimorbidity

The third Sprint National Anaesthesia Project (SNAP-3) aims to inform improvements to care for older surgical patients. The study will identify those who are frail, have multiple health conditions and look at their outcomes after surgery. It will investigate healthcare around the time of surgery and see if there are links between a patient’s health, healthcare provision and outcome. Frailty is a loss of physical and/or cognitive resilience that makes people vulnerable to sudden changes in health. Delirium is a period of temporarily altered, fluctuating consciousness, triggered by illness, surgery or environment. Surgical outcomes are worse for patients with frailty and delirium.

Our local teams have studied patients aged 60 years or older, who had an operation during a 5-day period in 2022. We have recorded the health and demographics of participants; the type of surgery and anaesthetic; and how their quality of life was after surgery.

The SNAP-3 team rely on data linkage (gathering data from central databases) to understand other information about participants. Participants have been asked if they agree to share centrally gathered information with our team. Data linkage will tell us how long participants spent in hospital, their discharge destination and how long they lived after surgery.

By combining all the data, we will identify the likely effect frailty and having health problems has for future surgical patients. We will publish this data to help clinicians and patients decide whether to proceed with surgery. It will also help hospitals to identify where to improve surgical pathways.

2122-0015 Claire Lawrie NHS National Services Scotland
Scottish Acquired Brain Injury Network (SABIN)

Traumatic brain injuries are relatively common injuries affecting approximately 300–400 per 100,000 population. Four percent of these are severe enough to require admission to the Intensive Care Unit (ICU), with nearly two thirds of patients dying or living with disabilities at 1 year.

Despite being common, with poor outcomes, little is known about the day-to-day care provided to these patients and the impact on patient outcome. In addition, over the last few years the approach to managing major trauma has changed, with increased provision of pre-hospital anaesthetic interventions and the transfer of patients direct to Major Trauma Centres, often bypassing hospitals closer to the site of injury. This practice has required significant human and financial resource, however the benefit of it is unknown.

Scotland is in the unique position to describe the care given to these patients from the point of injury to the point of hospital discharge. This is possible due to the presence of the Scottish Trauma Audit Group (STAG) and Scottish Intensive Care Society Audit Group (SICSAG) databases, which contain information on every severe trauma & ICU admission in Scotland respectively. This audit will link data from these two databases and the National Records of Scotland Death Records so we can produce the first detailed description of this population.

This will allow the network to understand the care pathway and outcomes of patients with severe traumatic brain injury in Scotland. This work has been commissioned by the network. With this data, clinicians and commissioners will have an increased understanding regarding the treatment delivered, and importantly outcomes in Scottish patients who suffer a severe traumatic brain injury, ultimately with the aim of improving outcomes for patients, reducing variation across the country and improving the quality.

2122-0038 Dr Andrea Sherriff University of Glasgow
Evaluation of the national Childsmile Programme

Childsmile is a multi-component national programme designed to improve the oral health of children in Scotland and reduce inequalities both in dental health and access to dental services. We want to study the role of Childsmile on:

- Dental registration, attendance and treatments
- Dental extractions under general anaesthetic.

- Dental caries (tooth decay).
- Non-dental health outcomes including obesity and other morbidities (and multimorbidity)
- Education outcomes such as school attendance
- Intermediate service outcomes

In addition, we would like to study which groups the Childsmile programme is reaching including those considered more vulnerable (children with educational additional support needs, care experienced children etc) and whether the programme is managing to reduce inequalities in oral and general health and access to services for all groups.

Finally, we will study the economic impact of the programme to assess the wider benefits of the programme.

The study’s findings will help shape the delivery of the Childsmile services to children and families in communities, nurseries/schools and in dental practices across Scotland. This well help improve the dental and general health of children in Scotland and reduce inequalities in regard to children’s dental health and access to dental services. At the same time, it will ensure that public money is being spent efficiently. This research will inform key stakeholders at the policy and practitioner level, not just in Scotland but across the world in high-, middle- and low-income countries as to what interventions work, for whom in what circumstances.

2122-0053 Professor Graeme MacLennan University of Aberdeen
THISTLE

THISTLE (Trial of Hands-on Interprofessional Simulation Training for Local Emergencies) was a study initially conducted to find out if a multi-professional training programme for maternity unit staff - Practical Obstetric Multi-Professional Training (PROMPT) - was effective in improving maternity care. The published results of this study (https://qualitysafety.bmj.com/content/29/2/122.long) must be reassessed with longer follow-up of the studied maternity units.

The research study provides maternity units with training to respond to emergency situations that may arise, from the onset of labour through to the delivery of the placenta, during childbirth. The study uses the Apgar score, a routinely collected indicator which measures 5 signs: Appearance, Pulse, Grimace, Activity and Respiration of babies at 1 and 5 minutes after birth with up to 2 points per sign giving a score out of 10 where the higher the score the better the baby is doing. In this study we are interested in the Apgar score at five minutes.

This follow up study is based on births recorded from the year 2000 to the end of September 2021 to allow longer follow-up of the maternity units with the aim of addressing the same research question that was studied in our previous study.

‘Does the implementation of an intrapartum emergencies training package across a health service reduce the rate of an Apgar score of less than seven points at 5 minutes, in term babies (excluding elective caesarean births)?’

2122-0060 Lucy Kilburn Institute of Cancer Research

The HER2-RADiCAL study (Response ADaptive CAre pLan) – Tailoring treatment for HER2 positive early breast cancer

This proposal is requesting data for use in the HER2-RADiCAL Health Economic (HE) analysis, this forms part of the wider HER2-RADiCAL study (Tailoring treatment for HER2-positive early breast cancer – Response ADapted CAre pLan), which is for patients with early HER2-positive breast cancer who meet the following requirements:

- started their course of drug treatment (chemotherapy + trastuzumab + pertuzumab) before surgery;
- have had breast surgery;
- and have been found to have the best possible response to treatment (a “pathological complete response” or “pCR”).

HER2 stands for human epidermal growth factor receptor 2, this is a protein that is sometimes over expressed in cancer cells which can help them to grow. HER2-positive breast cancers can be effectively treated with HER2-targeting agents such as trastuzumab and pertuzumab.

A pCR means that there were no remaining living cancer cells in tissue removed at surgery. We already know that such patients have good outcomes with only a small chance of the cancer returning, and so it is possible that the side effects and risks of continuing all of these treatments in combination could outweigh any benefit.

HER2-RADiCAL is investigating whether a more personalised treatment plan can be offered, with the aim of allowing patients with a pCR to safely receive less drug treatment after surgery. The overarching HER2-RADiCAL study aims to recruit around 720 patients across the UK (a proportion of which will be from Scotland) with HER2-positive breast cancer and a pCR, to test whether these patients can safely receive less trastuzumab, pertuzumab and chemotherapy after surgery. This reduction of drug treatment may not only benefit the patient, but also save NHS resources.

This parallel HER2-RADiCAL health economic (HE) analysis observational study which is the focus of this application will collate data (collected at the beginning and end of the study) from routine NHS records on all UK HER2+ breast cancer patients. The data will be used to better understand standard of care options and to populate a Health Economic model (a tool developed by the University of Edinburgh which is used to demonstrate value for money and economic impact of the study intervention compared with standard of care treatment). The objective of this HER2-RADiCAL HE analysis is to We will use this model to help us assess the cost-effectiveness of the HER2-RADiCAL treatment pathway compared with both a maximum therapy hypothetical comparator pathway (the maximum amount of treatment for HER2-positive breast cancer a patient could receive) and the current observed standard care pathway for HER2-positive early breast cancer patients as estimated from whole-population UK routine data. Should data be of sufficient quality in routine NHS sources, study outcome data will be collected via routine data sources.

2122-0095 Elizabeth Thomson University of Glasgow

Management to Optimise Outcomes in Unstable Coronary Syndromes: a developmental clinical study of management guided by coronary angiography combined with fractional flow reserve (FFR) measurement versus management guided by coronary angiography alone (standard care) in patients with non-ST elevation MI)

Approximately 10,000 people have a heart attack in Scotland each year. A heart attack is caused by a blocked blood vessel supplying the heart. Most patients who experience a heart attack have several narrowed blood vessels.

The treatment options include tablets only, placing a thin metal tube (stent) into the affected blood vessels, or coronary artery bypass surgery.

Usually, blood vessel narrowings are challenging for doctors to reliably assess. Fractional flow reserve (FFR) is a new test of whether the narrowing is severe i.e. blocking blood flow to the heart, or not.

In 2011 – 2013, we undertook a funded by the British Heart Foundation. We assessed whether FFR-guided management is safe. 250 patients were included in NHS Scotland. FFR-guided management was feasible (all patients), changed the diagnosis (1 in 5 patients), and reduced the use of stents and bypass surgery (1 in 10 patients). However, by one year, more patients experienced a further heart attack suggesting avoidance of stents and surgery may not be safe in the longer term.

Based on ethics and grant approvals, we wish to update the results hence our application to the HSC-PBPP. The analyses will be undertaken by the University of Glasgow

The results urgently needed to inform doctors and their patients on whether the FFR test should be routinely used in the NHS to guide the treatment of heart attack patients. There are no other studies in the world that can answer this question.

2122-0119 Dr Samira Bell University of Dundee

Understanding equity of access to best care for people with kidney failure

Kidney transplantation is the best treatment option for most patients with kidney failure. Ensuring that all patients with kidney failure have equitable access to transplantation is an ongoing and important issue. There are concerns that factors such as age, sex, geography, social deprivation and coexisting health conditions, including mental health issues, can disadvantage patients and these inequalities may have been further increased by the COVID-19 pandemic. Our proposal aims to examine important patient priorities with the aim of addressing these inequities thereby improving the future care and continuing health of patients with kidney failure. We will do this by combining, for the first time, multiple routinely collected healthcare datasets containing real-world information about patients with kidney failure in Scotland. We will ascertain whether socioeconomic deprivation and other health conditions, including mental health disorders, affect access to transplantation as well as the impact of the COVID-19 pandemic. We will use this information to address these inequities through national policy.

2122-0143 Professor Vittal Katikireddi University of Glasgow & Public Health Scotland

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

Welfare policy exerts large health impacts, particularly for socially disadvantaged groups. The Work and Pensions Longitudinal Study is a large database held by the Department for Work and Pensions (DWP) which contains information about what benefits (e.g. Jobseeker's Allowance, Universal Credit) people receive over time. It will be linked to health data (deaths, hospitalisations, and prescriptions for depression and anxiety) for working-age people in Scotland to allow us to study the effects of welfare benefits and policies on specific health conditions. Analyses will first allow us to understand the health needs of different benefits claimants. Second, we will focus on better understanding causal pathways between welfare benefits, employment, and health. For example, we will study if poor mental health is a cause of job loss and needing welfare benefits, and the timing of any increased risk. The third phase focuses on evaluating health impacts of welfare policy reforms. For example, Incapacity Benefit was replaced by Employment and Support Allowance – a policy change which led to differences in eligibility for benefits and changes to the generosity of payments. We will therefore study the health consequences of this policy reform, as well as others, including Universal Credit.

We anticipate our work will help plan services and inform policy improvements. There is increasing interest in co-locating health and welfare services, allowing joint interventions to be developed. Similarly, the design of welfare policies undergoes regular changes. This is particularly likely if UK government changes and as new welfare benefits are introduced within Scotland.

2122-0224 Dr Emma Russell University of Glasgow

HEalth And Dementia outcomes following Traumatic Brain Injury (HEAD-TBI)

BACKGROUND: There is growing recognition that traumatic brain injury can lead to a lifelong impact on health, including a higher risk of dementia. Indeed, it is estimated that around 3% of dementia cases in the community are due to brain injury. Notably, poor health outcomes after brain injury include not only dementia. A wide range of conditions are observed in brain injury survivors, many of which also increase dementia risk. As such, our theory is that the increased dementia risk associated with brain injury may be due to both the direct effect of the injury on the brain and the indirect effects of wider, poor health outcomes after brain injury which, in turn, increase dementia risk.

To test this theory we propose a series of interlinked studies titled "HEalth And Dementia outcomes following Traumatic Brain Injury (HEAD-TBI)". These studies are designed to compare differences in health between people with and without a history of brain injury and how these might contribute to dementia risk. This will give us a better understanding of the link between traumatic brain injury and dementia, which will help us identify ways that we might act to reduce this risk.

AIMS: The aims of HEAD-TBI, therefore, are to:

- analyse risk of dementia and other neurodegenerative diseases in those with a history of traumatic brain injury compared to uninjured individuals from the general population.
- analyse common causes of death and common health issues, including mental health, in those with a history of traumatic brain injury compared to uninjured individuals from the general population.
- analyse brain scans to look for changes that may help us understand who is most at risk of dementia following a traumatic brain injury.

DESIGN AND METHODS: We will use unique, comprehensive digital health records and death certificate data, together with diagnostic brain scans available for research. Patients with a history of brain injury will be identified from a search of available health records. The lifelong health outcomes and brain scans in these individuals will then be compared to people from the wider population without a history of brain injury, matched to our brain injured patients by year of birth, sex and degree of social deprivation.

DISSEMINATION: As results emerge these will be presented at appropriate multi-disciplinary research conferences and made available as draft manuscripts through open access platforms before formal, peer-reviewed journal publication. We anticipate HEAD-TBI will have wide interest and, when appropriate, we will leverage news and social media communications and participate in broad public engagement events.

2122-0230 Dr Louise Marryat University of Dundee

Maternal health, and preschool developmental, outcomes following opioid use in pregnancy

Internationally, the rising use of opioid drugs has been described as a crisis. In Scotland, around 500 children a year are born to women who use opioid drugs, for example, heroin and methadone. We know little about what happens to these women and children after birth, but the little we do know suggests that they are likely to have poorer health. We also know they are more likely to be disadvantaged in other ways, e.g. living in poverty and unstable housing.

A previous study (1617-0324) identified 6,408 children exposed to opioids in pregnancy and looked at their very early outcomes up to age 1. We found that children exposed to opioids had a range of poorer outcomes, including being born early, having lower birth weight, spending more time in the neonatal unit and being more likely to be discharged from hospital with someone other than their birth mother e.g. to foster care. This new study builds on the previous study to look at outcomes up to age 5 for children, and to explore what happens to women themselves in the three years after childbirth.

This study has three stages to it. The first stage of the study will bring together routine health data (e.g. health visitor data) to allow us to compare the health and development of children who were exposed to opioids in pregnancy, compared with those who were not in the preschool period.

The second stage will be to look at outcomes for women themselves. This will include exploring their continuing substance use patterns (where relevant), as well as their own health outcomes and health service usage.

Finally, this study will look at the social work data on children born to mothers who used opioids in pregnancy. Many of these children will spend time living away from home, either with other family members or with foster carers. We will look at patterns of movement between different carers and what factors make a child more at risk of having different patterns of care away from home.

Findings will help women and clinicians make the best decisions on treatment in pregnancy and beyond.

2223-0008 Dr Kirsty Dunn University of Glasgow

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. 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. 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. 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.

2223-0010 Dr Samuel Scott Ogletree University of Edinburgh

Using secondary data to examine whether a programme of physical and social interventions in urban forests enhances community health and wellbeing: the impact of WIAT interventions on child development

Our innovative research plan will make use of the Scottish Longitudinal Study, which provides individual census records which can be linked to individual health service records. The data provided is pseudonymised, or done by data linkage, so that the researchers cannot identify anyone. We will link these to Scottish Forestry data that capture the location, nature, costs and timing of all “Woodlands in and Around Town” (WIAT) interventions delivered in three phases between 2005 and 2018. Together, these data will allow us to assess the impacts of WIAT interventions on child development, using both ‘within subjects’ (i.e., comparing children’s development and health before and after the WIAT intervention) and ‘between subjects’ (i.e. comparing trajectories of development and health between those exposed and not exposed to the WIAT intervention).

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

2223-0047 Dr Mohamed Shoaeir NHS Lothian

Improving the identification of sepsis in SICSAG data

Sepsis is a life threating condition that causes damage to body's organs in response to infection. It is a leading cause of admission to critical care, and contributes to high number of deaths from hospital admissions. This outcome can be improved by proper identification and diagnosis of sepsis. The audit seeks to understand the patients admitted with sepsis to the intensive care units in Scotland, causes of Sepsis, demography, organ support and treatment received. This will help to build a definition of sepsis in the Scottish Intensive Care Society Audit Group database. This would be to improve the recognition of patients with sepsis and so will aid in understanding and treatment of sepsis.

2223-0068 Professor Jill Belch University of Dundee/NHS Tayside

Fourth follow-up of SHHEC Cohort (renewal to 1516-0578)

Between 1984 and 1995 18,000 Scots volunteered for health screening and long-term follow-up to study disease causes and prevention: the Scottish Heart Health Extended Cohort (SHHEC).

We aim to use SHHEC and linked hospital data to identify novel risk factors for disease, potentially informing future medical practice and treatments eg dementia, cancer, macular degeneration and cardiovascular disease. This study is an extension of a previous application and required so that we can finish planned investigations which were delayed due to covid and staff changes eg change of statistician with a period of no-one in post, technician leaving and not replaced (blood analyses), and during covid the labs were shut. Further analyses took longer than anticipated.

We are close to completing the following: a systematic review with SHHEC data for macular degeneration; sex bias and cardiovascular operations; prediction of cancer using ASSIGN risk score. Publications are drafted but require access to data for final analyses.

We have analysed blood samples taken originally, to investigate novel risk factors for dementia and osteoporosis. This was delayed for reasons as above. A grant of £100,000k was obtained for the tests and we require access to the eDRIS data to determine if these novel biomarkers will be useful for early diagnosis of those at risk, allowing early prevention. We were also in the process of starting a systematic review for dementia.

Further work includes: hormone replacement therapy (HRT) and cardiovascular events; statin use and peripheral arterial disease; and, statin compliance; and cancer incidence and markers.

2223-0074 Euan Smith Scottish Government
Cancer Patient Experience Survey 2023/24

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

SCPES is part of the Scottish Care Experience Survey Programme – a suite of national surveys which aim to provide local and national information on the quality of health and care services from the perspective of those using them.

The SG Cancer Recovery Plan states that with Macmillan Cancer Support, we will develop and deliver the third SCPES Survey, benefitting from benchmarking against previous surveys to further understand COVID-19 impacts on cancer patients.

The Care Experience Programme supports three strategic objectives for both the SG and NHS Scotland – that care be safe, effective and person centred. It does this by providing a basis for the measurement of quality as experienced by people across Scotland.

In particular, the surveys support the person-centred quality ambition which is focused on putting people at the centre of care; ensuring that care is responsive to individual personal preferences, needs and values; and assuming that individual values guide all care decisions. More information on the Care Experience Survey Programme can be found at https://www.gov.scot/collections/social-care-analysis-statistics/#scottishcareexperiencesurveyprogramme

2223-0089 Dr Huan Wang University of Dundee
Multivariable Lung Nodule Malignancy Prediction

This project aims to develop and evaluate the impact of a multivariable artificial intelligence (AI) tool for the detection of lung nodules, which may go on to develop into cancerous growth. We know from previous publications that the risk of these nodules is not uniform, and some have characteristics that may increase the risk for cancer development. This is a University of Dundee led project, in partnership with Aidence B.V. who are a medical imaging AI company, servicing the healthcare industry. The Company focuses on early recognition of lung cancer by applying AI algorithms to medical imaging.

In order to gain the necessary information to train the multivariable AI tool, we plan to go back in time and collect a large number of computed tomography (CT) lung scans and link the imaging findings with other variables namely essential clinical data, including outcome data, cancer diagnosis, risk factors of patients, and general information like sex and age. This will result in a risk score, which will then be linked to the CT findings. It is anticipated that the multivariable AI tool, which uses computer prediction models incorporating multiple variables including imaging markers, clinical data and risk scores from the imaging-based predictor to be developed by industry partner Aidence B.V. (PBPP application 2324-0017), will be able to highlight those nodules that were more likely to become lung cancer, and that this would allow this tool to be used for future application when patients attend for CT lung scans in the context of lung cancer screening or follow-up of lung nodules that were detected incidentally in the context of other clinical indications.

2223-0103 SR171 Heather Clark University of Aberdeen
Aberdeen Children of the 1950s cohort study – transfer of NHSCR deaths and embarkations

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 from early life – their school tests, 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 to enable research on cognitive ageing or resilience in older age.

2223-0127 Professor Lindsay Jaacks University of Edinburgh Dietary Intake in Scotland's CHildren (DISH)

We are asking children and young people living in Scotland, what they eat and drink, in a national dietary survey.

The University of Edinburgh is leading the survey, with around 17,000 children, on behalf of Food Standards Scotland (FSS). FSS are the public sector organisation responsible for helping people to eat more healthily. FSS will not have access to your data. Taylor McKenzie, a market research company based in Glasgow, will conduct the survey and have access to the data collected. The University of Edinburgh, the University of Aberdeen and Biomathematics and Statistics Scotland will also have access to some of the data collected but not names, emails, addresses, or phone numbers.

We have used health records to look for households with children aged 2-15 living there, so that we can write to them and invite them to the survey. We have not requested any details about their health.

We will ask parents/guardians of younger children to complete a short questionnaire, and an online food diary of all the food and drinks their child had on the previous day. Children in secondary school may complete the food diary themselves. Parents/guardians (or children) will be asked to complete up to 4 food diaries in two weeks.

The results will be used to help us to support children and families living in Scotland to have healthier diets.

2223-0150 Duncan Hill SIPBS, Strathclyde University / NHS Lanarkshire Evaluation of the association between physical health comorbidities and opioid dependency using Opioid Agonist Treatment as a proxy in older patients: a retrospective matched population cohort study.

The number of older patients treated for opioid dependence is increasing. Reports have stated patients who have used substances may be biologically 15 years older than their actual age. The has led to an older substance user in Scotland being classed as aged 35 years or older.

Treatment for opioid dependence involves using medications – called Opioid Agonist Treatment (OAT) - normally methadone or buprenorphine.

As the patients are “older” than their real age, there is an increase in physical health conditions they are developing at a younger age, e.g. cancers, respiratory disease.

This study is determining what physical health conditions are presented in the older patients (35 years or older) prescribed methadone or buprenorphine. We will use OAT to identify the population that have been treated for opioid dependence from existing databases and will use other health databases to determine which physical health conditions this population group will be at a greater risk of developing and how often in real life.

This information will be compared to patients who have not been prescribed methadone or buprenorphine.

All data will be anonymous and no individual identities will be reported.

2223-0155 Dr Amanj Kurdi University of Strathclyde
UK Antimicrobial Virtual Registry (Scotland)

Collecting information on medicines, including antibiotics, in one place (via a registry for instance) is critical to understanding how a medicine is used in routine care which helps to see if the medicine is used appropriately in line with recommended guidelines and whether they produce the desirable and intended benefits to patients. Effective antimicrobial agents, such as antibiotics, are vital to modern medicine. Bacteria can become resistant to antibiotics (antimicrobial resistance) when used overused or misused, making them less effective at overcoming infections. Antimicrobial stewardship is key in the fight against antimicrobial resistance. Monitoring antibiotic use allows us to track when, where, and why they are prescribed, and to assess how well they worked and whether there was any antimicrobial resistance.

Understanding antibiotic use in routine care is important. Clinical trials of new antibiotics are often done in select (relatively fit) patient groups, and in specialist centres. These studies do not capture how well the antibiotics work for patients who are very sick or have multiple health problems. Estimates of safety and effectiveness from clinical trials may not reflect how well antibiotics work in the general population.

The UK Antimicrobial Virtual Registry (Scotland) will examine the use of newly-licensed antibiotics in Scotland, investigating which patients were given these drugs, for what reasons and whether the antibiotics worked. The registry will pull together information from several NHS databases providing information on:

- antibiotic use;
- tests and other treatments that patients receive;
- medication safety/effectiveness.

These datasets will be linked together by NHS staff and anonymised to remove personal details like names and addresses. Researchers will only access the pseudonymised anonymised data from a secure NHS network and it will not be possible to de-anonymise a patient (i.e., will not be able to identify individuals). They will look at how these antibiotics are currently being used and try to identify how they might be used more effectively.

2223-0158 Dr Andrea Woolner University of Aberdeen

Progesterone for Threatened Miscarriage: A prospective cohort study in Scotland – [Shortened title: PROgesterone for ThrEAtened Miscarriage, “PROTEA” Study]

Bleeding in the earliest stages of an ongoing pregnancy is known as threatened miscarriage. It affects 1 in 5 pregnant women, a third of whom will ultimately go on to lose their baby. The hormone progesterone has been shown to reduce the risk of pregnancy loss in women who have had one or more previous miscarriages. Although this treatment has recently been recommended by the National Institute of Clinical Excellence (NICE), progesterone is not equally effective in all women and appears to be more beneficial to those who have had several previous miscarriages. In addition, as with any medication used in pregnancy, the benefits of treatment need to be balanced against any possible unforeseen effects on babies. NICE guidance is gradually being rolled out across Scotland in the next few years with some hospitals offering the treatment earlier than others. In this proposed research, we aim to use electronic hospital medical records from all Scottish hospitals to study how well progesterone works in terms of preventing miscarriage and what additional NHS resources are needed to support this service. The information collected will also help us to understand whether progesterone treatment affects the risk of other complications in pregnancy such as pre-eclampsia and if it has any effect on babies. We believe it is critical that this research is started soon as this treatment is rolled out and that much-needed information on the benefits, safety, and consequences of progesterone use is made available before this treatment becomes part of normal care.

2223-0159 Rashmi Mathew Moorfields Eye Hospital NHS Foundation Trust

Deterioration Of Sight Caused By Delay In Review Or Treatment: Frequency and Morbidity

Two previous surveillance projects to establish the frequency of sight loss due to delay in review or treatment were undertaken in March 2015 - February 2016 and April 2018 and March 2019. The initial study identified a minimum rate of 14 cases per month, with a likelihood of the true rate being between 16 and 22, the repeat study identified 12.5 new cases per month although less this was not a significant difference. In both studies the majority of cases were in patients with chronic eye conditions requiring long-term continuous follow-up, most notably glaucoma. Delayed follow-up appointments were the cause in most cases indicating a lack of system capacity.

In addition to pre-existing service pressures the cessation of normal clinical practice during the coronavirus pandemic and reduced capacity in the return to normal service provision may have increased the number and length of delays. Anecdotal concerns are growing amongst those responsible for providing the hospital eye service making now a timely opportunity to re-examine the current situation to quantify the magnitude of any changes in morbidity caused by harm due to delays. These data will also allow the research team to describe the demographic and clinical characteristics of patients suffering these harms to help direct resources to help reduce this cause of avoidable sight loss.

The study will be run through the British Ophthalmological Surveillance Unit (BOSU). The BOSU is a function of The Royal College of Ophthalmologists and supports researchers to identify cases of rare eye diseases, conditions or events by asking all UK ophthalmologists via a monthly email if they have seen any cases of interest (the BOSU typically has 5-8 conditions under surveillance at any one time) and if an ophthalmologist does report a case they can then provide further details via a bespoke online system. The information sought from reporting ophthalmologists will include some demographics, measurement of vision before and after the delay along with the diagnosis and the cause and length of the delay. The data collected will provide a contemporary estimate of the size of the problem across the UK. It will be able to describe which patient groups are worst affected by under capacity in the hospital eye service along with any existing socioeconomic or demographic inequalities. The findings will be of use to Eye care specialists, and professional bodies to highlight under capacity in the eye care system and to inform health service planning in determining future capacity needs. Data from previous studies has also been utilised by patient pressure groups to help highlight their future needs.

2223-0166 HACE23 Gregor Boyd Scottish Government Scottish Health and Care Experience Survey

The Health and Care Experience Survey (HACE) asks about people's experiences of their GP practice; Out of hours healthcare; care, support and help with everyday living; and caring responsibilities.

This application seeks permission for Public Health Scotland (PHS) to select a random sample of people who are registered with a GP Practice in Scotland, live in Scotland and are aged 17 and over. PHS will co-ordinate checks against the NHS Central Registry and the Community Health Index (CHI) database to remove people from the sample who have died.

People selected will be contacted by post, and can participate online, by phone or by completing a paper questionnaire. Survey responses will be linked to information from the CHI database including GP Practice, sex, age band, urban/rural and index of multiple deprivation. Professional analysts in the Scottish Government and PHS will analyse this dataset to publish national and local results of the survey. Anonymised free text comments will be shared with GP practices to allow them to act on feedback, while not being able to identify who has commented.

HACE is part of the Scottish Care Experience Survey Programme of national surveys measuring the quality of health and care services from the perspective of people using them. This supports three strategic objectives – that care be safe, effective and person-centred.

The surveys support the person-centred quality ambition to put people at the centre of care; ensure care is responsive to personal preferences, needs and values; and that individual values guide all care decisions.

2223-0167 Dr Louisa Pollock NHS Greater Glasgow & Clyde
Maternal Immunity and Infant Sars-CoV-2 Study

SARS-CoV-2 infection is mild in most children, but infants are amongst those most likely to be admitted to hospital. Infants are not included in current Covid-19 vaccine programmes. We know Covid-19 antibodies from mothers can be passed to babies in the womb. We don't yet know how well those antibodies protect infants against SARS-CoV-2 infection, or whether vaccinating mothers offers further protection to infants.

To find out whether maternal Covid-19 immunity can reduce babies' risk of SARS-Cov2 infection we will undertake two studies.

Study 1 will include all babies born in Scotland between 1st July 2021 and 30th June 2022. Using routinely collected NHS data, we will determine whether maternal vaccination, or prior maternal SARS-Cov-2 infection, reduces the risk of SARS-CoV-2 infection in the first year of life. We will also look at other factors which might change the risk of SARS-CoV-2 infection including gestation, maternal age, ethnicity, deprivation, and urban/rural location.

Study 2 will identify a sub-group of infants born within NHS Greater Glasgow & Clyde between 1st July 2021 and 30th June 2022. Using blood left-over from antenatal screening, we will measure maternal Covid-19 antibodies. We will compare maternal antibody levels in 500 cases (infants with SARS-CoV2 infection) and 1000 controls (infants without confirmed SARS-CoV-2) to see whether higher antibody levels are associated with protection against SARS-CoV-2.

These studies will help us understand how maternal covid-19 immunity can help protect infants. This will help us plan vaccine programmes, predict how many babies might be infected, and help inform vaccine choices for women in Scotland and elsewhere.

2223-0168 Dr Sarah Bowers University of St. Andrews
Healthcare utilisation in the last year of life for people with multimorbidity in Scotland

Research shows that many people do not receive the Palliative Care they need, but we do not know enough about why this is. Understanding more about who isn't able to access Palliative Care, and why, will help us to design services that offer exactly what people need.

Nearly 1 in 4 people in Scotland live with multiple long-term conditions. We know that people with multiple long-term conditions (multimorbidity) spend more time in hospital, have a lower quality of life and often die earlier than people with only one condition. People with multiple long-term conditions often have as many symptoms as people with incurable cancer. This can mean they have lots of uncertainty – particularly around how they manage their conditions and the coordination of their care.

We do not know very much about how people with multiple long-term conditions who are near the end-of-life access healthcare. We plan to learn from healthcare data about the kind of care these people use in the last year of life. We will look for differences in how people use healthcare and if understanding the types and combinations of long-term conditions they have helps explain any differences. This forms part of a PhD project and the results will be shared in Scientific journals. We hope to use our learning to help design healthcare services that offer the kind of care people with multiple long-term health conditions tell us they need.

2223-0179 Professor Vittal Katikireddi University of Glasgow

Early Assessment of COVID-19 epidemiology and Vaccine/anti-viral Effectiveness (EAVE II): additional analysis of social and ethnic inequalities

This research is a sub-study of the wider project Early pandemic evaluation and enhanced surveillance of COVID-19 (EAVE II) and aims to assess the epidemiology of SARS-CoV-2 infection by ethnic group and investigate the mechanisms through which ethnic inequalities in COVID-19 arise. Understanding ethnic inequalities in COVID-19 has been a major policy priority of the Scottish Government since the beginning of the pandemic. Evidence shows that ethnicity influences the risk of both infection and adverse outcomes for COVID-19. However, empirical research within Scotland remains limited and subject to major limitations arising from systematic misclassification of ethnicity. Our research has so far found that misclassification in Scottish health records is higher among minority ethnic groups and that this can attenuate or reverse the observed risk of adverse COVID-19 events. We have also established, using ethnicity data derived from the 2011 Census, that most minority ethnic groups were at a higher risk of SARS-Cov-2 infection and adverse COVID-19 events (hospitalisation and death) in Scotland compared to the White Scottish majority. These findings are currently out for publication in peer-reviewed journals. Our research will now focus on interactions between ethnicity and other socio-demographic factors and the pathways mediating ethnic inequalities in COVID-19 in Scotland. We will also explore vaccination uptake as a possible mediator. This research has been commissioned by Public Health Scotland in collaboration with Scottish Government.

2223-0182 John Kerr University of Dundee

NHS Research Scotland Diabetes Research Register (register): Facilitating mailouts to patients with diabetes with an opportunity to join the Diabetes Register

NHS Research Scotland (NRS) Diabetes is a Scottish Government funded group that aims to support research into diabetes in Scotland. Research is critical in making sure we understand diabetes and develop new treatments.

Diabetes research can only happen if there are people with diabetes who are willing to take part. It can be very difficult to find the right people to take part in research and this is often the biggest challenge to being able to make research happen. Likewise, it can be difficult for people with diabetes, who are interested, to find out about research that they may be a good match for.

NHS Research Scotland Diabetes want to be able to give people with diabetes, living in Scotland, the opportunity to give their permission to be matched to and contacted about research that they are a good match for.

NHS Research Scotland Diabetes have a system and process that we call the Diabetes Research Register. If a patient with diabetes joins, it means that NHS Research Scotland Diabetes can check if they are a good match for any research that comes along and contact them to ask if they are interested.

NHS Research Scotland Diabetes want to try and make sure that everyone is given this opportunity. So, this proposal aims to allow us to get permission to identify people who have diabetes from information collected in Scotland's electronic patient record for diabetes. We can then use this information to send people a letter and a leaflet to consider joining the Diabetes Research Register.

NHS Research Scotland Diabetes requires a persons name and address to send a letter. NHS Research Scotland Diabetes will receive lists of names and addresses in electronic spreadsheets that are sent over the NHS computer network using an NHS secure data transfer system. Upon receipt of the lists, letters can be prepared and issued by NHS Research Scotland Diabetes. Sometimes, NHS Research Scotland Diabetes may use Royal Mail to help print, pack and send letters. In these situations, electronic lists of names and addresses will be sent through a secure online site to Royal Mail's approved print partner who will then print, pack and post your mailing with Royal Mail.

2223-0186 SMR104 Ms Lucy Lennon UCL
SMR104- British Regional Heart Study Renewal

The British Regional Heart Study (BRHS) is a study of the causes and prevention of heart disease in middle-aged and older men drawn from the general population in all major regions of Britain. The men taking part have had detailed assessments of risk factors made when they were aged on average 50, 70, 80 and 88 years and have been followed up to see whether they develop cardiovascular disease (CVD), cancer and/or other ill health. CVD and cancer are the leading causes of death. Individual patients are at risk for both CVD and cancer simultaneously possibly as a result of shared modifiable cardiovascular risk factors and overlapping molecular mechanisms. The BRHS cohort is set up to investigate the causes of CVD as well as the impact of CVD risk factors on cancer in later life and examine the scope for prediction and prevention of CVD, cancer and related disability, particularly in older ages. To do this, it will be important to continue to follow the surviving men for mortality, cancer ill health and disability. If we can prevent or delay the onset of both heart disease and cancer in later life and understand why and how people who develop CVD are more likely to become frail or disabled, this could help a considerable number of people to not just live longer without heart disease or cancer but free of disability resulting from heart disease – allowing older people better quality of life and greater independence but to also improve management of people with heart disease and cancer.

2223-0189 Dr Claire Tochel University of Edinburgh

Research using the Scottish Collaborative Optometry and Ophthalmology Network e-research (SCONe) dataset

Scotland has a unique system of eye care delivery with good integration of primary and secondary ophthalmic services and well-equipped and skilled community optometrists. Millions of retinal images have been taken in practice since 2006 when a new General Ophthalmic Services contract was introduced. These images constitute a rich, longitudinal, population-based resource which could support research into how the retina changes in diseases of the eye, body and brain.

Between 2020-22 we successfully established the Scottish Collaborative Optometry-Ophthalmology Network e-research (SCONe) retinal image repository within the Public Health Scotland (PHS) National Safe Haven. This two year Proof of Concept study successfully demonstrated the feasibility of securely transferring community-acquired retinal images in a format which facilitated robust linkage to NHS healthcare data. In December 2022, the Scottish Government issued national guidance describing SCONe as a “globally important study that has the potential to save the lives of millions of people” and encouraged all community optometrists to participate (SD4 SG PCA).

Working towards that goal, this proposal will expand the SCONe retinal image resource by recruiting more optometry practices from across Scotland, aiming to create a cohort which is representative of the population, and to enhance its capacity to support research on important areas of human health by linking to additional national, routinely-collected datasets.

This is an enabling proposal which will support a range of potential research around eye, body and brain health which will be submitted in separate PBPP proposals.

2223-0195 Mr Paul Bradshaw Scottish Centre for Social Research

Perinatal and Infant Mental Health: Survey of Mothers

This application requests permission for National Records Scotland (NRS) to randomly select a representative sample of mothers from Birth Registration Records in order that those mothers may be invited to participate in an online survey. The survey has been commissioned by Public Health Scotland (PHS) as part of their evaluation of the Scottish Government’s expansion of mother and baby mental health support under the Perinatal and Infant Mental Health Programme Board.

To carry out the survey, names and addresses of selected mothers will be shared with the Scottish Centre for Social Research (ScotCen) - an independent research institute and charitable trust – who have been commissioned by PHS to undertake this work. Selected additional information will also be provided to allow ScotCen to assess bias in the survey results.

Using the information provided by NRS, ScotCen will issue a letter inviting mothers to complete a questionnaire online. The questionnaire will gather information on mothers’ awareness, use and satisfaction with services to support their mental health and the mental health of their child during pregnancy and in the first few years after birth (the ‘perinatal’ period).

The survey will provide robust and comparable information about women’s knowledge and experiences of the mental health care and support that was available to them and/or which they may have accessed during their pregnancy and in the period after the birth of their baby. This will provide vital evidence locally and nationally to inform service improvement, leading to improved outcomes for future mothers and babies.

2223-0200 Dr Alexander Doney University of Dundee
Scottish AI in Neuroimaging to predict Dementia and Neurodegenerative Disease (SCANDAN)

We are working on a big challenge in healthcare: finding out who is at risk of dementia or other brain diseases. If we could do this, people could take charge of their own health better, and it might be easier to test new treatments.

How will you do this?

Our plan is to create computer programs (called artificial intelligence, or ‘AI’ algorithms) to estimate who is at risk of dementia. To do this, we will use data collected by NHS Scotland. We will use data from brain scans and medical records that make a diagnosis of dementia. NHS doctors record dementia when people are admitted to hospital, or are prescribed a medicine, or when they die. Dementia can be caused by several conditions, such as vascular dementia and Alzheimer’s diseases. We will try to look at each of them.

We will look at two types of brain scans: computerised tomography (CT) and magnetic resonance imaging (MRI). By studying these scans and then seeing who actually gets dementia, we can train our computer programs to estimate dementia risk.

We will use data that is held by NHS Scotland. The data includes all people who have had a brain scan in NHS Scotland from 2010, and when these people have been in hospital, prescribed a medicine or have died.

Why is this new?

Researchers have tried to estimate dementia risk before, but they have not done so accurately. We hope that by using brain scans we can make better estimates of dementia risk than before. We will use a much larger amount of data than has been used previously. More data usually make estimates of risk more accurate.

How might the public benefit?

If our predictor is accurate, it would be a big help. It could make finding people for new studies of dementia prevention medicine easier, which is currently a major limitation to the development of new treatments. People could use their risk level to plan their future health care or care needs. In the long run, it might even help people start treatments to stop dementia before it begins. At the moment these treatments are expensive (for example a drug called lecanumab), but they will grow cheaper and more accessible over time.

If our computer program is used widely, then the NHS will benefit financially.

2223-0204 Professor Andrew Smith NHS GGC
Epidemiology of Streptococcus pyogenes in Scotland

Streptococcus pyogenes or Group A Streptococcus (GAS), is a bacteria that can be found in throats of about 1 in 10 healthy children and adults but can cause severe skin and blood infections. When doctors investigate infections they collect specimens from which the hospital microbiology laboratory can grow bacteria. When GAS is found in severe infections, the bacteria are sent to the Scottish Reference laboratory (SRL) for further testing. Here GAS isolates are classified into groups, known as “emm types”, based on the shapes of a cell surface protein. Grouping helps us understand how GAS is spreading. More detailed intelligence on the spread of GAS can be obtained by analysing the bacterial genome by whole genome sequencing (WGS). Our study will review data submitted to SRL with the aim to better understand the occurrence of GAS infections in the Scottish population. We will consider the type of specimens collected (e.g., blood culture, leg swab, wound swab), date of specimen collection, age and sex of patient, GAS emm and WGS types causing disease. No individual identifying data, such as name or address, is required. The output from this study will be a thorough description of the patterns of severe GAS infections in different age groups, throughout time and from different specimens. Moreover, we will be able to present the importance of different GAS emm types causing disease. This work will allow us to characterise important aspects of GAS infections, facilitating future efforts to reduce the burden of disease.

2223-0216 SR264 Dr Richard Haylock UK Health Security Agency
Nuclear Weapons Test Participants Study (NWTPS)

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

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

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

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

We seek permission to continue to receive mortality and cancer incidence information for members of this cohort.

2223-0217 SMR47 Dr Richard Haylock UK Health Security Agency National Registry for Radiation Workers (NRRW)

The National Registry for Radiation Workers (NRRW) is a long term follow up cohort study. Its goal is to examine the health effects of occupational exposure to ionising radiation in workers in the UK and thereby provide high quality direct evidence to help protect radiation workers and the public from harm through excessive ionising radiation exposure.

2324-0029 Dr Claire Tochel University of Edinburgh Predicting ocular disease using the Scottish Collaborative Optometry and Ophthalmology Network e-research (SCONe) dataset

Scottish Collaborative Optometry-Ophthalmology Network e-research (SCONe) is a retinal image repository within the Public Health Scotland (PHS) National Safe Haven. It comprises community-acquired retinal images linked to routinely collected healthcare data. In December 2022, the Scottish Government issued a national guidance describing SCONe as a "globally important study that has the potential to save the lives of millions of people" and encouraged all community optometrists to participate (SD8 SG PCA).

This research proposal will begin working towards achieving that potential. We will focus on ocular (eye) diseases including but not limited to glaucoma and Age-related Macular Degeneration which each currently affect more than half a million people in the UK, causing them to irreversibly lose the peripheral and central areas of their vision, respectively. There are treatment options for glaucoma and some types of Age-related Macular Degeneration so early intervention once the disease process has begun is crucial to preserve vision. Early detection is therefore absolutely vital.

We will use the SCONe dataset to identify people who have been diagnosed with an ocular condition such as glaucoma or Age-related Macular Degeneration. We will analyse their retinal images to detect features which predated the diagnosis and learn how those features changed as the disease developed. Disease prediction models will be developed, which would allow the earlier detection of such diseases in people, ideally when they have not yet experienced any vision loss. If successful we will use these models to create a diagnostic tool which would be suitable for use in the community.

2324-0064 Dr Tariq Ahmad Royal Devon University Healthcare NHS Foundation Trust

CLARITY IBD

Inflammatory bowel disease (IBD), comprising Crohn’s disease (CD) and ulcerative colitis (UC), is a chronic inflammatory disease of the gastrointestinal tract that affects approximately 1% of the UK population. The CLARITY IBD study is looking at the impact of two biologic medicines (infliximab and vedolizumab) on COVID-19 infection, vaccination and immune response in people with IBD. Vedolizumab and infliximab are both types of immunosuppressive medicine. These medicines work by blocking some parts of the immune system – which reduces the inflammation in IBD. We will compare the level of antibodies made by people taking vedolizumab with people taking infliximab. This is because vedolizumab works specifically on immune cells in the gut, whereas infliximab can affect the immune response throughout the whole body.

The study also takes into account other medicines that people may be taking alongside their infliximab or vedolizumab, for example azathioprine or methotrexate. We aim to see if people on these medicines produce the same immune response to coronavirus and to coronavirus vaccines. Because COVID-19 is caused by a new virus, SARS-CoV-2, we don’t yet know if these drugs increase the risk of infection, life-threatening illness or reduce immunity that usually follows infection or vaccination. As a precaution the UK Government advised patients taking these medicines to follow strict social distancing measures, known as shielding, during lockdown periods. This study will investigate the impact of specific drugs and shielding on COVID-19 infection and subsequent immunity following infection or vaccination. The results of this study will help inform public health policy decisions for patients with IBD as well as millions of other UK patients treated with immunosuppressive drugs.

Since the start of the study, we have had an agreement with Public Health Scotland that the following data items will be made available to us to matched participants via their CHI number in the study:

1. COVID-19 test results
2. Reporting lab/pillar
3. Data on COVID-19 vaccination (added during the conduct of the study)

Analyses of these data requested in this application will define the impact of commonly used immunosuppressive drugs and physical distancing strategies on SARS-CoV-2 infection and immunity following either infection or vaccination, which is directly in line with our study aims and objectives.

2324-0072 Professor Colin Palmer University of Dundee

SHARE Research Database and Biobank for cohort building and use for research

SHARE's aim is to help researchers find study participants and offer the public opportunities to participate in studies. The benefit is improving healthcare and discovering new treatments for disease.

This proposal is to renew the approval (1617-0338), for data linkage within the Health Informatics Centre (HIC); this enables the building of specific groups of registrants for studies, when SHARE receives applications from researchers, AND to continue the approval (2122-1365) to use the health data for research.

SHARE is a register of volunteers agreed to be contacted by SHARE and invited to participate in research.

Registrants permit HIC to interrogate their health records to check if they are eligible to participate in projects. Searches are completed using codes which look for e.g. disease information. HIC receives monthly data updates from Public Health Scotland, linking to SHARE registrants; this ensures data is relevant for searches completed for study applications.

Registrants also permit collection of leftover blood from routine clinical tests, to be used for anonymised genetic research.

SHARE contacts potential participants to ask if they would like to hear from researchers about studies; if so, researchers contact to explain the details; registrants can decide if they would like to participate or not.

Any information which has a potential to identify a person is removed in order to facilitate safe research. No individual is identified at any stage.

2324-0105 Prof Michel P Coleman London School of Hygiene & Tropical Medicine

Global surveillance of cancer survival (CONCORD programme)

This application refers to the 4th cycle of the CONCORD programme and to the VENUSCANCER study.

CONCORD-4 will update the surveillance of world-wide trends and inequalities in cancer survival in Scotland and many other countries. We will examine survival up to 5 and 10 years after diagnosis for 22 types of cancer in adults (aged 15-99 years at diagnosis) and all types of cancer in children (0-14 years) who were diagnosed during 2000-2019, or more recent years where data are available. Survival figures will be reported by age at diagnosis and for all ages combined, by sex, by country and, where possible, by race or ethnicity. Inequalities in cancer survival are likely to reflect differential effectiveness of health services. Estimates of the proportion of patients who may be considered "cured" after their cancer can be helpful for healthcare planners and clinicians who develop the treatment guidelines that are designed to reduce the burden of long-term clinical follow-up after diagnosis, both for patients and the health service.

The VENUSCANCER project is embedded within CONCORD-4. It aims to explain why international inequalities in survival for women with breast, cervical or ovarian cancer are so wide and so persistent. We aim to examine whether these inequalities are attributable to international differences in the biology of cancer, or in access to treatment, or in the socio-economic status of women with these cancers. For example, we will examine whether treatment for each type of cancer conforms to international guidelines, and we will report short-term survival. We will examine data for women diagnosed during 2015-2018. We expect to provide actionable evidence for health policy designed to reduce the burden of women's cancers world- wide.

2324-0138 Carole Morris PHS

Automated Feasibility Analysis (aka Cohort Discovery Tool)

eDRIS/Research Data Scotland (RDS) provide a service to Researchers to provision secure access to data for research. As one of the first steps in the process researchers must engage with eDRIS/RDS to understand whether there are enough cases and controls in the data held to answer their specific research question. This could be at the grant writing stage (where they need to provide such evidence to funding panels) or prior to drafting a data governance application. Asking such questions is called cohort discovery or feasibility analysis. A researcher may alter their question multiple times until a suitable cohort is discovered. Each time they do so, it is often the case that a member of the eDRIS team must write bespoke queries across multiple databases to determine the number of people who meet the search criteria. Each iteration can take significant effort of eDRIS team and significant time for researchers. Such cohort discovery/feasibility analysis is not cost recoverable as this work is prior to researchers obtaining funding for their research study.

This project will automate much of this process, providing a tool for researchers to directly query the number of cases and controls which are available within the PHS datasets. The underpinning data will not leave the control of PHS and all that will be returned to researchers will be fully anonymous counts of the number of records that meet their criteria.

Set up of this tool should:

- significantly reduce the time it takes for researchers to understand the data enough to put in their PBPP application to access the data
- reduce the amount of support researchers need from eDRIS/RDS
- allow researchers more opportunity to understand the data through rapid querying of the data – potentially leading to fewer challenges at later stages of the project
- reduce the burden on the eDRIS team, freeing eDRIS up to provide more support elsewhere.

An explainer video for a general audience about how this tool works can be found here:

https://www.youtube.com/watch?v=yvFrnbXlqRk and a general description here: https://www.healthdatagateway.org/about/cohort-discovery.

The infrastructure has already been tried and tested through the CO-CONNECT project, which connected COVID related datasets to the platform.

This application will expand the breadth of data available for researchers to query, to cover all diseases.

2324-0146 Dr Diana Withrow University of Oxford
Analysis of survival from blood cancer in the UK

Blood cancer is a type of cancer that affects the cells in your blood. There are three main types of blood cancer: leukaemia, lymphoma, and myeloma. There are many more subtypes within those categories. In the UK every year, more than 40,000 people find out they have blood cancer, and there are over 250,000 people living with it right now.

Blood Cancer UK has commissioned a study of blood cancer survival rates across and within the four nations in order to include the results in their UK Blood Cancer Action Plan. In the Action Plan, they will to show where differences in survival exist, to understand what needs to change to make sure that survival for all people with blood cancer in the UK is as high as is achievable. They recognize that lives can be saved by making sure that everyone has an equal chance of surviving blood cancer, no matter their ethnicity, how much money they have, or where they live in the country.

The audiences for the action plan and any related academic publications are people who are in positions to make decisions about the way care is delivered by health care professionals to people with blood cancer. This includes policy makers in government and the NHS but also within the pharmaceutical industry and other charities. Ultimately, the results can lead to changes in policy and resources to improve outcomes for people diagnosed with blood cancer.