

2024/2025 Applications approved by HSC-PBPP to 28th February 2025

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)
2324-0110 SR187	Dr Simon Cox	University of Edinburgh	Lothian Birth Cohort 1936 (LBC1936) study: renewal of deaths linkage application for SR187 (previously 1718-0327)	Approved	Tier 1 Review	12
2223-0090	Dr Alexander Doney	University of Dundee	Prediction of Individual Risk of Dementia (PIPaRD)	Approved	Tier 1 Panel Meeting	48
2324-0136 SR335	Dr Esther Ainley	Picker Institute Europe	Redesign of Urgent Care Evaluation	Approved	Tier 1 Review	46
2223-0016	Ashra Khanom	Swansea University	Building an understanding of Ethnic minority people's Service Use Relating to Emergency care for injuries.	Partial Approval (Approved with conditions)	Tier 1 Review	13
2122-0207	Rafael Pinedo-Villanueva	University of Oxford	The Fractured Ankle Management Evaluation (FAME) Trial	Approved with conditions	Tier 1 Panel Meeting	6
2324-0121	Dr Sarah Kotecha	Cardiff University	Clinical and cost-effectiveness of a maternity quality improvement programme to reduce excess bleeding and need for transfusion after childbirth: the Obstetric Bleeding Study UK	Approved with conditions	Full Committee	74
2223-0113	George Dunn	Royal College of Obstetricians and Gynaecologists	National Maternity and Perinatal Audit (NMPA)	Approved with conditions	Tier 1 Review	39
2324-0065 SR170	Professor John Cleland	University of Glasgow	Clinical Research in Heart Failure – Long-term follow-up	Approved with conditions	Tier 1 Review	25
2122-0173	Professor Bill Nailon	University of Edinburgh	PROSECCA: Improving radiotherapy in PROState cancer using EleCtronic population-based healthCAre data: The PROSECCA study, answering new questions in prostate cancer	Approved with conditions	Tier 1 Review	24

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2223-0157	Professor Chris Cardwell	Queen's University Belfast	Antibiotic use and survival from cancer	Approved with conditions	Tier 1 Panel Meeting	10
2324-0050 SR208	Professor Helen Colhoun	University of Edinburgh	SDRN Type 1 Bioresource (SDRNT1BIO) Data Linkage	Approved	Tier 1 Panel Meeting	13
2223-0194 SR239	Dr Andrew Wong	MRC Unit for Lifelong Health and Ageing at UCL	MR1 – Health and Development Study	Approved with conditions	Tier 1 Panel Meeting	14
2324-0106	Professor Fergus Caskey	University of Bristol	The High-volume Haemodiafiltration vs High-flux Haemodialysis Registry Trial (H4RT)	Approved	Tier 1 Panel Meeting	15
2324-0084 VC300V3	Dr Alethea McHardy	University of Glasgow	Gender and Scottish Veterans' Health	Approved with conditions	Tier 1 Review	18
2223-0005	Professor William Whiteley	University of Edinburgh	Establishment of Brain Health Data Pilot	Approved with conditions	Tier 2 OOC	44
1819-0250	Professor Colin McCowan	University of St. Andrews	Impact of Maternal & Paternal epilepsy medication use on child health outcomes	Approved with conditions	Tier 1 Review	21
2324-0233 SR276	Professor Amanda Cross	Imperial College London	Multicentre randomised controlled trial of 'once only' flexible sigmoidoscopy in prevention of colorectal cancer morbidity and mortality. Short Title: The UK Flexible Sigmoidoscopy Screening Trial (UKFSST)	Approved	Tier 1 Review	14
2324-0043	Dr Athina Spiliopoulou	The University of Edinburgh	Safety and real-world effectiveness of advanced treatments used in rheumatology and bone disease	Approved	Tier 1 Review	33
2324-0108	Miss Faith Campbell	University of Dundee	Intergenerational multiple long term conditions and pathways to oral health in early childhood	Approved	Tier 1 Review	30
2122-0033	Dr Dwayne Boyers	University of Aberdeen	REFLECT (A randomised controlled trial to Evaluate the effectiveness and cost benefit of prescribing high dose FLuoride toothpaste in preventing and treating dEntal Caries in high-risk older adultTs)	Approved with conditions	Tier 1 Review	20
2324-0192	Dr Maira Hameed	University College London Teaching Hospital	Magnetic Resonance Enterography (MRE) predictors of disease relapse after stopping biologics	Approved	Tier 1 Review	32
2223-0064	Dominique Hughes	University of Glasgow	Retrospective epidemiological study of upper limb amputations in Scotland between 2005-2019.	Approved	Tier 1 Panel Meeting	20

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2324-0160	Dr Mairead Black	University of Aberdeen	Cervical Ripening at Home or In-Hospital - prospective cohort study and process evaluation (CHOICE Study) extension	Approved	Tier 1 Panel Meeting	9
2425-0069	Dr Katherine Hawton	University Hospitals Bristol and Weston NHS Foundation Trust	ROHHAD* British Paediatric Surveillance Unit (BPSU) Survey	Approved	Tier 1 Panel Meeting	16
2223-0136	Dr Tamsin Nash	University of Edinburgh	How do socioeconomic inequalities arise in cancer care? Epidemiological analyses to identify priorities for treatment equity.	Approved with conditions	Tier 1 Review	18
1920-0146	Professor Phyo Kyaw Myint	University of Aberdeen	Enhancing a local birth cohort for the multidisciplinary study of ageing: Aberdeen Children of the 1950s (ACONF) in the years after retirement	Approved	Tier 1 Review	25
2324-0122	Ms Kate Hulse	NHS Lanarkshire	Scottish Laryngeal Dysplasia Audit	Approved	Tier 1 Review	19
2324-0011 SR336	Mrs Emily Zhao	University of Cambridge	The Epidemiological Study of Familial Breast Cancer (EMBRACE) Scotland Data Application	Approved	Tier 1 Panel Meeting	21
2324-0003	Simon Sawhney	University of Aberdeen	The effect of the herpes zoster vaccine on cardiovascular, cerebrovascular, and neurodegenerative diseases.	Approved with conditions	Tier 1 Review	25
2324-0130	Professor Peter Murchie	University of Aberdeen	NASCAR+: Exploring associations between geography, treatment, follow-up care and survival of cancer patients in Northeast Scotland	Approved	Tier 1 Panel Meeting	9
2324-0018	Dr Catriona Rooke	Scottish Government	Evaluation of the expansion of funded early learning and childcare to 1,140 hours: linkage of data on children's development from the Scottish Study of Early Learning and Childcare to Child Health Review data on development concerns.	Approved with conditions	Tier 2 OOC	37
1920-0032	Dr Úna McMenamin	Queen's University Belfast	Common medications and conditions and clinical outcomes in gynaecological cancer patients: a population-based investigation	Approved	Tier 1 Review	42
2324-0177	Dr Malihe Javidi	University of Edinburgh	Predicting neurodegenerative disease using the Scottish Collaborative Optometry and Ophthalmology Network e-research (SCONE) dataset	Approved	Tier 1 Panel Meeting	14
2223-0076	Dr Annemarie Docherty	The University of Edinburgh	Evaluation of interventions linked to treatable traits in acute critical illness in adults to enable precision medicine: Data	Approved	Tier 1 Review	13

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			enabled Bayesian adaptive platform randomised clinical trial with embedded biological characterisation (TRAITS)			
2223-0176 SR337	Zina Eminton	University of Southampton	BRITISH Study (Benchmark Risk Indication Tool for Implantable cardioverter defibrillators in patients with Non-Ischemic Cardiomyopathy and Severe systolic Heart failure)	Approved with conditions	Tier 1 Panel Meeting	6
2324-0254	Ms Alice Milligan	Moorfields Eye Hospital NHS Foundation Trust	Adult gonococcal eye infection: a study of the incidence, clinical features, management, complications and antimicrobial resistance in the United Kingdom.	Approved	Tier 1 Review	19
2324-0240	Elizabeth Nuthall	National Perinatal Epidemiology Unit (NPEU)	The neoGASTRIC trial	Approved with conditions	Tier 1 Review	37
2223-0046	Rosalind Brown	University of Edinburgh	Impact of COVID-19 on short and long term outcomes after stroke: R4VaD and COVID-19	Approved	Tier 1 Panel Meeting	13
2425-0108	Dr Suzanne Breeman	University of Aberdeen	Longer-term follow-up of the HEALTH trial (Hysterectomy or Endometrial Ablation trial for Heavy menstrual bleeding)	Approved	Tier 1 Panel Meeting	7
2425-0193	Professor James Cole	University College London	Access to the Brain Health Data Pilot (2223-0005 Whiteley) - Cole	Approved with conditions	Tier 1 Panel Meeting	13
2324-0102	Professor Aileen Mill	Newcastle University	Third study of infectious intestinal disease in the UK (IID3) – work package 5	Approved with conditions	Tier 1 Review	12
2425-0124 SR274	Acer Blake	UCL	Whitehall II	Approved	Tier 1 Panel Meeting	6
2021-0122	Andrew Boyd	University of Bristol	UK Longitudinal Linkage Collaboration: The National Trusted Research Environment for Longitudinal Research	Approved with conditions	Full Committee	67
2425-0031	Archie Campbell	University of Edinburgh	Generation Scotland linkage 2024-29	Approved with conditions	Tier 1 Review	18
2324-0023	Dr Maxim Wilkinson	Glasgow Caledonian University	Missed opportunities for blood-borne viruses' testing and diagnosis in Scotland	Approved	Tier 1 Panel Meeting	11
2425-0133	Carole Morris	PHS	Connect4: enriched metadata	Approved with conditions	Tier 1 Review	15
2223-0115 SR319	Professor Rosalind Eeles	The Institute of Cancer Research	UK Genetic Prostate Cancer Study	Approved with conditions	Tier 1 Review	28
2324-0239	Professor Amanj Kurdi	University of Strathclyde	Medicines in Acute and Chronic Care in Scotland (MACCS)	Approved	Tier 1 Panel Meeting	21

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<u>2425-0142</u>	Professor Jugdeep Dhesi	Older Person's Assessment Unit, Guy's and St Thomas' NHS Trust	Implementation of Comprehensive Geriatric Assessment based perioperative medicine services to improve clinical outcomes for older patients undergoing elective and emergency surgery with cost effectiveness	Approved with conditions	Tier 1 Review	37
<u>2425-0009</u>	Dr Oliver Llewellyn	University of Edinburgh	Nephrostomy and stent in obstructing pelvic malignancy	Approved with conditions	Tier 1 Review	32
<u>2324-0096</u>	Dr Emily Ball	The University of Edinburgh	How does physical health in later life influence depression risk?	Approved with conditions	Tier 1 Review	18
<u>2425-0083</u>	Professor Jill JF Belch	University of Dundee	POPADAD Follow-up Study	Approved	Tier 1 Panel Meeting	18

Lay summaries for approved applications

1819-0250 Professor Colin McCowan University of St. Andrews Impact of Maternal & Paternal epilepsy medication use on child health outcomes

Children born to mothers using antiepileptic drugs (AEDs) during pregnancy are more likely to have major malformations and significant developmental disorders. The highest risk is associated with sodium valproate, a drug commonly used in epilepsy, particularly in the young. As a result the Government agency responsible for the safety of medication have recommended that sodium valproate should no longer be used in women of child-bearing age.

There is little robust evidence with regards to the effect on offspring to assist clinicians and policymakers on whether sodium valproate can be used safely in men. Studies in animals have suggested valproate may affect sperm production but in clinical practice we know very little about children whose fathers were taking AEDs. One study has suggested there is no evidence of harm but further robust corroboration is needed.

Sodium valproate is commonly given to men of all ages with almost 3000 men in Greater Glasgow receiving it.

Using information from birth certificate records researchers are able to look at parents of specific children although all three people are pseudonymised to protect their identity. These recent developments will allow us to look at the effect of sodium valproate on health and development of children born to fathers taking this drug at and prior to conception. We will compare the developmental outcome of these children against others whose parents did not take anticonvulsant medication.

1920-0032 Dr Úna McMenamin Queen's University Belfast Common medications and conditions and clinical outcomes in gynaecological cancer patients: a population-based investigation

Gynaecological cancers of the endometrium (or womb), ovaries and cervix make up a significant burden of cancers diagnosed in females. Treatment of gynaecological cancers often involves removal of all or part of the reproductive organs, which presents challenges for younger patients who may wish to maintain fertility. Some hormonal therapies can be used to treat early-stage endometrial cancers, to delay surgery, but there is limited data with respect to their longer-term impact on survival. Other commonly prescribed medications (for example metformin, bisphosphonates) have also not been thoroughly investigated with respect to gynaecological cancer prognosis.

The Scottish Cancer Registry will provide robust information on cancer diagnoses and treatments. The detailed drug prescription data from the Prescribing Information System will provide information relating to drug use. Information on adverse events will be retrieved from hospital records. Linkage to the maternity records will provide information on birth outcomes. For additional comparisons, the Community Health Index (CHI) database will be used to identify cancer-free controls from the Scottish population.

This study will provide a unique opportunity to assess the potential harms associated with medications, and may lead to safety warnings for the use of these medications in Scotland (and elsewhere). Alternatively, potential benefits for some medications may be identified which may justify the conduct of randomised controlled trials in Scotland of medications used as an addition to cancer therapies. This research may also identify patients most at risk of developing adverse events after cancer diagnosis, who may benefit from more intense clinical follow-up.

1920-0146 Professor Phyo Kyaw Myint University of Aberdeen
Enhancing a local birth cohort for the multidisciplinary study of ageing:
Aberdeen Children of the 1950s (ACONF) in the years after retirement

The purpose of this project is to follow-up the Aberdeen Children of the 1950s (ACONF) cohort study members by postal questionnaire. Founded in 1962 and followed-up in 2001, the cohort provides a wealth of information on 12,150 adults born in Aberdeen and has been used extensively by a range of researchers to answer scientific questions in social epidemiology, social sciences, and public health. The cohort is currently registered as a research database.

As the cohort members enter their seventies, we propose to ask them about their current life circumstances including health and wellbeing, lifestyle behaviours, social connections and family life, as well as socioeconomic trajectories. This will provide additional data and enable researchers to further a broad population health research agenda that includes the biological, psychological, and social aspects of ageing from a longitudinal perspective. Despite the cohort members' consent to be recontacted in future, those records are now 20+ years old. We therefore seek permission and assistance from Public Health Scotland to establish status and whereabouts of cohort members using the Community Health Index. Public Health Scotland will provide address information to an external company, who will process this data for the sole purpose of mailing study packs, and update the study team with information about cohort members' vital status and whether their records were successfully retrieved so that they could be used for mailing. The resulting data from returned questionnaires will be compiled and added to the existing records as part of ACONF as a research database. Finally, we will conduct data analysis in order to produce an updated cohort profile to facilitate and guide future research endeavours.

2021-0122 Andrew Boyd University of Bristol
UK Longitudinal Linkage Collaboration: The National Trusted Research
Environment for Longitudinal Research

The UK has a long-standing tradition of conducting 'longitudinal research'. Longitudinal studies work by selecting a group of individuals or properties and then repeatedly collecting data on them. The groups of people – known as 'cohorts' – are typically selected by having something in common, such as cohorts of pregnant women or people living in a certain

area. The value of longitudinal research lies in collecting a broad range of data, and then repeating this data collection at regular intervals.

For many years the data provided by study participants has been enhanced by 'linking' data collected by the study to data in participants health and other routine government records (such as school records) with their consent. UK Longitudinal Linkage Collaboration (UK LLC) has developed a new centralised approach for linking study participants to their routine records. UK LLC hosts the linked data in a Trusted Research Environment – a highly secure computing system - where this data can be used in research.

Longitudinal study data allows researchers to investigate the interactions between different things that occur in individuals lives and how changes in this can lead to changing health status or personal circumstances. Linking this data with routine and environmental records provides new information which is hard to collect directly from people and data which can improve the accuracy of study findings. It is also a way in which groups who find active study involvement difficult can be included in the research and therefore benefit from the value research brings.

2122-0033 Dr Dwayne Boyers University of Aberdeen
REFLECT (A randomised controlled trial to Evaluate the effectiveness and cost
benefit of prescribing high dose FLuoride toothpaste in preventing and treating
dEntal Caries in high-risk older adulTs)

Standard fluoride toothpaste available to buy on the high street contains around 1400 parts per million (ppm) fluoride. Despite the lack of clear evidence of a clinical benefit, dentists are advised by national guidance to prescribe high dose fluoride toothpaste, containing 5000ppm fluoride, to patients judged to be at risk of tooth decay. In 2016 prescriptions of high dose fluoride toothpaste cost the NHS over £20 million and these costs are increasing rapidly.

The REFLECT study (a randomised controlled trial to Evaluate the effectiveness and cost benefit of prescribing high dose FLuoride toothpaste in preventing and treating dEntal Caries in high-risk older adulTs) was commissioned and funded by the National Institute for Health Research (NIHR) Health Technology Assessment programme to investigate the clinical and economic outcomes of prescribing high concentration fluoride toothpaste to older adults in primary dental care. The study aims to establish whether prescribing high concentration fluoride toothpaste offers good value for money to the NHS, by reducing the need for dental treatments. Access to the routine dental data set is required for one of the main outcomes to compare the treatment and costs of care received by trial participants randomised to receive high fluoride toothpaste with those randomised to usual care only. To calculate net benefits, the primary economic outcome, we need to know about all dental care received by trial participants for the duration of study follow-up including information on individual treatment items provided, patient exemption status and treatment dates. This information will ensure that we derive the correct breakdown between NHS and patient incurred charges so that different stakeholders are provided with the most relevant information to aid decision making.

2122-0173 Professor Bill Nailon University of Edinburgh
PROSECCA: Improving radiotherapy in PROState cancer using EleCtronic
population-based healthCAre data: The PROSECCA study, answering new
questions in prostate cancer

Methods to personalise an individual's radiotherapy treatment have, to date, been based on biological information and the use of new radiotherapy treatment machine technology. Little or no account is taken of the vast array of data that is available for each patient from their healthcare record, the extensive digital imaging data collected at diagnosis and during treatment, and during a course of radiotherapy.

We are proposing the use of advanced computing techniques to analyse the healthcare records from 10,000+ prostate cancer patients who underwent radiotherapy in the treatment of their cancer in Scotland. Through in-depth analysis of the data from each patient's unique healthcare history we believe that we will discover new relationships between a patient's medical history and how well they respond to radiotherapy in treating their cancer. By establishing what factors in a patient's complex healthcare record indicate that they may have a poor response to treatment, or an increased risk of side effects from radiation, it will be possible to identify these patients earlier and adapt their treatment accordingly. Furthermore, by identifying these important factors we would aim to improve radiotherapy treatment for prostate cancer patients in the future.

Nearly half of all cancer patients receive radiotherapy as part of their treatment and although it is effective at destroying cancerous lesions deep within the body, this comes at the cost of damaging healthy, or normal, tissues. With 50% of cancer patients surviving for 10 years or more, these patients can be left with life-changing side effects from their radiotherapy. It is clear that more must be done to limit damage to normal healthy tissue without compromising annihilation of the tumour and curing patients. The key to this is personalising an individual's radiotherapy treatment, in other words rather than assuming that all tumours respond similarly to radiotherapy, the treatment is optimised for an individual. To date, approaches to do this have been restricted to small numbers of carefully selected patients, are inordinately expensive, and not suitable for rolling out into everyday practice across the NHS. There is however another way, namely AI combined with one of the most valuable datasets we have, our healthcare record. By linking together large numbers of healthcare records at a national level, combined with the power of AI, the PROSECCA project will transform radiotherapy and cancer care.

As an example of how this technology is beginning to emerge, proof of concept data from our team has shown that using AI it is possible to identify patients at increased risk of damage from radiotherapy long before they receive any radiation as part of their treatment. However, to move these AI-based approaches from the research domain into the clinic requires significant effort, which is the aim of PROSECCA study.

We are proposing the use of AI to analyse healthcare records from up to 15,000 prostate cancer patients who underwent radiotherapy in the treatment of their cancer in Scotland. Through linkage of data obtained specifically for radiotherapy and data held within each patient's unique healthcare history it will be possible to establish new relationships between a patient's medical history and how well they respond to radiotherapy in treating their cancer. By establishing what factors or information in a patient's complex healthcare record

indicate that they may have a poor response to treatment, or an increased risk of side effects from radiation, it will be possible to identify these patients earlier than is currently possible and adapt their treatment accordingly. Furthermore, by identifying these important factors we would aim to improve radiotherapy treatment for prostate cancer patients in the future.

2122-0207 Rafael Pinedo-Villanueva University of Oxford
The Fractured Ankle Management Evaluation (FAME) Trial

Ankle fractures can cause pain and physical impairment for months or years after injury. Treatment aims to maintain the alignment of the ankle joint while reducing the risk of complications. Unstable fractures involve bones and ligaments, which can tear or pull off a small chip of bone where they attach. They are usually treated with surgery, but this can cause complications. Non-surgical treatments like close contact casting (CCC), which involves applying a snug plaster cast carefully shaped to your ankle to hold the bones correctly while they heal can avoid surgical complications but may yield inferior outcomes compared to surgery. A previous study showed that outcomes for ankle fractures in patients over 60 years of age were equivalent for patients treated with CCC or surgery.

This trial aims to investigate whether CCC treatment for unstable ankle fractures in younger adults will yield similar outcomes compared to surgical treatment. Specifically, the objective of the trial is to determine whether ankle function, four months after treatment in patients with unstable ankle fractures treated with CCC, is not worse than in those treated with surgical intervention, which is the current standard-of-care. A comparative cost-effectiveness analysis between the trial treatment groups over five years will be conducted alongside the trial.

Randomisation will be used to produce two groups of patients: those who undergo surgery, and those who undergo CCC. Participants will be asked if they consent for their confidential information to be shared for the purposes of the trial analysis. The results will be presented and published internationally. The findings of this trial will also inform the NICE 'non-complex fracture' (i.e. those that can be treated in the emergency department or orthopaedic clinic) recommendations at their anticipated update in 2024. A report of long-term outcomes at five years will be produced at the end of the project.

2223-0005 Professor William Whiteley University of Edinburgh
Establishment of Brain Health Data Pilot

The Brain Health Data Pilot (BHDP) project aims to be a shared database (like a library) of information for scientists studying brain health, especially for diseases like dementia, which affects about 900,000 people in the UK. Its main feature is a huge collection of brain images linked to routinely collected health records, both from NHS Scotland, which will help scientists learn more about dementia and other brain diseases. What is special about this database is that it will get better over time – as scientists use it and add their discoveries, it becomes more valuable.

This project is also mindful of the environment and cost. It tries to reduce the time, money, and environmental impact of studying this kind of brain image data. Keeping the data safe and private is important so, the project follows strict rules to make sure the information is easy to find, use, share, and re-use, all while keeping it secure. The data will be stored in a very safe computer system called the National Safe Haven. All research outputs will be checked to ensure that individual-level data will not be released.

More than just a database, the BHDP wants to build a community where scientists work together in new ways to better understand and take care of our brain health. The project is funded by the Alzheimer's Disease Data Initiative (AD Data Initiative), a medical research organisation that aims to speed up breakthroughs in understanding and treating brain diseases.

2223-0016 Dr Ashra Khanom Swansea University
Building an understanding of Ethnic minority people's Service Use Relating to
Emergency care for injuries.

BE SURE aims to understand how people from minority ethnic backgrounds present their injuries to emergency ambulance services and emergency departments. We want to know if there are differences in the care they receive and what happens to ethnic minorities when presenting with injuries, compared to the white British population.

Part 1: We will examine past health records between August 2016 and July 2021 for those that went to hospital or were seen by an ambulance with an injury. These records are anonymous so that individual identities are protected. We will compare the health care treatments provided and care outcomes of people from ethnic minority backgrounds to those with a white British background.

We hope to publish our findings in scientific journals, social media outlets and public websites to increase awareness of any disparities and hopefully improve our NHS.

2223-0046 Rosalind Brown University of Edinburgh
Impact of COVID-19 on short and long term outcomes after stroke: R4VaD and
COVID-19

Stroke is one of the most prevalent diseases worldwide and the lack of information relating to potential cognitive issues following a stroke has been highlighted as a major concern for patients, their families and carers, as well as becoming a priority for funders. Rates, Risks and Routes to Reduce Vascular Dementia (R4VaD) is a UK-wide study of memory and thinking problems after stroke. It commenced recruitment in Sept 2018 and completed recruitment in December 2022 with 2442 participants. Patients are recruited 4-8 weeks after stroke, complete early follow up a few weeks later, then annual assessment up to 2 years.

The aim of this proposal is to link to available SMR01, SMR04, NRS deaths, and prescribing information datasets, which will allow us to find out further outcomes for our participants,

including whether they have had a recurrent stroke or vascular event, whether there have been changes to their medication and whether or not they are still alive. This important information will allow us to build on our findings in the main study and assist with our work on whether we can predict memory and thinking problems after stroke, how common it is and what the outcomes for participants are.

We also collected information on covid-19 infection in our cohort and would like to determine how this has impacted survival by collecting further information on hospitalisation of stroke patients with covid-19 and outcomes.

Stroke and dementia are two of the most common diseases worldwide. People who have had a stroke are at an increased risk of difficulties with their memory and thinking, and increasing our understanding of the link between stroke and dementia has been highlighted as a priority for patients, their families and carers. Rates, Risks and Routes to Reduce Vascular Dementia (R4VaD) is a UK-wide study of memory and thinking problems after stroke. It recruited 2442 patients who had experienced a stroke, between 2018 and 2022.

Participants were followed up for up to two years after recruitment. The aim of this proposal is to link the data collected from the baseline and follow up visits with routinely-collected hospital admissions (medical and psychiatry admissions), mortality and prescribing data. By obtaining linkage to these datasets we will have longer follow up data to enable us to explore the links between having a stroke and later developing dementia, further strokes, death, and other problems.

There are important links between COVID-19 and stroke. We know that people who have a COVID-19 infection are at an increased risk of stroke, but we do not know how an infection may affect someone's longer term risk of dementia, hospitalisation, further stroke and death if they have already had a stroke. We will also explore the effects of the COVID-19 pandemic itself on these outcomes, as we know that people had reduced access to health and social care during the early stages of the pandemic.

In the short term, the results of this study will improve our understanding of the long term consequences of stroke including dementia and how COVID-19 may affect these outcomes. In the longer term, this information will feed into the development of trials of treatments and public health policies, aimed at reducing the risk of post-stroke dementia.

2223-0064 **Dominique Hughes** **University of Glasgow**
Retrospective epidemiological study of upper limb amputations in Scotland
between 2005-2019.

Upper limb amputation is a highly debilitating injury, with life-altering consequences. It can range from amputation of a single finger or tip only to amputation of the entire hand, forearm or upper limb and anything in between.

Across the United Kingdom, there is a vast discrepancy in health services available to these patients. In Scotland there has been no study that has reviewed the distribution, patterns and determinants of upper limb amputations or the health service utilisation for upper limb amputation patients. The researchers will review the cases of patients who underwent some form of upper limb amputation from 01/01/2005 to 31/12/2019 in Scotland.

By using data provided by Public Health Scotland we will describe the epidemiology of upper limb amputation in Scotland in the years 2005-2019, in terms of nature of injury, the frequency and distribution and causes. We will also report on the total number of upper limb amputations and numbers according to different demographics. In relation to patients' hospital admissions, we will review the information on admitting specialities, length of stay, hospital size, discharge destinations, number of admissions per patient and mortality. Finally, we will use the data to determine the frequency of outpatient attendances and attendances at anaesthetic, physiotherapy and occupation therapy, pain and psychiatric clinics post injury as a marker of the quality of life and incidence of chronic pain in this patient group.

The researchers hope is that by defining the burden of this injury type in terms of health resource utilisation this will permit future health economic assessment and future service design. Ultimately, we aim to lay the groundwork for this patient group, and improve service delivery, generating evidence to support future research.

2223-0076 **Dr Annemarie Docherty** **The University of Edinburgh**
Evaluation of interventions linked to treatable traits in acute critical illness in adults to enable precision medicine: Data enabled Bayesian adaptive platform randomised clinical trial with embedded biological characterisation (TRAITS)

Critical illness is a challenge all over the world. In Scotland, around 1 in 5 patients admitted to ICU will die during their hospital stay, and around 2 in 5 will die within 60 days of their hospital stay. The TRAITS programme aims to enable time-critical precision medicine (TCPM) to be used in critically ill patients to see if matching treatments to patients improves their outcomes.

Precision Medicine is about giving the right treatment to the right patient at the right time. Precision Medicine is growing in use in cancer care, providing precise treatments for patients based on their genetics or proteins. Currently it isn't used in ICU because patients admitted to ICU have life threatening illnesses and doctors need to make decisions on the best way to treatment very quickly. It means that it is not always possible to wait for test results to match interventions like what is done for cancer patients.

In TRAITS we will apply precision medicine to critically ill patients by first grouping them into trait groups. Trait groups are groups of patients whose bodies are fighting disease or injury in the same way - this means the same treatments can be used for each group. Patients who are in a trait group will be randomised to a specific treatment and usual care, or usual care alone. We will follow up all patients, and use this data to make decisions on whether the specific treatment (or precision medicine) has made a difference to these patients outcomes compared to the patients that are treated in the usual way.

2223-0090 Dr Alexander Doney University of Dundee
Prediction of Individual Risk of Dementia (PIPaRD)

Dementia, particularly Alzheimer's, remains largely a clinical diagnosis, which means it is based on a doctor's assessment of symptoms such as memory impairment and other psychological tests. Brain scans may be used to exclude other possible diseases of the brain, but the disease process underpinning dementia occurs at a microscopic level throughout the brain tissue and even well-trained clinical radiologists are not able to see or describe the subtle indicators of its presence. We have been developing an artificial intelligence (AI) algorithm that can "look" at a brain scan and distinguish the presence of very early disease in people who therefore have high future risk of developing dementia symptoms.

We did this using data from the Scottish Health Research Register (SHARE) which comprises individuals across Scotland who have consented to their medical records being used for research. We used healthcare data collected over many years to find patients who had undergone brain Magnetic Resonance Imaging (MRI) for any reason in the past. We then excluded all patients who, on or near the date of the MRI brain scan, already had evidence of a diagnosis of dementia in their medical record. We then found those who developed evidence of dementia in the medical record after the scan and then trained an AI algorithm to "look" at MRI brain scans to distinguish between these patients and those who remained dementia free.

In SHARE we were only able to make a dataset of 500 individuals. To further train the AI algorithm to have a clinically meaningful accuracy as well as external validity (ie be broadly applicable to many healthcare settings) we require a much larger training dataset. Using data from people across the whole of Scotland will provide the required scale and population-wide representativeness, long-term follow-up, and real-world variation needed to achieve this.

People who have very early dementia disease but no symptoms yet, have the most to gain from disease prevention strategies and medical treatments. Demonstrating the ability to detect such individuals using a routine image of the brain could in future empower people to manage their own risk of brain diseases, streamline trials of new treatments, and support improved healthcare delivery.

2324-0102 Professor Aileen Mill Newcastle University
Third study of infectious intestinal disease in the UK (IID3) – work package 5

This application relates to the input of Public Health Scotland (PHS) to the third study of Infectious Intestinal Disease (IID) in the UK (IID3). IID are human illnesses, usually characterised by diarrhoea and/or vomiting, caused by infectious agents such as bacteria, viruses, or very small parasites. There have been two previous UK-wide studies of IID; in the 1990s and early 2000s. This third study aims to update estimates of how great a health burden these diseases are, and what the main causes are. IID3 is a multi-partner project, led by Newcastle University and commissioned by the Food Standards Agency.

For this project, PHS will share Scottish national surveillance data relating to: (1) positive tests for IID organisms from Scottish microbiology laboratories; (2) NHS24 calls about

diarrhoea or vomiting. The research team will compare this with data from other parts of the study that diagnose and record all cases of IID in patients recruited to the study, and in patients attending their GP. Surveillance systems capture only some IID cases, in part because not everyone with symptoms seeks medical attention. The comparison will tell us how well our current surveillance methods detect disease burden for different infectious agents.

More reliable estimates of IID rates are important to identify the real impact of changes in surveillance figures, target new areas of concern early, understand risks for the population and better judge whether interventions are working.

2223-0113 George Dunn Royal College of Obstetricians and
Gynaecologists
National Maternity and Perinatal Audit (NMPA)

The National Maternity and Perinatal Audit (NMPA) is a large-scale project that uses information recorded as part of women's NHS care during pregnancy and birth to look at a range of outcomes that women and babies may experience.

The NMPA aims to support improvements in maternity and perinatal care by providing national figures and enabling comparison between maternity services. The audit is funded by NHS England and NHS Improvement, the Welsh Government and the Health Department of the Scottish Government.

The NMPA uses information collected as part of women's maternity care, combined with information collected when women are admitted to hospital and information recorded when babies are admitted to a neonatal unit.

The NMPA results take into account that there can be differences between maternity services in terms of characteristics of the women who give birth; for example, the proportion of first time mothers can influence results, as they have a higher chance of some procedures and outcomes. Adjusting the results for such differences makes it easier to compare services.

2223-0115 SR319 Professor Rosalind Eeles The Institute of Cancer Research
UK Genetic Prostate Cancer Study

The UKGPCS was first established in 1992 1993 and is the largest prostate cancer study of its kind in the UK, involving nearly 200 hospitals.

We are based at The Institute of Cancer Research in Sutton, Surrey, and collaborate with The Royal Marsden NHS Foundation Trust. Our aim is to find genetic changes which are associated with prostate cancer risk. If we can find alterations in genes that increase the chances of getting prostate cancer, it may be possible in the future to use this knowledge to screen other family members to see if they are also at a higher risk of developing prostate cancer. We would also be able to develop new prostate cancer treatments for the future.

The study recruited patients who gave consent to participate in the study. Identifying details of consented participants were provided to NHS England (or predecessor organisations) for linkage. Notifications of participant deaths (date and cause of death), cancer registrations and Demographics data (NHS number, Forenames/Surname, latest patient registration) were provided back to the ICR for the purpose of the study.

By 2023, the study had recruited over 23,826 participants and the study closed to recruitment on 27/11/2023 but is kept open for treatment follow up until 31/12/2027. Each consented patient gives a saliva or blood sample, and a family history questionnaire, and The Institute of Cancer Research (ICR) obtain clinical data from their referring hospital or consultant.

The study aims to find genetic changes which are associated with prostate cancer risk. If the study can find alterations in genes that increase the chances of getting prostate cancer, it may be possible in the future to use this knowledge:

- To screen other family members to see if they are also at a higher risk of developing prostate cancer,
- To develop new prostate cancer treatments for the future.

The planned outputs have included over 50 published papers in peer-reviewed scientific journals which have been submitted over the last 30 years, on the causes and risks of prostate cancer and cause-specific mortality. Recently, the NHS England data received for the UKGPCS study have been used to develop a genetic risk model that can provide personalised predicted prostate cancer risks based on known moderate-to high-risk pathogenic variants, low-risk common genetic variants, and explicit cancer family history. The model will assist in counselling men concerned about their risk and can facilitate future risk-stratified population screening approaches.

451 regions of the genome have now been associated with prostate cancer (the majority found by the UKGPCS research group and collaborations). This new result will be important for risk assessment in multi-ethnic populations.

The Institute of Cancer Research has also publicised the results to patients and society more widely by press releases and blogs, to professional standard, from the Institute's very active communications department.

Further aims of the study are to find new genetic markers to identify who might be at risk of developing prostate cancer in the future; to be able to target appropriate treatments more accurately to those patients who are most likely to have aggressive disease and to develop new drug treatments for prostate cancer. This has the potential to be able to target screening to those who would benefit from this manoeuvre and the potential to improve survival.

2223-0136 Dr Tamsin Nash University of Edinburgh
How do socioeconomic inequalities arise in cancer care? Epidemiological analyses to identify priorities for treatment equity.

Despite Scotland offering universal healthcare to all patients, inequalities in cancer outcomes exist for those from poorer backgrounds and patients in ethnic minorities. There

are multiple reasons why patients in these groups might struggle to access good quality treatment. However, previous work has been unable to show whether the quality of treatments is different for patients in these demographic groups, or whether this explains differences in survival.

This study will use new National Quality Performance Indicator (QPI) data, National Systemic Anti-Cancer Therapy (SACT) data and the 2011 Census to answer these questions. The project work is divided into two phases or 'work packages'.

Work package 1:

In work package 1, we will develop protocols to link data sets together and discover which elements of the new data are of the best quality and are most useful for clinical research. This step is necessary because the new QPI and SACT datasets have not been used for research before. We also plan to describe how accurately ethnicity is recorded in PHS datasets compared to the 2011 Census. If ethnicity is not recorded very accurately, this makes it difficult to understand whether services are provided equitably. We will measure the effect of ethnicity on survival for cancer patients, and how estimates derived from health data compare to the 'gold standard' Census data.

This will require us to collaborate with the PHS Cancer team, who will provide us with access to the data. PHS will also benefit as this project will help them to develop protocols and validate their data .

Work package 2: describe how the quality of cancer treatment varies by socioeconomic position for breast, bowel, cervical and lung cancer.

We will use the data that from work package 1 to develop standardised measures of treatment quality.

SACT data contains more detail than has previously been available, such as regimens of chemotherapy, and the length and specific doses of treatment. National QPI data contain information on treatment quality, such as the way patients were referred, the time between referrals and treatments, and molecular tests. By linking these data to other health records, we will be able to describe the quality of treatment delivered to individuals. We will assess whether treatment quality differs by ethnic group and socioeconomic position (SEP), and how this affects patients' survival from cancer. We will need to consider differences in general health and age, the stage of their cancer at diagnosis, and rurality, as these factors can influence the treatments offered to patients.

Past studies looked at how neighbourhood deprivation affects survival rates using measures such as the Scottish Index of Multiple Deprivation (SIMD). But this doesn't tell the whole story, as many people who live in affluent areas face deprivation as individuals. The 2011 Census provides more detailed information, like occupation and education. We will use both SIMD and Census data to describe variation in the quality of treatment by SEP and ethnicity, as well as survival. We will then model how survival might improve if all patients received the same high quality standard of treatment. This will help us understand where to focus efforts to make sure everyone gets the best treatment possible.

2223-0157 Professor Chris Cardwell Queen's University Belfast
Antibiotic use and survival from cancer

Recent animal studies have suggested that antibiotics could impact upon cancer progression. Antibiotics are widely used to treat infections in patients with cancer. However, the impact of antibiotics on cancer development and progression has received limited attention.

Our objectives are to determine whether cancer patients who frequently use oral antibiotics have increased risk of cancer-specific mortality. We will investigate cohorts of patients with common cancer from Scotland. Cancer registry data will be used to identify cancer patients, national mortality records to capture death from cancer and dispensing records to determine frequency and type of antibiotics prescribed.

Our study will provide evidence on the association between antibiotic use and survival in patients with common cancer. Should our study observe differences in survival in cancer patients using antibiotics this could inform antibiotic prescribing practices in cancer patients.

2223-0176 SR337 Zina Eminton University of Southampton
BRITISH Study (Benchmark Risk Indication Tool for Implantable cardioverter
defibrillators in patients with Non-Ischemic Cardiomyopathy and Severe systolic
Heart failure)

The **Benchmark Risk Indication Tool** for Implantable cardioverter defibrillators in patients with Non-Ischemic Cardiomyopathy and **Severe systolic Heart failure** (BRITISH) trial is investigating whether we can improve the way we treat patients who have non-ischaemic cardiomyopathy (NICM).

Some patients with NICM have a higher risk of experiencing serious abnormal heart rhythms that might be life threatening. Current guidelines recommend doctors consider fitting a device that can correct these serious abnormal heart rhythms. This device is called an Implantable Cardioverter-Defibrillator (ICD). However, we know from previous research studies that a lot of patients – perhaps as many as 90% - who have an ICD never need to use it because they won't experience any serious heart rhythm abnormalities.

We want to try and work out which patients will benefit from having an ICD and which patients are better off not having an ICD.

Research has shown that patients who have scar tissue in their heart, seen on Cardiac Magnetic Resonance Imaging (CMR), are at a higher risk of dying suddenly from an abnormal heart rhythm. We would like to test whether the presence of scar tissue on the heart scan (CMR) can be used to decide if patients need an ICD or not.

Currently, there is no agreement on how best to decide which patients with Non-Ischaemic Cardiomyopathy actually need an ICD. The BRITISH Trial aims to answer this question. The information gained from this research has the potential to change treatment guidelines and improve how patients with this condition are managed around the world.

In this application, we are requesting yearly death data for the patients randomised into the study during the recruitment phase. This is to ensure that we provide accurate data to the committee that review the study data to ensure that the study does not present any additional risk to the patients taking part and to monitor the safety of the study

2223-0194 SR239 Dr Andrew Wong
and Ageing at UCL
MR1 – Health and Development Study

MRC Unit for Lifelong Health

The MRC National Survey of Health and Development (NSHD, 1946 British birth cohort study) is the oldest and longest running of the British birth cohort studies. The NSHD study team is housed within the MRC Unit for Lifelong Health and Ageing (LHA) at University College London.

The NSHD has followed up the study members for the past 78 years and their data has informed UK health care, education, and social policy. Today, with study members in their late seventies, the NSHD offers a unique opportunity to explore the long-term biological and social processes of ageing and how ageing is affected by factors acting across the whole of life.

As the cohort is entering older age, health care utilisation becomes increasingly frequent and study members are thus less likely to report health events or hospital admissions over a number of years accurately. It is therefore important to capture this information in other ways. We therefore request data linkage to several datasets held within Public Health Scotland, including hospital admissions, outpatient, Accident and Emergency, mental health, and COVID-19 datasets, and cancer and mortality registration.

This proposal aims to link this NHS health information to our already existing rich dataset, which includes brain and heart imaging, cognitive and physical function, social, lifestyle, self-reported health, biomarker, and genetic data, collected since 1946. The overarching aim of this research is to investigate the risk and protective factors from across the life course that influence the ageing process. Findings from this research will inform policy in this area.

2324-0003 Simon Sawhney University of Aberdeen
The effect of the herpes zoster vaccine on cardiovascular, cerebrovascular, and neurodegenerative diseases.

A first infection with the varicella zoster virus manifests as chickenpox, after which the virus remains “hibernated” in nerve cells in the body and can break out occasionally to cause shingles. Shingles in people who are elderly or immunocompromised can be serious, and sometimes life-threatening. The virus has also recently been linked with the potential development of inflamed blood vessels (in the heart and brain), but the consequences of this are uncertain. This means that shingles may have a greater role in the deterioration of health in elderly people than is currently recognised. There is an effective vaccine to reduce the chance of getting shingles. Since 2013 the vaccine has been available to everyone in

Scotland, England and Wales aged 70 - 79 through a progressive rollout. The benefits of this policy across all groups of people, and consequences both for shingles and other conditions also linked to the virus in the elderly are uncertain. It would not be feasible to test this through a randomised controlled trial because the policy was widespread and occurred 10 years ago. In fact, the specific practicalities of this particular annual roll out led to a “birthday paradox” each year where some people become eligible and others do not despite having a difference in age of just a few days. This means that while a trial is not possible, it is possible, using data linkage of routine national datasets and advanced statistical methods to use “pseudo”-randomisation approaches that our team have developed to address this need.

A first infection with the varicella zoster virus manifests as chickenpox. After the initial infection, the virus remains “hibernated” in nerve cells in the body and can reactivate to cause shingles. In elderly or immunocompromised individuals, shingles can be serious, and sometimes life-threatening. Recently, the virus has been linked to potential inflammation of blood vessels in the heart and brain, but the consequences are uncertain. This suggests shingles may have a greater role in the deterioration of health in elderly people than currently recognised.

There is an effective vaccine to reduce the chance of getting shingles. Since 2013, the vaccine has been available to people aged 70 - 79 in Scotland, England and Wales through a progressive rollout. Each year, the vaccine is given to a new group of people turning 70, as well as a catch-up cohort, consisting of individuals aged 79 (or 78) years. The eligibility for the annual rollout is based on an exact date of birth cutoff each year, leading to a “birthday paradox”. Some people become eligible and others do not, despite having a difference in age of just a few days. In 2013, anyone born before September 2, 1933, never became eligible for the vaccine.

Our aim is to understand the benefits and impact of this policy on both shingles and other conditions linked to the virus across all groups. Leveraging the eligibility cutoff and applying advanced statistical methods to linked routine national datasets, our team developed “pseudo”-randomisation approaches to study the effects of the vaccine.

2324-0011 SR336 Emily Zhao University of Cambridge
The Epidemiological Study of Familial Breast Cancer (EMBRACE) Scotland Data
Application

The Epidemiological Study of Familial Breast Cancer (EMBRACE) aims to better understand how certain genetic mutations increase the risk of breast and ovarian cancer, along with other types of cancer. These mutations occur in genes such as BRCA1, BRCA2, PALB2, and others. Knowing if someone carries these mutations can help doctors make important decisions about their treatment and how to manage their cancer risk. This study focus on people across the United Kingdom, including Scotland, who have these mutations and tracks their health over time.

While we know that these mutations increase the chances of developing cancer, we don't fully understand the risks involved for different types of cancers or how factors like lifestyle and other genes might affect these risks. The EMBRACE study will help fill those gaps in

knowledge and improve the way we manage cancer risk for those with these genetic mutations.

The EMBRACE study collects information on lifestyle factors, like exercise and diet, through questionnaires over the course of 20 years. Participants also provide blood samples, and permission to access their health records, including cancer diagnoses, treatments, and outcomes.

How will this benefit health and social care in Scotland and beyond? The results will help doctors and patients make more informed decisions about cancer prevention and treatment. By providing accurate cancer risk estimates and identifying the best ways to reduce those risks, this research will improve cancer care and help reduce the number of cancer-related deaths among those with mutations in these cancer genes.

2324-0018 Dr Catriona Rooke Scottish Government
Evaluation of the expansion of funded early learning and childcare to 1,140 hours: linkage of data on children's development from the Scottish Study of Early Learning and Childcare to Child Health Review data on development concerns.

From August 2021 the entitlement to funded early learning and childcare (ELC) in Scotland increased from 600 to 1,140 hours per year. This expansion of ELC aims to contribute to improving children's development and increasing parents' opportunities to take up work, study or training.

The Scottish Study of Early Learning and Childcare (SSELC) is collecting survey data to evaluate whether and how the ELC expansion has improved child and parent outcomes. To evaluate the impact of increased ELC hours, the development of two different groups of children is compared at the point they leave ELC in 2019 (the 'pre-expansion' group) and 2024 (the 'post-expansion' group) at age 4-5. However, the timing of the Covid-19 pandemic meant that the post-expansion group experienced both pandemic lockdowns. Evidence shows that the pandemic has negatively affected children's development. So we need to try to account for any possible effect of the pandemic on children's outcomes when assessing the impact of the ELC expansion.

To do this we wish to link two of the SSELC survey datasets to individual-level Health Visitor data that measured developmental concerns when children were aged 27-30 months – prior to starting funded ELC. To estimate the impact of the pandemic, differences in the proportion of children with a developmental concern would be compared between the two groups.

The results of the wider evaluation of the expansion of funded ELC will guide future decisions about provision and funding of ELC in Scotland, and will support improvement of ELC provision.

2324-0023 **Dr Maxim Wilkinson** **Glasgow Caledonian University**
Missed opportunities for blood-borne viruses' testing and diagnosis in Scotland

Blood borne viruses (BBVs), including Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV) & Hepatitis C Virus (HCV), greatly impact the lives of many people in Scotland. The Scottish Government has developed three strategies to tackle BBVs:

- i. HCV elimination strategy,
- ii. HIV transmission elimination delivery plan and
- iii. Sexual Health and Blood Borne Virus Action Plan.

This project aims to inform these Scottish strategies by identifying healthcare settings for new or enhanced interventions. The analysis will determine if we are missing opportunities to test and diagnose people living with chronic BBV infection. We will focus on missed opportunities for testing in hospital and A&E (Accident and Emergency) settings.

To do this we will use the Community Healthcare Index (CHI) number, a unique patient identifier, to link data sets on people tested and diagnosed with BBV to hospital and deaths data to establish who had a late diagnosis for a BBV. For HCV and HBV this will be indicated by presentation to hospital or death with severe liver disease within two years of their diagnosis. For HIV, we can base this on a patient's white blood cell count at the point of diagnosis. Thereafter, we will take this cohort and investigate presentations to hospital prior to their BBV diagnosis. By reviewing the reasons for presentations, we will produce specific recommendations for focussed testing that will help to identify and diagnose people with BBV infection earlier in the future.

2324-0043 **Dr Athina Spiliopoulou** **The University of Edinburgh**
Safety and real-world effectiveness of advanced treatments used in rheumatology and bone disease

Before doctors can prescribe medicines, clinical trials must show that they are safe and that they work. However, trials last for a short period of time, and not everyone can take part in them. Thus, we still have unanswered questions about how safe and effective these medications are in real life.

This research will examine conventional and newer medications used in rheumatology. This will include medicines for inflammatory diseases, like rheumatoid arthritis and lupus. These diseases occur when the body's immune system overreacts, causing swelling and pain. It will also include medicines used in diseases that affect the bones, like osteoporosis and rickets. We will study the benefits and side effects of medications over a longer time period compared to trials and consider groups often excluded from trials, such as those with more medical conditions. We will also examine differences in clinical factors and patient characteristics to see if these can help with treatment decisions. This is important because in many cases we cannot predict which medication will work for a patient before starting the treatment.

We will use Scotland's excellent healthcare information system to create the necessary linked dataset. It will have data on people seen in rheumatology clinics across Scotland. It will combine data on deaths, hospital admissions, cancer registrations, lab test results and

medical imaging with data on prescriptions. Public Health Scotland will link the datasets and remove all personal identifiers. We will then analyse the data inside the National Safe Haven, which is a safe computing environment owned by Public Health Scotland. We will first process the data to clean it and make it ready for research. Then, we will use statistical methods to look at differences in outcomes by drug and clinical factors.

This research can address safety concerns for newer medications. It can reduce the number of people getting harmful side effects. It can increase the number of people eligible for certain medications. It can inform treatment strategies and help identify who might end-up with substantial disability long-term.

2324-0050 SR208 Professor Helen Colhoun University of Edinburgh
SDRN Type 1 Bioresource (SDRNT1BIO) Data Linkage

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

2324-0065 SR170 Professor John Cleland University of Glasgow
Clinical Research in Heart Failure – Long-term follow-up

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

In particular, we wish to find out:

- a. death and its place and cause (most of the people screened will now be dead)
- b. hospitalisations and their duration and causes, with a special interest in heart attacks, stroke and heart failure

- c. amongst patients surviving beyond 2009 (when national prescribing records became available), what medicines patients were taking.

This information will be used to describe the incidence (new-onset) of disease (especially heart disease), how well the heart tests could predict events and the pathways by which patient's health deteriorated.

A series of studies was conducted between 1994 and 2006 in Glasgow inviting people to have a panel of tests to assess heart function with subsequent long-term follow up.

One study invited a cross-section of the general population to attend for these tests. Other studies focussed on the older population or those known to have heart disease.

We want to find out what happened to these patients and how accurately their heart test results predicted their long-term outcome.

In particular, we wish to find out:

- a. death and its place and cause (most of the people screened will now be dead)
- b. hospitalisations and their duration and causes
- c. amongst patients surviving beyond 2009 (when national prescribing records became available), what medicines patients were taking.

This information will be used to describe the incidence (new-onset) of disease (especially heart disease), how well the heart tests could predict events and the sequence of events that led to the persons death (for example, did they have hospitalisations for a heart attack, heart failure, chest infections or cancer or other conditions).

2324-0084 VC300V3 Dr Alethea McHardy University of Glasgow
Gender and Scottish Veterans' Health

This study will continue the investigation of the long-term health of Scottish veterans in comparison with people with no record of military service, up to the end of 2022. It will follow on from two previous studies, the Scottish Veterans Health Study which looked at the position up to the end of 2012, and the Trends in Scottish Veterans Health study which looked at changes in their health up to the end of 2017. The objective of these studies was to provide an up-to-date evidence base from which stakeholders and providers (Scottish Government, UK Government, NHS, MOD and charities) can draw in planning services, support and interventions to improve the long-term health of the veteran community and reduce inequalities. It is important that the evidence base is updated in order to continue to provide a source of relevant data. There is also a need to monitor some unexpected trends observed in the 2017 study, including the deterioration in the mental health of middle-aged veterans in comparison with the non-veteran population.

Furthermore, a number of issues which are important to policy development have emerged since the 2017 study. These include the mental health of young veterans, who may have experienced a dual disadvantage in being early service leavers (who are known from the earlier work to be at higher risk), and also through being affected by the deterioration in the mental health of young people in the community overall which has been identified in national studies. Hence a comparison with an age-matched non-veteran population is

important. Young veterans were essentially out of scope for the previous two studies, which concentrated on long-term and chronic health conditions, but recent health challenges facing young people, and especially young veterans, have emerged as an area of concern. Valid epidemiological data is essential to provide a firm foundation for policy.

The impact of military service on the health of women veterans has also recently become an important objective in accordance with the Armed Forces Covenant, which mandates that veterans should experience no disadvantage in comparison with people who have not served. It is now 30 years since women began to undertake almost all the roles of their male colleagues, and concerns have been expressed that these extended roles may have had an impact on their mental health and, perhaps more importantly, on their fertility and reproductive outcomes. It is therefore proposed to explore these outcomes in women veterans in comparison with non-veteran women. If negative impacts are found, the evidence base resulting from the study will enable appropriate protective policies to be developed to address inequalities between women veterans and women who have never served. Alternatively, if no adverse impacts of military service are found, reassurance in this respect can be given to women considering a military career, and to women who have served. This will be central to the PhD study.

The study will use information held by NHS Scotland on routine databases, and in order to protect privacy, the data will be pseudoanonymised and people's identity will not be available to the researchers. The first two studies looked particularly at the health of older veterans, but as recent concerns have centred round the health impacts of military service in young veterans, the new study will also look at veterans from the age of 16 upwards to capture emerging health issues in people who may have experienced recent combat, and to observe health trends following the implementation of a number of initiatives aimed at protecting people in potentially high-risk groups through the Veterans Strategy Action Plan, the Armed Forces Covenant and the Defence Health Promotion Strategy. Papers will be published in academic journals as the study progresses, and a report aimed at a general (lay) readership will be written at the end of the study.

2324-0096 Dr Emily Ball The University of Edinburgh
How does physical health in later life influence depression risk?

Why is this research needed?

As people get older, they are more likely to have problems with their physical health (e.g., stroke, cancer) and mental health (e.g., depression/low mood) at the same time. Older people are also more likely to take several medications for their physical health problems. What we do not understand is why some older people with a physical health problem become depressed, but others do not.

What impact could this research have?

If we did understand which physical illnesses make someone more likely to become depressed, healthcare professionals could target support to those most at risk and help them to make changes to prevent them from developing depression.

What are the research questions?

In this project, we will work with health data that is collected when a person interacts with clinical services (e.g., hospital data, or data about prescribed medications). We will analyse this de-identified health data in a secure environment. Using this data, we plan to address the following research questions:

1. Over recent years, has there been an increase in older adults being diagnosed with depression?
2. Which physical health conditions make someone more likely to develop depression in later life?
3. Which medications increase someone's likelihood of developing depression in later life?
4. Do social factors (such as where a person lives) influence whether a person will develop both physical health problems and depression in later life?

2324-0106 Professor Fergus Caskey University of Bristol
The High-volume Haemodiafiltration vs High-flux Haemodialysis Registry Trial (H4RT)

Most people with kidney failure need blood cleaning treatment (haemodialysis) 4 hours 3 times a week up at a hospital/ clinic. By adding filtration (the removal and replacement of fluid) to regular haemodialysis we get haemodiafiltration. As far as the patient is concerned the two procedures are very similar – the dialysis machine is just set up slightly differently.

Haemodiafiltration requires a greater volume of high quality water. By removing toxins more effectively, haemodiafiltration should have benefits, especially if high volumes are used (i.e. more than 21L of water removed and replaced per dialysis session). On the downside, however, such volumes of filtration could remove essential proteins from your blood stream.

This trial aims to see whether there is any difference between high-volume haemodiafiltration and high-flux haemodialysis in terms of longer term survival and hospitalisation from heart disease or infections in people with kidney failure. Effects on quality of life, admission to hospital, symptoms, infection rates and costs will also be examined.

Individuals who choose to take part will consent for some of their personal identifiable information to be sent to organisations required for the outcomes of the trial, such as Public Health Scotland (PHS) for patients living in Scotland. These personal identifiable data will be securely sent, along with a unique study number, from the clinical trials unit in Bristol to organisations named in the study information sheet. The required clinical outcomes data will then be returned to the clinical trials unit along with the unique study number only.

2324-0108

Faith Campbell

University of Dundee

Intergenerational multiple long term conditions and pathways to oral health in early childhood

Background

Dental decay (caries) is a hole in the tooth caused by a process involving the build-up of plaque on the surface of teeth and sugar in the diet. It is preventable and is the most common disease worldwide. It has a significant impact and, when severe, can impact quality of life, for example causing abscesses, school absence, and problems eating and sleeping. Caries may result in pain and chronic infection or failure to thrive. The cause of dental caries is multifactorial. Risk factors such as lower socio-economic status, high sugar diets and poor care or self-care, are shared with multiple long term health conditions (MLTC). MLTC also have a significant impact on quality of life.

Approach

There is a significant amount of dental health and maternal data available in Scotland. We will explore these data to determine if there is an association between maternal MLTC and child oral health. Our hypothesis is that there is a link between maternal multimorbidity and child oral health outcomes, even after controlling for demographic characteristics.

The data will be explored by linking maternal health data and child oral health data. We will investigate whether there is a relationship between maternal multimorbidity and poorer child oral health, i.e. do child of mothers with multiple long-term conditions have increased incidence of dental caries. We will also control for confounding factors such as socioeconomic deprivation, child multimorbidity and breastfeeding. This will include describing maternal and child multimorbidity as well as demographics and child oral health outcomes. Large amounts of data are required in order to robustly produce a 'maternal multimorbidity' and 'child multimorbidity' variable. This is defined as more than one health condition lasting 3 or more months. For this reason, we need to access lots of different sources or maternal/child diagnostic data to be as thorough as we can in compiling this.

Impact

This proposal will identify whether maternal MLTC impacts children's oral health. These findings will inform qualitative researchers with relevant stakeholders including mothers with MLTC and their children and healthcare professionals. This will aim to explore the reason for any links between maternal MLTC and dental caries in children. Along with guiding future research, this will inform recommendations to policymakers around services for improving child dental health.

More specifically this will inform policy regarding targeted interventions for groups who are at increased risk of poor oral health (due to being affected by maternal multimorbidity) to reduce their caries risk and experience. This may include introducing defined care pathways led by dental health support workers, increased dental recall intervals or the implementation of enhanced preventive dental care including targeted toothbrushing instruction, provision of high fluoride toothpaste or dietary interventions.

By reducing caries risk and experience in this group, this will also reduce the quality of life, financial and care burden that these individuals experience.

2324-0177 Dr Malihe Javidi University of Edinburgh
Predicting neurodegenerative disease using the Scottish Collaborative Optometry
and Ophthalmology Network e-research (SCONe) dataset

Scottish Collaborative Optometry-Ophthalmology Network e-research (SCONe) is a retinal (eye) image repository within Public Health Scotland's Safe Haven, containing community-acquired images linked to healthcare data. The Scottish Government (2022) called SCONe a "globally important study" with life-saving potential for millions.

This project focusses on dementia: a set of symptoms characterised by memory loss and other mental abilities severe enough to interfere with daily life. Dementia results from various brain diseases including, but not restricted to, Alzheimer's, and Parkinson's diseases, vascular dementia, and certain cases of multiple sclerosis.

Alzheimer's is the UK's leading cause of dementia, while Parkinson's is the fastest-growing brain disorder globally. Both are leading contributors to cognitive and motor impairment, severely affecting individuals' lives. Alzheimer's results in cognitive decline, affecting basic activities in daily life. Tasks like remembering, communicating, and recognising faces become increasingly challenging, impacting personal interactions and emotional connections. Parkinson's primarily affects movement, leading to difficulties in coordination and fine motor skills. These conditions often progress slowly, increasing severity over time, impacting individuals' overall well-being and functionality.

Emerging treatment options offer hope for managing these conditions, especially with early intervention, which is essential to preserve cognitive and motor functions.

Using SCONe, we will identify individuals diagnosed with brain disorders such as Alzheimer's, analyse retinal images for features predating the diagnosis and learn how these change. We aim to develop disease prediction models for earlier detection, ideally before cognitive impairment. If successful, we will use these models to create a diagnostic tool for use in the community.

2324-0110 SR187 Dr Simon Cox University of Edinburgh
Lothian Birth Cohort 1936 (LBC1936) study: renewal of deaths linkage
application for SR187 (previously 1718-0327)

This proposal outlines the continuation of a vital linkage research project that tracks the lives of a group of people born in 1936, known as the Lothian Birth Cohort 1936 (LBC1936). Since 2004, this group has been regularly studied to understand how ageing affects the brain, health, and overall well-being. Importantly, this project connects data collected from this group with official records of when and why people pass away.

This linkage project is extremely valuable: It allows researchers to answer critical questions about the LBC1936 group, like how long they live and what causes their deaths. Additionally, it helps us understand factors that influence their chances of survival and what role early-life experiences, such as childhood intelligence, education, and social background, play in their later health and lifespan. By regularly connecting the data collected from this unique

group with information about when they pass away, we can also keep accurate records of the cohort. This helps us stay in touch with them, invite them for follow-up assessments, and share important knowledge and events related to their health.

In essence, the LBC1936 study is a treasure trove of information that helps us better understand ageing, health, and longevity. The study is ongoing and this proposal is a request to continue to receive notifications of death records at quarterly intervals. Mortality records are vital to our research programme and help to guide policies that benefit the ageing population. We wish to highlight that the deaths data requested here should cause minimal privacy concerns due to their being publicly-available data.

2324-0121 Dr Sarah Kotecha Cardiff University
Clinical and cost-effectiveness of a maternity quality improvement programme to reduce excess bleeding and need for transfusion after childbirth: the Obstetric Bleeding Study UK

Bleeding is the most common complication of childbirth. Every year about 50,000 women in the UK lose 1L (2 pints) of blood or more. Many women develop post-traumatic stress disorder, need blood transfusion or admission to intensive care. There is a lack of knowledge about how best to treat excess bleeding.

A new way of managing bleeding after birth was developed in Wales using a number of related intervention called a care bundle. This care bundle was rolled out across Wales as a quality improvement programme called the 'Obstetric Bleeding Strategy' (OBS). The care bundle has four parts: 1) assessment of each woman's bleeding risk, 2) accurate measurement of blood loss at all births, 3) consistent approach to escalation of care to more senior clinicians and 4) bedside tests to identify and treat abnormal blood clotting.

The OBS was associated a reduction in major bleeding and blood transfusion but we do not know whether the improved outcomes were due to the OBS programme.

We will recruit about 189,000 women from 36 UK maternity units including 3 NHS boards in Scotland (Lanarkshire, Grampian and Tayside), over 30-months. All women giving birth in these units will be included, whether they have excess bleeding or not. Maternity units will have a period during which standard care will continue and data collected. Units will then adopt the new care bundle over 9-months followed by at least 3-months of data collection. We will compare the rate of blood transfusion after childbirth before and after the OBS was introduced. The effect of the OBS on the psychological well-being of women and birth partners and its financial cost will also be studied. A further data-linkage study using national datasets will be used for follow-up of the women in this study.

2324-0130 Professor Peter Murchie University of Aberdeen
NASCAR+: Exploring associations between geography, treatment, follow-up care
and survival of cancer patients in Northeast Scotland

The Northeast and Aberdeen Scottish Cancer and Residence (NASCAR) study explored whether where a person lives affects how long it takes to be diagnosed and treated for cancer. It also observed whether people from further away were more or less likely to survive for one-year after cancer diagnosis. The NASCAR database contains information about 12,339 people from Northeast Scotland diagnosed with one of eight common cancers from 2007-2014. Postcodes were used to calculate how long journeys to their GP and to hospital would take. What we found is surprising: people with the longest journeys to hospital were much more likely to be diagnosed and treated quickly but were still more likely to die within a year of diagnosis, compared to those living closer-by. We can't explain why we found this, so this project aims to find out why. We now seek funding to link our existing data to new information from Scottish Government. Particularly, we want to look in detail at the treatment people have received and how the NHS has followed them up afterwards. We hope to work out why longer journeys mean poorer survival and learn how we can reorganize local cancer services to improve the situation.

2324-0122 Kate Hulse NHS Lanarkshire
Scottish Laryngeal Dysplasia Audit

Laryngeal dysplasia is a pre-malignant condition, which means it might develop into cancer. Dysplasia refers to abnormal cell changes, in this case within the lining of the voice box (larynx). These changes can progress into cancer in around 15% of patients. Cigarette smoke causes damage to cells which can lead to the development of laryngeal dysplasia and laryngeal cancer. Stopping smoking appears to slow or stop abnormal cells from becoming cancer. Patients with laryngeal dysplasia should therefore be offered help to stop smoking.

According to UK best practice guidelines, patients with laryngeal dysplasia should be seen in clinic for 5 years if the degree of cell change is severe or they continue to smoke. Patients who have mild or moderate cell change and have stopped smoking are considered "low risk" and can be discharged after 6 months. We do not know how much or how quickly the risk of developing cancer is reduced after stopping smoking.

We aim to audit find out how often we refer patients with laryngeal dysplasia who smoke to services to help them quit. We will also check how well we follow guidelines recommendations relating to for diagnosis and follow up. These include, photographing the voice box before and after treatment and assessing the quality of the voice. This audit will help us to improve the care we give to patients with this condition.

2324-0136 SR335 Dr Esther Ainley
Redesign of Urgent Care Evaluation

Picker Institute Europe

In December 2020, Scotland's urgent care pathway was re-designed with the aim to improve the way people access urgent and unscheduled care. The Scottish Government has commissioned Picker to conduct an evaluation of the Redesigned Urgent Care pathway (RUC). As part of this evaluation, we want to understand the experiences of patients and carers using redesigned pathways.

We will conduct a paper postal survey to understand the experience of people who have called NHS 24 111 and accessed the redesigned urgent care pathway (i.e., selected the A&E option via the Interactive Voice Response system). NHS 24 will select a sample of eligible adults who called 111 over a two-week period.

The questionnaire will be mailed to a sample of 3,500 patients following their contact with NHS 24. Recipients will have the option to access the survey online if preferred. The questionnaire will cover people's experiences of calling NHS 24 111 and any other urgent care services accessed before or after their call. The respondent's answers will be put together with the answers of other people (aggregated) to understand how the changes have affected people's experiences of accessing urgent care and to show where improvements are needed. The aggregated findings will be presented in an evaluation report that will be published by the Scottish Government here:

<https://www.gov.scot/publications/>

2324-0160 Dr Mairead Black University of Aberdeen
Cervical Ripening at Home or In-Hospital - prospective cohort study and process evaluation (CHOICE Study) extension

Induction of labour (IOL) is offered to 1 in 3 pregnant women. IOL is considered when risks of continuing a pregnancy may outweigh risks of birth. The first part of IOL, cervical ripening, has traditionally been performed using medication during an in-hospital stay. Recently some UK hospitals have offered a balloon to stretch the cervix open instead. Women often then go home until the balloon has had 12-24 hours to work. This change in practice was evaluated in the recent CHOICE study. CHOICE also found that delays during IOL and a lack of information about IOL affected women's experiences.

Remaining unanswered questions around UK IOL practice relate to the impact of cervical ripening method used, delays during IOL, whether women's outcome of IOL can be predicted, and how IOL practice varies across the UK. The CHOICE study dataset will allow these evidence gaps to be addressed.

The CHOICE data (routinely collected electronic records from 26 UK maternity units) will be shared with University of Aberdeen researchers. They will assess how cervical ripening methods and delays during IOL are linked to birth outcomes, and whether existing prediction tools can predict IOL outcomes. Variation in IOL practice across the 26 units (6 in Scotland) will also be assessed. Information that might easily identify women or their babies has been removed (pseudonymised). Women were able to opt-out of the CHOICE study.

The findings will inform national efforts to reduce unwarranted variation in clinical practice, and to ensure a more personalised approach to IOL.

2324-0192 Dr Maira Hameed University College London
Teaching Hospital
Magnetic Resonance Enterography (MRE) predictors of disease relapse after
stopping biologics

Crohn's disease is condition resulting in inflammation of the bowel. Patients are often prescribed powerful medication to reduce this inflammation- "biologics". The drugs are effective but are usually injected, have side effects and are expensive. Therefore, patients and their doctors consider stopping biologics when the patient is well. Unfortunately, in almost half disease comes back quickly (relapses) within 1 year. We currently have limited ability to predict which patients stopping biologics will relapse quickly and need to restart drugs. Currently blood and stool tests, colonoscopy, and symptoms are considered before making a joint decision. However, there is considerable uncertainty around this decision.

This study aims to see if Magnetic Resonance Enterography (MRE) improves our ability to predict which patients will become unwell (relapse) after stopping biologics. MRE is a safe MRI scan of the bowel, widely used in Crohn's disease monitoring.

We will identify 150-200 patients stopping biologics and recently had an MRE during their usual care. We will analyse these MRI scans for signs of bowel inflammation, and also on routinely collected clinical data. We will see if patients remained well or relapsed (became unwell) after 1 year after stopping biologic drugs. Based on a review of scientific journals, we will use promising predictors of disease relapse to build a prediction tool that provides a risk of a patient relapsing within 1 year. We will then see if MRE improves our ability to predict relapse, leading to more personalised, informed management decisions.

2324-0239 Professor Amanj Kurdi University of Strathclyde
Medicines in Acute and Chronic Care in Scotland (MACCS)

We aim to create a shared data asset, the Medicines in Acute and Chronic Care in Scotland (MACCS) resource, which will be a large library of information for scientists studying medicines.

Medicines play a vital role in keeping us healthy, but the growing number of available treatments make it difficult for clinicians to ensure they are used safely (with minimum harms) and effectively. Problems such as side effects can occur, especially in patients with complex health needs caused by multiple long-term conditions. This is increasingly common as our population ages and more people live with several ongoing health issues. The MACCS resource will make the use of medicines safer and more effective by supporting the development of treatment guidelines and clinical decision support tools which, in turn, will help clinicians choose the most appropriate medication for a patient. This will reduce potential harm and ensure people get the best possible benefit from their treatments.

In addition, the availability of the MACCS resource will make research more efficient. Keeping the data safe and private is important; our project will follow strict rules to make sure the information is easy to find, use, share, and re-use, all while keeping it secure.

2324-0240 Elizabeth Nuthall National Perinatal Epidemiology
Unit (NPEU)
The neoGASTRIC trial

About one in seven babies born in the UK each year need specialist neonatal care in a hospital because they are born too early, are born very small or have a medical condition. Ensuring these babies have enough nutrition is a key part of their care.

Premature babies are fed milk every few hours through a soft plastic tube into their stomach, called a gastric tube. As their stomachs and digestive systems are not yet ready for lots of milk, the amount given each feed is increased slowly. Some doctors and nurses regularly check how much milk is left in a baby's stomach, called 'routinely measuring gastric residual volumes'. They check because they believe it will help them know how the baby is coping with the milk feeds and they also think it may help to identify a severe disease called necrotising enterocolitis. However, others think measuring gastric volumes may be bad for babies and that it is inaccurate, uncomfortable for the baby and may actually be harmful.

We want to answer the question: Is routinely measuring gastric residual volumes good or bad for babies? To do this we will conduct a randomised controlled trial to test whether not routinely measuring gastric residual volumes, compared to routinely measuring them, helps premature babies get to full milk feeds quicker without more necrotising enterocolitis.

The trial will involve babies born more than 6 weeks early and will recruit about 7000 babies across the UK and Australia. Premature babies will either have no routine gastric residual volumes measured, or have gastric residual volumes measured regularly. This will be decided by chance: babies will have an equal chance of being in either group.

The two approaches being compared are already used across the UK and Australia, so there is nothing new about either type of care. NeoGASTRIC will use an opt-out consent, designed to be as simple as possible for families. All parents will be given an information booklet prior to enrolment and the opportunity to ask questions and opt-out their baby if they wish.

2324-0233 SR276 Professor Amanda Cross Imperial College London
Multicentre randomised controlled trial of 'once only' flexible sigmoidoscopy in prevention of colorectal cancer morbidity and mortality. Short Title: The UK Flexible Sigmoidoscopy Screening Trial (UKFSST)

Colorectal cancer (CRC), also known as bowel cancer, is a common malignancy that is very treatable when diagnosed at an early stage. The use of flexible sigmoidoscopy (FS) as a screening tool can not only identify cancers at an earlier stage but can also remove precursor lesions potentially leading to long-term protection. When this project began in

1994, there was no evidence demonstrating the benefit of FS screening and this project aimed to address this knowledge gap.

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

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

This research will build on existing knowledge on the impact of FS and will provide evidence to the national screening programmes on the long-term effectiveness of a single FS examination on the reduction in new cases and deaths from CRC over a period of up to twenty-five years.

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

2324-0254
Foundation Trust

Ms Alice Milligan

Moorfields Eye Hospital NHS

Adult gonococcal eye infection: a study of the incidence, clinical features, management, complications and antimicrobial resistance in the United Kingdom.

This epidemiological study will aim to establish a current incidence rate of adult patients with gonococcal conjunctivitis (GC) (which affects the conjunctiva - the surface membrane of the eye and eyelids) or keratoconjunctivitis (GKC) (which affects the conjunctiva and also affects the cornea the clear central window) in the UK.

It will also outline the clinical features, management, complications and antimicrobial resistance. Prospective case ascertainment will be undertaken through the British Ophthalmological Surveillance Unit (BOSU) monthly reporting system. This is an active surveillance system involving all United Kingdom (UK) consultant and trainee ophthalmologists. This epidemiological study will only be using information available from the patient case notes. Ophthalmologists will indicate that they have seen a new case through the BOSU and then data collection will be undertaken within a specific online platform using the data safe haven at University of Dundee. The research work will be carried out at one site (Moorfields Eye Hospital), with the data held in the data safe haven at the Health Information Centre University of Dundee. Local collaborators are only required to fill out the data collection proforma seeking clinical information available from the hospital notes of patients who have been notified as have a laboratory confirmed diagnosis of gonococcal eye infection. They do not need to carry out any procedures mentioned in the Standard Operating Procedures for ethics committees in the UK which require a principal

investigator to be appointed at each site. Analysis will be descriptive and all findings reported in an aggregated format and at no point will the patients routine standard care be altered or impacted as a result of this study. The data will never leave the safe haven. Once analysis is complete, aggregated tables and graphs will be produced in a format suitable for publication in peer review journals.

This study aims to look at the occurrence of gonococcal conjunctivitis (GC) (which affects the conjunctiva - the surface membrane of the eye and eyelids) or keratoconjunctivitis (GKC) (which affects the conjunctiva and also affects the cornea the clear central window) in adult patients, in the UK.

As part of the study, data will also be collected about the management, complications, clinical features and antimicrobial resistance. This will help provide better understanding of newly diagnosed cases of GC and GKC.

This study is part of the British Ophthalmological Surveillance Unit (BOSU), where a monthly reporting system is put in place to allow consultants and Trainee Ophthalmologists across the UK to report on new cases of patients with GC or GKC.

The data collected will be information that is available in patients' medical notes (case notes) from new cases. Ophthalmologist can share this data collected through BOSU via an online platform in a data safe haven, where the information collected will be held in the data safe haven at the Health information centre, University of Dundee.

Any UK based Ophthalmologist can complete a designated questionnaire to collect data from new cases of GC or GKC after confirmation of the diagnosis from a laboratory. The questionnaire is located in the data safe haven at the Health Information Centre, University of Dundee, and is accessed using a secure username and password unique to each reporting user.

Moorfields Eye Hospital NHS Foundation Trust will be the sponsor of the study and will look at the data collected to analyse. The analysed data will be presented in tables and graphs which will be in a format suitable for publication in a peer review medical journal. Results from the information collected and published for this study can help raise awareness of the condition to help with identifying patients with the condition faster and help prevent further complications that are linked to this condition.

At no point will the patients routine standard care be altered or impacted as a result of this study.

The data will never leave the safe haven.

2425-0009 Dr Oliver Llewellyn University of Edinburgh Nephrostomy and stent in obstructing pelvic malignancy

The kidneys make urine. Tubes called ureters take the urine from the kidney to the bladder. Urine then leaves the bladder when we urinate. Cancer within the tummy can grow and squash the ureters. This stops the urine getting from the kidney to the bladder and the kidneys can fail. The stagnant urine can then also get infected. These can delay cancer treatment or be fatal.

Two procedures are offered for this. 1) A plastic tube (called a stent) can be placed up the squashed ureter via the bladder with the patient put to sleep. Or, a tube (called a nephrostomy) can be put directly into the kidney through the patient's back with the patient awake but the area numbed. The urine then drains into a bag which is stuck onto the skin. Sometimes not doing a procedure is an appropriate choice.

Each procedure can lengthen life but how long is different for each patient. Also, having the tubes may cause further physical illness or reduced wellbeing. Doctors do not know who these will happen to. Because of this, some doctors act one way and others act another.

We aim to look at this problem in many patients from many UK hospitals. We will only record patient's care, not change it. First, we will work out how many people are affected. Then, we will record how doctors are treating patients and which patients are doing best. Using our findings we will make an online tool to help with these decisions.

2425-0031 Archie Campbell University of Edinburgh Generation Scotland linkage 2024-29

Generation Scotland (GS) is a bioresource of data and samples for medical research. We have had over 450 applications to use the resources across a range of health conditions. GS has consent from over 30,000 participants across Scotland to link study data to their medical records for research purposes. Several projects accessing GS data received approval from the PBPP to receive CHI linked data including hospital inpatient, dental and prescribing data in the period 2014-17. GS received approval in 2018 to receive regular annual updates of linked data to keep the longitudinal follow up of its participants up to date. Regular data releases were disrupted during the pandemic, but releases of Covid-related data enabled GS to contribute to virus research. Other datasets have been added to the releases as they have become available, eg imaging data, making for a rich data set for health research. This has contributed to dozens of research publications over the last 5 years.

GS has used the data internally to assess the scope and viability of potential projects, e.g. by counting the number of cases of a condition (or unaffected controls). GS has also made linked data available to other researchers approved by the GS Access Committee, rather than requiring separate applications to PBPP for every use by external collaborating researchers. The GS Access Committee has applied the same requirements for data security and training as PBPP, only releases de-identified data, and only the minimum required to answer a specific research question.

The main use of the linked data is to identify cases of particular conditions in order to include or exclude for a particular research project. Usually the researcher only needs to know who has a condition, and the date of incidence. Full dates of events are requested in order to determine timelines between different tables, or exact age at an event, but usually the researcher only requires month and year in their data release. We already know the date of birth of a volunteer.

2425-0069 Dr Katherine Hawton University Hospitals Bristol
and Weston NHS Foundation Trust
ROHHAD British Paediatric Surveillance Unit (BPSU) Survey

We are seeking approval for a new British Paediatric Surveillance Unit (BPSU) study into rapid-onset obesity, hypoventilation, hypothalamic-dysfunction and autonomic dysfunction (ROHHAD) syndrome.

ROHHAD is a rare syndrome which causes life-threatening obesity, trouble breathing at night, a wide range of hormone problems and an irregular heartbeat. Children often need masks and machines to breath at night, take hormone tablets and injections for the rest of their lives, as well as having a higher risk of getting certain types of cancer in their lifetimes.

We do not know why children get this syndrome. There is no single test for diagnosis, and it can take a long time for families to get a diagnosis. We do not yet know of any treatments that can cure the syndrome. As ROHHAD is rare, many doctors in the UK will not have heard of it.

We want to find out how many children ROHHAD affects in the UK and how patients are being cared.

For a year, all senior children's doctors in the UK and Republic of Ireland will be asked each month to record any children they have seen with symptoms suggestive of ROHHAD. We will then ask the doctors for more anonymous details of the child, their symptoms and any treatment they have had.

This study will help to estimate how many children have ROHHAD, more about the condition, how it is being managed and may help raise awareness. We hope that the study will help to improve how we care for patients with ROHHAD.

2425-0083 Professor Jill JF Belch University of Dundee
POPADAD Follow-up Study

Scotland has high levels of cardiovascular disease and cancer. Previous research suggests that aspirin may protect against cardiovascular disease, such as heart attack and stroke, particularly in patients with diabetes. A simple treatment like aspirin would be a cheap and effective way of preventing these events. However, aspirin is not without its harms, such as gut bleeding and should not be taken without an evidence base. The prevention of progression of arterial disease and diabetes (POPADAD) trial was designed to look at the effect of aspirin and antioxidants on heart disease and death in patients with diabetes who had hardening of the arteries. Between 1997-2001, 1,276 people were recruited to the study, and were followed up until 2006 (average follow up 6.7 years). The original analysis showed no benefit, however we wish to see if there is a long-term benefit, as cardiovascular events take time to develop.

We aim to add hospital records from the last 15 years to the trial data to determine whether aspirin or antioxidants given in the trial have affected the rate of heart disease, amputation, cancer and death. Access to hospital data (SMR records) and death data (NRS deaths) is required to identify the end points of interest. Prescription data is required to

identify patients who have been prescribed aspirin during or following the trial to identify those patients who may have switched treatment groups (i.e. if a patient was on placebo only but went on to be prescribed aspirin after the trial).

2425-0108 Dr Suzanne Breeman University of Aberdeen
Longer-term follow-up of the HEALTH trial (Hysterectomy or Endometrial Ablation trial for Heavy menstrual bleeding)

Heavy periods cause women distress and limits their activities, with many needing an operation that removes the lining of the womb (endometrial ablation) or completely removes the womb (full hysterectomy). Previous research found that a full hysterectomy is better at relieving symptoms but has a higher risk of complications and a longer recovery time.

A newer operation is available that removes only the part of the womb causing periods (keeping the cervix or neck of the womb) and is called a laparoscopic (keyhole) supracervical hysterectomy (LASH).

We compared endometrial ablation with the LASH operation for women with heavy periods. Between May 2014 and March 2017, 660 women joined the study from 31 UK hospitals. Everyone had an equal chance of getting either an endometrial ablation or a LASH operation.

At 15-months after they joined the study, most women were very satisfied with their treatment and felt their symptoms were better. However, satisfaction was higher and symptoms better in those who had the LASH operation, although they stayed in hospital for longer, took more time to recover and the operation was more expensive for the NHS.

This proposal is looking to see how the women are now, 5-8 years after they joined the study. The women will be asked to complete a questionnaire about how they feel and what treatments they have had for heavy periods and other relevant symptoms. We will also collect information from routinely collected data. This longer-term follow-up study is required to better evaluate the two treatments.

2425-0124 SR274 Acer Blake UCL
Whitehall II

The Whitehall II study (WHII) was established in 1985 to investigate the relationship between socioeconomic status, stress and cardiovascular disease. The study recruited civil servants working in London who underwent a clinical examination and completed questionnaires covering a wide range of topics. Since its initiation, 13 phases of data collection have been completed (for further information see Data Collection | Psychiatry - UCL – University College London). The study has been expanded to include new measures of cardiovascular function and also captures information about other aspects of physical and mental health. As with previous phases, we are seeking to ascertain participant health through linkage to electronic health records in NHS Scotland. This involves obtaining regular

updates on cancer and death registrations and participant hospitalisations. These data together with the research data allow the primary objectives of the study to be fulfilled.

2425-0133 Carole Morris PHS
Connect4: enriched metadata

The Connect4 project is a first step towards connecting data from separate Trusted Research Environments (TREs) across the 4 UK nations. Data controllers use TREs to provide a secure environment to hold their datasets and give access to researchers to perform data linkage studies.

However, this comes with some challenges. Researchers may want to link datasets that are managed by different TREs, but it can sometimes be difficult to know if there is value in doing this prior to getting access to all the data.

To help with this, researchers can consult the metadata catalogues published by the different data controllers. Metadata is defined as the information that describes and explains the data itself. For instance, metadata describes things like who controls the data, and what a valid value for a given variable is. Metadata could also describe if a dataset has good geographical coverage of a population of interest (e.g. people resident in Scotland)

The problem is that published metadata can vary in quality and level of completeness. PHS, within the wider context of the Connect4 project, is therefore investigating if the metadata they offer to researchers could be improved and extracted in a more automated way than the manual process currently done. To test this, three PHS datasets will be investigated in the National Safe Haven with the aim to develop code which can semi-automatically extract relevant metadata and improve its overall level of completeness.

If successful, the developed code will be able to be re-used in different TREs (including those managed by partner organisations on the Connect4 grant) and on different datasets. This type of development work would also improve the service offered by PHS/eDRIS to their community of researchers.

2425-0142 Professor Jugdeep Dhesi Older Person's Assessment
Unit, Guy's and St Thomas' NHS Trust
Implementation of Comprehensive Geriatric Assessment based perioperative
medicine services to improve clinical outcomes for older patients undergoing
elective and emergency surgery with cost effectiveness

Older people have more operations than younger people but often have more complications related to other problems like heart disease or poor memory. These problems need treatment from experts called geriatricians. It is not usual to have geriatricians managing older people who need operations in the NHS. A service called Perioperative medicine for Older People undergoing Surgery (POPS) was set-up at one NHS hospital to help older people get better outcomes after operations. POPS services reduce complications after surgery, help people leave hospital sooner and save the NHS money. Only some NHS

hospitals have set-up POPS services, meaning not all NHS patients get this care. We know that setting up POPS services can be hard, but our work has shown this can be done. Our research will test how new POPS services can be set-up in more NHS hospitals across the UK to improve care for older patients having operations and save money for the NHS. We will see if we can set-up POPS services in 18 NHS hospitals; whether we can do this quickly; how well services run; whether services help people to get better more quickly after an operation and whether this saves the NHS money. We will collect information about how long people stay in hospital after an operation, describe complications after surgery and measure patients' quality of life. We will talk to patients and staff about their experiences of new POPS services. Our research will use a mix of information from staff, hospital records and patients and carers.

2425-0193 Professor James Cole University College London
Access to the Brain Health Data Pilot (2223-0005 Whiteley) - Cole

Brain scanning is important to understand Alzheimer's and other causes of dementia. A measure of brain health can be calculated from a brain scan that is known as 'brain age'. The older someone's brain age, the higher their chance of developing dementia. However, we do not know how to apply brain age to everyone having a brain scan.

In Scotland, 1.7 million brain scans, from over 1 million patients, are available thanks to the Scottish Medical Imaging initiative (SMI), reflecting 10 years of NHS brain scanning. The scans are owned by NHS Scotland and will be made available for this project via the Brain Health Data Pilot.

We will develop a new way to calculate brain-age scores, using the most commonly type of brain scan in the NHS, Computed Tomography (CT). Despite being common in the NHS, CT is rarely used in brain-age research studies. We will compare brain age calculated with CT with brain-age calculated with magnetic resonance imaging (MRI), which is much more common in research studies. We will see if having an older brain age increases the chance of dementia, after taking into account someone's actual age.

The importance of the project is:

- It will show that we can use very large routinely collected brain imaging datasets for research.
- It will test brain age in real world scans, rather than scans done for research. This will demonstrate it can work in a more diverse population.

This pilot project will be an important step towards using brain-age and similar brain-health measures in clinical practice for Alzheimer's and other causes of dementia.