**HSC-PBPP End of Project Reports – April 2025**

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| **Application Reference**  **(click on reference for EPR Summary)** | **Applicant** | **Applicant Organisation** | **Title and Purpose of study** | **Date of Approval** |
| [1819-0079](#_1819-0079_Professor_Jennifer) | Professor Jennifer J Kurinczuk | University of Oxford | A confidential enquiry of intrapartum-related perinatal deaths in births planned in midwifery-led settings in Great Britain (ESMiE) | 29/11/2018 |
| [1819-0150](#_1819-0150_Peter_Murchie) | Peter Murchie | University of Aberdeen | National Cancer Diagnosis Audit (NCDA) Scotland - Analyses | 06/12/2018 |
| [1819-0256](#_1819-0256_Gerald_Humphris) | Gerald Humphris | University of St Andrews | A pilot trial of the Mini-AFTERc intervention to manage  Fear of Cancer Recurrence in breast cancer patients | 26/02/2019 |
| [1819-0270](#_1819-0270_Su-Gwan_Tham) | Su-Gwan Tham | University of Manchester | Suicide by middle-aged men | 11/10/2019 |
| [1819-0183](#_1819-0183__Lucy) | Lucy Irvine | Public Health England (PHE) | UK Children, Teenage and Young Adults (CTYA) cancer statistics |  |
| [1819-0153](#_1819-0153_Alastair_Ross) | Alastair Ross | University of Glasgow | FACTORS- (Fluoride Application: a Co-designed Toolkit of ORganisational Strategies) | 14/01/2019 |
| [1819-0340](#_1819-0340_George_Ramsay) | George Ramsay | University of Aberdeen | Characterising cause of mortality trends of patients admitted to Emergency General Surgery in Scotland | 11/01/2019 |
| [1819-0251](#_1819-0251_Steve_Turner) | Steve Turner | University of Aberdeen | What was the effect of the “Take it Right Outside” public health campaign on paediatric hospital admissions? | 04/04/2019 |
| [1819-0356](#_1819-0356_Dr_Will) | Dr Will Atkinson | Nuvia Limited | MR110 UKAEA Mortality & Morbidity Study | 19/07/2021 |
| [1819-0264](#_1819-0264_Dr_Charis) | Dr Charis Marwick | University of Dundee | Antibiotic Research in Care Homes (ARCH): unscheduled care use as a safety outcome measure |  |
| [1819-0117](#_1819-0117_Jill_Ireland) | Jill Ireland | Public Health Scotland | SPARRA and High Health Gain predictive modelling |  |
| [1819-0236](#_1819-0236_Sandra_Robb) | Sandra Robb | Public Health Scotland | Excellence in Care (EiC) |  |
| [1819-0325](#_1819-0235__) | Lee Barnsdale | Public Health Scotland | Scottish Public Health Drug Linkage Programme | 13/01/2022 |
| [1819-0287](#_1819-0287_Christopher_McGovern) | Christopher McGovern | University of Glasgow | Mortality and long term morbidity in survivors of burn injuries and acute pancreatitis | 10/11/2020 |
| [1819-0183](#_1819-0183__Lucy) | Lucy Irvine | National Cancer Registration and Analysis Service, National Disease Registration Service (NDRS), NHS Digital/NHSE | “The transfer, use, and retention of anonymised cancer data from the Scottish Cancer Registry, Population Health to enable the National Cancer Registration and Analysis Service (NCRAS), NDRS, NHS digital (formerly Public Health England (PHE)) to collate a UK dataset and carry out analysis needed for the  “UK Children, Teenage and Young Adults (CTYA) cancer statistics” report” |  |
| [1819-0315](#_1819-0315_Helen_Colhoun) | Helen Colhoun | University of Edinburgh | SDRN Type 1 Bioresource Data Linkage | 01/07/2019 |
| [1819-0186](#_1819-0186__) | Professor Richard Anderson | University of Edinburgh | Reproductive outcomes in survivors of childhood, adolescent and young adult cancer in Scotland: a population based cohort study |  |
| [1819-0224](#_1819-0224_Archie_Campbell) | Archie Campbell | University of Edinburgh | Generation Scotland linkage |  |
| [1819-0176](#_1819-0176_Prof_Duncan) | Prof Duncan Porter | University of Glasgow, | Scottish Early RA inception cohort |  |

**Appendix: End of Project Report Summaries**

## 1819-0079 Professor Jennifer J Kurinczuk

**A confidential enquiry of intrapartum-related perinatal deaths in births planned in midwifery-led settings in Great Britain (ESMiE)**

**End of Project Summary**

**Public Benefit Impact**

The ESMiE study findings have highlighted areas of care for mothers and babies where care for women planning birth in midwifery-led settings can be improved with future perinatal deaths potentially avoided. Issues with care were identified in relation to: risk assessment and decisions about planning place of birth; the use and frequency of intermittent auscultation; transfer during labour; neonatal resuscitation and transfer; follow-up and local review.

The findings do not call into question the evidence about the safety of midwifery-led settings for healthy women with straightforward pregnancies but have identified areas of care which could be improved and made safer. We recommend that all NHS organisations delivering midwifery-led care should review their services in relation to the issues we have identified.

Aims

To review the quality of care in births planned in midwifery-led settings, which resulted in an intrapartum-related perinatal death.

Data

Intrapartum stillbirths and intrapartum-related neonatal deaths in term births where the planned place of birth was an alongside midwifery unit (AMU), freestanding midwifery unit (FMU) or at home. Deaths were sampled from MBRRACE-UK national (England, Wales and Scotland) perinatal surveillance data for 2015-16 (planned AMU births) and 2013-2016 (planned FMU and home births). Sixty-four perinatal deaths were reviewed, 30 stillbirths and 34 neonatal deaths; five of the deaths sampled and reviewed occurred in Scottish Health Boards.

Methodology

Following established MBRRACE-UK confidential enquiry methodology the clinical notes of the sampled mothers and babies were requested. The identifiers were redacted, the notes scanned and made available for review by expert reviewers via the MBRRACE-UK web-based viewing system. Multi-disciplinary panels reviewed and discussed the maternal and neonatal medical notes for each death. Each stage of care was systematically assessed with reference to relevant national standards and guidance, and the overall quality of care was graded by consensus,

Outcomes

At the start of labour care, 23 women were planning birth in an AMU, 26 in an FMU and 15 at home. In 75% of deaths, improvements in care were identified which may have made a difference to the outcome for the baby. Improvements in care were also identified which may have made a difference to the mother’s physical and psychological health and wellbeing in 75% of deaths. Issues with care were identified in relation to: risk assessment and decisions about planning place of birth; the use and frequency of intermittent auscultation; transfer during labour; neonatal resuscitation and transfer; follow-up and local review.

## 1819-0150 Peter Murchie

**National Cancer Diagnosis Audit (NCDA) Scotland - Analyses**

**End of Project Summary**

Public Benefit Impact

Only by understanding patient pathways to cancer diagnosis, including what works and what doesn’t work, can we make improvements and ensure patients are diagnosed as early as possible.

The proposed analysis of the Scottish national data from the NCDA has provided unique insights into pathways to cancer diagnosis in Scotland and provided vital intelligence for the development and improvement of cancer services to achieve better outcomes and experiences for patients and their families in future.

Aims

This proposal aimed to use data collected as part of the National Cancer Diagnosis Audit (NCDA) for Scotland on patients diagnosed with cancer in 2014 in order to enhance our understanding of pathways to cancer diagnosis.

Objectives:

1. Characterise the cohort of patients included in the NCDA Scotland 2014 and compare to the national cancer incidence in Scotland in 2014

2. Describe the primary care interval from first presentation to referral, including number of consultations before referral and use of primary care-led investigations

3. Explore what patient and other factors affect pathways to cancer diagnosis and may be associated with longer intervals and avoidable delay

Data

Access to the dataset collected through the NCDA in Scotland was required. This dataset contains individual level pseudonymised linked data from the following datasets:

• Scottish Cancer Registry;

• Cancer Waiting Times;

• National Records for Scotland (NRS) deaths;

• CHI database (to flag whether patients were still registered with the same practice at the time of the audit); and

• primary care information supplied by practices participating in the audit.

Methodology

For this project, the analysts used the linked NCDA dataset for Scotland and used appropriate descriptive and analytical statistical approaches to investigate and understand:

1. Sample composition compared to 2014 cancer incidence in Scotland

2. Patient characteristics for the NCDA cohort (ethnicity, language, communication, housebound status, co-morbidities, cancer stage)

3. Referral type that led most directly to cancer diagnosis (incl. emergency referrals) by gender, age, ethnicity, cancer site and other variables

4. Number of consultations before referral by gender, age, ethnicity, cancer site and other variables

5. Primary care interval, secondary care interval, diagnostic interval by gender, age, ethnicity, cancer site and other variables

6. Number and type of primary care-led investigations before referral by gender, age, ethnicity, cancer site and other variables

7. Avoidable delay by gender, age, ethnicity, cancer site and other variables

8. Impact of deprivation / rurality on pathways to diagnosis

The results of this work were published in academic journals. Outputs were also shared with key stakeholder organisations, including Scottish government, NHS Scotland and the Scottish Primary Care Cancer Group, in order to inform service delivery and improvements.

Outcomes

Most people diagnosed with cancer in Scotland present to a GP first. Most are referred and diagnosed quickly, with variations by cancer‐site. Intervals were longest for the most remote patients. GPs in Scotland and England appear to perform equally but, in view of growing differences between health systems, future comparative audits may be informative. There was no evidence that rural patients were more likely to be subject to prolonged cancer diagnostic delays than urban patients. Rural patients may experience primary care differently in the lead-up to a cancer diagnosis. The effect on outcome is probably negligible, but further research is required to confirm this.

## 1819-0117 Jill Ireland

**SPARRA and High Health Gain predictive modelling**

**End of Project Report**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | The aim of the study was to inform PBPP of ongoing work on the SPARRA and HHG models to ensure appropriate governance was in place. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | Healthcare professionals can use data from the SPARRA and High Health Gain tools in conjunction with their professional judgement to identify patients who could benefit from Anticipatory Care Planning, additional support and/or a multi-disciplinary discussion, thereby, helping facilitate a more community-based, preventative/anticipatory approach to a patient’s treatment, moving away from reactive treatment, and also for service planning. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | A SPARRA risk score is calculated automatically every month by the NHS NSS Business Intelligence team, for around 4.2 million individuals, using patient level hospital and prescribing data, along with some demographic data. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | In summary, SPARRA and High Health Gain are both predictive models which use routinely collected health data in Scotland. |
| How did you process the data? | Model updated monthly for SPARRA; Quarterly for HHG. |
| How did you provision/publish the information? | Both needed governance approvals in place to access the data in a secure environment. |
| Did your study scope change from its original aims? Please give brief details. | No, a separate PBPP was in place to cover SPARRA development work (1718-0370). |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | The SPARRA model will continue to be updated on a monthly basis. This process is owned by Public Health Scotland and will be run on an automated, scheduled basis at the end of each month by the NHS NSS Business Intelligence team. Users will continue to be notified via email when refreshed data are available to view. PBPP advised SPARRA should move to Business as Usual for PHS and the governance should now sit with the PHS Data Protection Team.  The Senior Leadership Team took the decision to stop High Health Gain modelling, due to a change in the collection of financial data, which was the key input to the HHG model. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | Yes, in terms of developing the model further and also to enhance model monitoring, to ensure the version deployed remains fit for purpose. |

## 1819-0153 Alastair Ross

**FACTORS- (Fluoride Application: a Co-designed Toolkit of ORganisational Strategies)**

**End of Project Report**

a) Key personnel/organisation

Dr Al Ross, Glasgow Dental School, University

of Glasgow

b) Public Benefit Impact

Results show broadly that Human Factors (also known as Ergonomics; HF/E) and systems thinking are acceptable as a way to approach Quality Improvement (QI) and that it is feasible to apply these scientific ideas in practice.

The project results will be important in supporting:

a) a return to preventive care after COVID; and b) implementation of the forthcoming Public Health England toolkit on “Delivering Better Oral Health” (our project staff were involved in developing this guidance).

The overall aim in Scotland as part of the Childsmile practice programme is to improve the oral health and general health of children in Scotland and to reduce inequalities in oral health and access to dental services. We believe that approaching preventive care in systems terms is a cornerstone of improvement efforts.

c) Aims

The aim of this project was to test for the first time the feasibility and acceptability of applying Human Factors and systems thinking for QI in general dental practice. This stage involved delivering an interactive QI ‘toolkit’ for General Dental Practitioners, prior to testing this approach in a randomised trial.

d) Data

We accessed fluoride varnish claims data from the Management Information and Dental Accounting System (MIDAS), which we used to personalise the toolkit for each GDP, by giving them feedback in relation to regional and national norms. 45 GDPs were introduced to the Human Factors approach via the fluoride varnish example, then asked to examine a further area of preventive care, before completing a survey. 14 of the 45 GDPs completing the toolkit were interviewed in-depth and a final dyadic interview was conducted with a GDP and Hygienist/Therapist from one practice.

e) Methodology

The MIDAS dataset was used to build a sampling frame of eligible GDPs (n = 991). Data were processed in IBM SPSS (Version 25). 500 GDPs were invited to take part in a period of just over 11 weeks.

45 GDPs were consented to work through the toolkit and complete the survey for two hours standard Research Participation fee.

Personalised versions of the Toolkit with individual claims data were uploaded to the University of Glasgow Transfer Service and GDPs were sent a link via email, immediately followed by another email with their personal password.

Data gathered during completion were captured on the University OneDrive.

f) Outcomes

Most of the participants (43/45; 96%) reported that working through the toolkit had enhanced their understanding of HF/E.

96% (43/45) agreed or strongly agreed that there is added value in the systems approach for dentists undertaking QI projects (4% [2]) were ‘not sure’).

93% [42] said teams could feasibly use these ideas during QI activity (7% [3] not sure).

69% (31) agreed the approach could be useful to look at systems and improve the resilience of processes as practices return to providing a range of care for the public after the SARS-Cov-2 and COVID-19 public health emergency (29% [13] said ‘maybe’, 2% [1] said ‘no’).

g) Future Questions: The PI was involved in a parallel catalytic project hosted at Dundee Dental School on the co-design of National Clinical Audits (including for fluoride varnish); discussions are underway as to how to share learning and further collaborate on research to support GDPs in these vital areas of child health

## 1819-0183 Lucy Irvine

**UK Children, Teenage and Young Adults (CTYA) cancer statistics**

**End of Project Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | The aim of the “UK Children, Teenage and Young Adults (CTYA) cancer statistics annual report” is to provide standardised national data relevant for the distinctive spectrum of cancers that occur for this age group. Previously there was limited CTYA statistics available of this nature.   * To produce statistical analysis by detailed cancer diagnostic subgroups relevant to the CTYA age group. * To present CTYA cancer incidence, both case counts and rates over a 20-year period. * Survival of CTYA diagnosed with cancer, both case counts and rates over a 20-year period. * Mortality of CTYA diagnosed with cancer, both death counts over a 20-year period. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | The statistics in the report are an important source for clinicians and the NHS, scientists, researchers (both domestic and international) and charities. The report provides evidence for CTYA with cancer, by providing granular and up to date statistics on cancer incidence, mortality and survival, which is relevant to healthcare planning, interventions and care. It will be used as key point of reference for epidemiology and research for this age group. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | NCRAS (National Cancer Registration and Analysis) PHE (Public Health England) collated cancer registration data extracts from each UK nation (Scotland, Northern Ireland, Wales and England) to create a UK dataset cases registered with cancer at the age of 0-24 during 1997-2016 and deaths up to the end of 2018, using the agreed data specification. The anonymised data extracts were provided to and collated by named analysts in the National Cancer Registration and Analysis Service, Public Health England. NCRAS produced the statistical analysis of anonymised data for theUK-wide analysis of cancer in CTYA, as agreed by all the 4 UK countries. The data was used to produce a national report and related outputs containing the most recent UK statistics for cancer incidence, mortality and survival – so that the report provides a valuable overview of CTYA (0-24 year olds) cancer statistics. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | In order to run the UK analysis, the Scottish Cancer Registry, Population Health provided an anonymised data extract for their country to PHE NCRAS for cancer cases diagnosed with cancer at the age 0-24 between 1997 and 2016. NCRAS collated these data with extracts (based on the same data specification) from Wales and Northern Ireland as well an extract of their English data from the National Cancer Registration and Analysis Service (NCRAS) ENCORE/CAS database, in order to create a UK dataset ready for analysis for the report. The data are held securely on the NCRAS network, under the secure environment used for the English cancer data. Only authorised NCRAS analysts will be able to access and analyse the data. The analysis was reviewed by each UK nation before release.  Process:   1. ISD Scottish Cancer Registry identified and extracted cases registered with cancer at the age of 0-24 during 1997-2016 and deaths up to the end of 2018, using the data specification. 2. ISD Scottish Cancer Registry, Population Health pseudonymised the data extract ready for secure transfer to NCRAS. 3. The data was transferred using secure file transfer processes (SFTp) between ISD Scottish Cancer Registry, Population Health and PHE. |
| How did you process the data? | NCRAS, PHE securely stores thepseudonymised Scottish dataset with equivalent cancer registration datasets from Wales, Northern Ireland and for England.  NCRAS, PHE collated the data extracts in excel to create a UK dataset and run the analysis statistical analysis for the report.  The project was be overseen/carried out with the project team which included David Morrison and analysts from ISD. We also worked in consultation with the PHE CTYA Expert Advisory Group (EAG), which includes charities and patient/parent representatives. They did not see case level data, only summary statistics. |
| How did you provision/publish the information? | The report was published on this website, and is supported by a blog on Publish Health matters.  <http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/cancer_in_children_teenagers_and_young_adults/> |
| Did your study scope change from its original aims? Please give brief details. | We were planning to produce more detailed cancer mortality analysis but we did not do this as we discovered there are slight differences in the way cause of death data is collected in each nation therefore we did not feel the data was comparable. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | The report has had excellent feedback. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | We did not include detailed trends analysis in our report, but this is something that may be explored further in the future. |

## 1819-0186 Professor Richard Anderson

**Reproductive outcomes in survivors of childhood, adolescent and young adult cancer in Scotland: a population based cohort study**

**The Public Benefit Impact Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | To explore the impact of cancer and its treatment on the fertility and mental health of girls and young women (aged up to 40) in Scotland. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | Identification of the impact of a cancer diagnosis on the subsequent chance of having a baby in an unbiased population-based cohort provides a robust basis for the provision of fertility provision services, currently being developed across the UK. This impact varied by diagnosis and over time, with our most recent publication focussing specifically on those under the age of 18 at diagnosis: these data allow for more accurate risk assessment for individual patients.  We have also shown the impact of a subsequent live birth on survival in women with breast cancer. This has been a long-debated subject, and a source of much anxiety to many women. Our analysis provides clear and reassuring information to women and their clinical teams to help them decide on whether to have a baby after a breast cancer diagnosis.  Analysis of mental health data shows that young women who have had cancer have fewer psychiatric admissions than matched controls. This is important new information relevant to care of such patients. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | SMR01, 02, 04 and 06, NRS and CHI over the period 1.1.81 to 31/12/2018 were provided. Data were as expected (e.g. from our previous analysis of similar data). |
| 4 | **Methodology** |  |
|  | How did you collect the data? | n/a |
| How did you process the data? | By data linkage and use of matched controls |
| How did you provision/publish the information? | After data check/release by eDRIS staff |
| Did your study scope change from its original aims? Please give brief details. | No changes |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | Girls and young women are less likely to have a baby after cancer, with this varying by diagnosis and period of diagnosis. Additionally, although childhood cancer survivors start their families at a slightly younger age, those that do have children have fewer than controls.  We found no evidence that having a baby after a breast cancer diagnosis had a negative impact on survival: in fact overall there was a survival benefit. This lack of negative impact was also confirmed in women with hormone-sensitive (ER+ve) cancers.  Young female cancer survivors have fewer psychiatric admissions than match controls. This is impacted by subsequent maternity, with a particular strong apparent protective effect of subsequent motherhood. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | The mental health findings were particularly unexpected, and differ in some respects from other reports. This may reflect that the data we analysed relate to admissions only: we are exploring whether primary care drug prescribing data can be obtained to further explore the mental health of young cancer survivors. |

## 1819-0256 Gerald Humphris

**A pilot trial of the Mini-AFTERc intervention to manage**

**Fear of Cancer Recurrence in breast cancer patients**

**End of Project Summary**

Public Benefit Impact

Fear of cancer recurrence is one of the main concerns that patients report after cancer

treatment. The Mini-AFTERc intervention is a 30-minute telephone discussion to be delivered by

cancer nurses at the end of treatment. It uses psychological principles to help patients manage

concerns about cancer recurrence. Breast cancer patients who received the Mini-AFTERc

intervention as part of this study reported an average reduction in fear of cancer recurrence.

This provides some initial evidence that delivering Mini-AFTERc as part of routine breast cancer

care may benefit patient overall wellbeing and enhance cancer recovery. We aim to use the

information we collected during this study to test the intervention fully by designing a larger

randomised controlled trial (RCT) study.

Aims

The main aim of this study was to understand how acceptable the Mini-AFTERc intervention was

to patients and nurses, and whether it could become part of everyday breast cancer care. The

study also aimed to collect important information needed to design a larger study to properly

examine how effective the intervention is for helping patients manage fear of cancer recurrence.

Data

We collected information about patients’ fear of cancer recurrence, mental health and quality of

life. We also audio recorded the Mini-AFTERc telephone discussions between patients and

nurses and asked patients to rate the discussion. Finally, we asked patients and nurses to

feedback about their experience of taking part in the study in a telephone interview.

Methodology

We measured how patients’ fear of cancer recurrence changed over a 3-month time period, for

a group of patients who received the Mini-AFTERc intervention and a group of patients who did

not. Patients received the intervention over the telephone from a trained breast care nurse. We

collected information using paper questionnaires, a mobile phone app, and telephone

interviews.

Outcomes

Both patients and nurses found the Mini-AFTERc intervention useful and acceptable. Patients

were recruited on to the study effectively, and the intervention was delivered successfully by

nurses. Differences in how cancer centres work mean that some changes to the study design will

be made to ensure a future study can run more efficiently.

Future Questions

This study found that the Mini-AFTERc intervention may be helpful for patients and we have

identified some changes that we believe would improve the intervention and the study design.

Next we intend to properly test the intervention with a larger group of patients and identify how

it can best be delivered as part of cancer care.

## 1819-0176 Prof Duncan Porter

**Scottish Early RA inception cohort**

**The Public Benefit Impact Summary**

1. **Aims**The purpose of the project was to link the SERA database to nationally held datasets, and to add an age, gender and post code matched cohort of five subjects for each SERA participant. Linking data enabled exploration of the relationship between clinical, demographic and/or biomarker data with a variety of patient outcomes, while the addition of matched controls allowed studies into the magnitude of risk of important outcomes in RA patients when compared to the general population.
2. **Public Benefit Impact**The studies completed have increased our knowledge of:
   1. the cost of illness and multimorbidity in RA
   2. comparative study of factors affecting the cost of illness in Scotland and Tanzania
   3. the relationship between frailty and disease activity, hospitalisation and mortality
   4. the relative frequency of the use of antibiotics (in patients and controls) in eras prior to symptoms, after symptoms develop but before diagnosis, and in early disease. Antibiotic use is significantly greater in the periods (i) immediately preceding the onset of symptoms (ii) when patients have symptoms but have not yet been diagnosed and (iii) in the first 12 months following diagnosis. The findings are of importance in teasing out whether bacterial infections may be the cause or result of the immune dysregulation seen in RA.
   5. the baseline factors that are associated with poor quality of life after 12 months following diagnosis – traditional markers of poor prognosis (e.g. disease activity, blood markers of inflammation etc.) proved not to be independent predictors of poor outcome, whereas psychosocial factors (social deprivation, mood, employment) were strong predictors.
3. **Data**
   1. NRS Census Data, Prescribing, SMR01, SMR04, SMR02, eCOSS
   2. Yes – no problems were encountered
4. **Methodology**
   1. Data collection – SERA data were collected using an electronic case report form and standardised questionnaires (for physical function, mood, fatigue, employment and health-related quality of life. Data were collected at diagnosis, every six months until 2 years, and annually thereafter.
   2. Data processing - the methods used were dependent on the specific project, and their planned use is part of the SERA Access Committee’s approval process
   3. Dissemination – results were presented at the Scottish Society for Rheumatology, British Society for Rheumatology, and American College of Rheumatology Annual Scientific meetings, in a PhD thesis and publication in peer-reviewed rheumatology journals.
   4. Scope – no change
5. **Outcome** – the project provided a resource that could be interrogated and used to answer diverse research questions. The nature of the ‘framework’ approval allowed delegation of the approvals process to the SERA Access Committee (guided by the SERA Access Policy). This worked smoothly and facilitated access to the enhanced SERA dataset on the secure analytical platform at the Glasgow Safe Haven for approved projects by researchers who demonstrated appropriate Information Governance training.
6. **Future Questions –** a new application is being made to re-use the study cohort for further projects that are approved by the SERA Access Committee. Another comparator cohort (the Scottish Observational Psoriatic Arthritis Cohort (SOPHOS) will be added which will facilitate comparative studies of rheumatoid and psoriatic arthritis. We are reviewing the DPIA and re expecting to stipulate a defined period of data retention for subsequent projects.

## 1819-0264 Dr Charis Marwick

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

**End of Project Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | The aim of this study was to design safety outcome measures for a potential future trial of an intervention to improve antibiotic use in care homes for older people. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | The ultimate aim of the ARCH (Antibiotic Research in Care Homes, which this is part of) is to reduce antibiotic use and antibiotic resistance for wider public health benefit. Outputs will also increase knowledge around antibiotic resistance and interventions in health and social care settings, informing other improvement programmes.  This particular study aimed to develop safety outcomes measures for a trial – to ensure that any benefits in terms of adverse effects of antibiotic use (including antibiotic resistance) are not offset by adverse outcomes of potential under-treatment of infections (use of unscheduled care, hospital admissions and deaths). |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | The full list of variables is in the application and involved the following datasets via UCD: SMR01, A&E, SMR04, GP out of hours, SAS, NHS24.  The cohort included residents of care homes for older people in the Tayside and Fife Health Board regions. The care home resident cohort had been created by the study team, working with HIC, using an address-based matching system.  The initial data received, and the timelines involved, were not as expected. PBPP approval was October 2019, and the plan was for 3 annual refreshes.  The first versions of two datasets were received in June (NHS24) and October (SAS) 2020 but the other datasets were not provided - the issues were discussed by email at length in 2020 but not resolved. As far as we understand, the problems and delays in data provision, above normal processing time, were due to COVID-19 studies affecting workload and priorities. The workplan of the ARCH project as a whole was also significantly affected by COVID-19.  In May 2020, we received a “refresh” which included all the approved datasets and the data were as expected and very usable to the analyst, who is very experienced with the type of data, although first use of UCD. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | All routinely collected administrative data. |
| How did you process the data? | Anonymised data were processed in accordance with PHS and HIC SOPs.  Statistical analysis of the data involved generating monthly rates (episodes per resident bed days) of use of unscheduled care services by care home residents. The rates included use of each service separately and combined “episodes of care”.  Variation was examined and can/will be used to plan outcome measures and sample size calculations for future trials. |
| How did you provision/publish the information? | Not published yet. |
| Did your study scope change from its original aims? Please give brief details. | No, but some elements of the wider ARCH project - feasibility study and stakeholder engagement - were limited due to COVID-19. This meant that we were not able to compare the nature of outcome measures from routine data to those manually collected in study care homes. It also limited stakeholder feedback on potential user interpretation of outcome data and their preferences on presentation and/or use in a future trial. We were still able to model the outcome measures for future trial(s) as above. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | The PHS data were successfully transferred and linked to bespoke cohort data in a regional data safe haven.  Use of unscheduled care services varied across 164 care homes in Tayside and Fife.  The mean monthly rate of linked unscheduled care episodes (i.e. if NHS24 were contacted about a resident and they advised SAS which resulted in A&E attendance – this would count as one episode) per care home varied from 0.93 (SD 0.61) to 33.3 (SD 11.2) per month in the 2020 calendar year.  Similar variation was seen on examination of the individual unscheduled care datasets. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | There is further work to be done in evaluation and assessment of the potential use and acceptance of these outcomes measures as safety outcome measures in the evaluation of social care interventions. |

## 1819-0236 Sandra Robb

**Excellence in Care (EiC)**

**End of Project Summary**

|  |  |  |
| --- | --- | --- |
| 1 | **Aims** |  |
|  | What did the study set out to achieve? | To develop a nationally agreed set of clearly defined key measures / indicators of high-quality nursing and midwifery care.  To present, via a dashboard, data on these measures to enable healthcare professionals to monitor and assure the quality of care delivered in nursing and midwifery care settings across NHS Scotland. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | The EiC programme is a response to the findings of the [Vale of Leven Inquiry](https://www.healthcareimprovementscotland.org/our_work/patient_safety/excellence_in_care/vale_of_leven_inquiry.aspx) and the [requirements of the Health and Care (Staffing) (Scotland) Act](https://www.gov.scot/publications/health-and-care-staffing-scotland-act-2019-overview/). It:   * ensures that NHS Boards and integrated joint boards have consistent and robust processes and systems for measuring, assuring, and reporting on the quality of nursing and midwifery care and practice. * contributes to improving patient care by ensuring consistency of standards across Scotland.   The CAIR dashboard provides data to enable health care professionals to monitor and assure the quality of care delivered in nursing and midwifery care settings across NHS Scotland. This provides reassurance to members of the public and patients in Scotland that they are receiving safe, quality care. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | The data variables received, processed, extracted were as outlined in the original PBPP application. It is not practical to provide a full list of variables here due to the large number of data items involved. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | Data was transferred via various routes. Boards either ‘pushed’ their data to NSS as files submitted via SWIFT or Automated File Transfer (AFT) which were then processed and loaded into the Corporate Data Warehouse (CDW) staging area or data was ‘pulled’ by NSS data virtualisation which acts as a bridge to allow NSS to access, reformat and transfer specific agreed data to be loaded into the CDW. |
| How did you process the data? | On receipt, data was loaded into the CDW staging area. Data was then extracted, transformed, and loaded into the CDW. Tableau extracts were then created, and the data presented as Tableau views within a dashboard. |
| How did you provision/publish the information? | Data was presented to authorised users via a Tableau dashboard (the CAIR dashboard) with user access to the dashboard controlled and authorised via the [User Access System (UAS)](https://useraccess.nhsnss.scot.nhs.uk/). This dashboard provides a range of data visualisations and analytics to assist the monitoring of quality of care. Users used this information to assist in monitoring and improving the quality of care provided to patients. |
| Did your study scope change from its original aims? Please give brief details. | No, the scope of this work was as described in the original PBPP application. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | The work carried out via this proposal has aided NHS Boards and integrated joint boards to have consistent and robust processes and systems for measuring, assuring, and reporting on the quality of nursing and midwifery care and practice. It has contributed to improving patient care by providing data to enable health care professionals to monitor and assure the quality of care delivered in nursing and midwifery care settings across NHS Scotland.  The EiC programme provides reassurance to members of the public and patients across Scotland that they are receiving safe, quality care. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | The benefits of the EiC programme in monitoring and improving the quality of care provided to patients have led to discussion around the possibility of extending the programme to other NHS job families / across multidisciplinary teams within the NHS e.g. allied health professionals. |

## 1819-0224 Archie Campbell

Generation Scotland linkage

**The Public Benefit Impact Summary**

|  |  |  |
| --- | --- | --- |
| 1 | **Aims** |  |
|  | What did the study set out to achieve? | Generation Scotland (GS) was granted program-level access to linked data for consented volunteers in our cohort. Third party researchers apply to GS for access to the linked data along with genetic, epigenetic, proteomic and other data collected by GS. Projects are mainly investigating genetic and environmental causes of diseases, or identification of biomarkers to assist in diagnosis and prevention. In most cases, GS has used the linked data internally to select relevant data for the project, only releasing minimised data to the applicants where required. All applications to access data are reviewed and approved or declined by the Generation Scotland Access Committee. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | The projects are mainly research into biological mechanisms to assist understanding of the causes of diseases, in order to work out how to treat or prevent them further down the line. The GS epigenetic dataset is in much demand for research into identifying biomarkers for a range of conditions.  GS has also been able to contribute to major discoveries and advances by international consortia in (for example) psychiatric genetics, breast cancer, colon cancer, cardiovascular disease, and cognitive aging.  Some more immediate benefits include assisting in the development of the “ASSIGN” algorithm used to assess cardiac disease risk in clinics, and demonstrating the value of biomarkers (troponin) in cardiac diagnoses. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | GS received releases of most of the CHI linked datasets available from eDRIS for research. The planned annual refreshes were interrupted by the Covid pandemic. For most datasets we only received two releases over the five years. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | The Dundee Health Informatics Centre (HIC) hold a list of GS CHIs which they sent to eDRIS for data extraction. De-identified data was released to GS by eDRIS by secure download. |
| How did you process the data? | The datasets were imported into the secure GS SQL database, and linked to the genotype and other data collected by GS from consented volunteers using a linkage key table from HIC. |
| How did you provision/publish the information? | After approval of a request involving linked data by the GS Access Committee, the IT team extracted the data required from that project from the datasets. The principle of data minimisation was applied to data released to the researchers. Inmost cases, eg selection of disease cases or controls, the researcher only received a status flag, or age at first incidence, rather than linked data details.  Deidentified data was encrypted for delivery to researchers after signature of a transfer agreement, which includes data security and privacy provisions. |
| Did your study scope change from its original aims? Please give brief details. | In 2019 GS was awarded a grant to expand the cohort, and recruit from age 12+ (with parental consent). There are now over 10,000 more volunteers in the cohort, but the overall aims of the study remain the same. None of these new volunteers have been linked to NHS Scotland data yet, a new application is currently under review to establish these linkages. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | From 2018 to 2023 GS approved 108 applications involving linked data, resulting in over 100 peer-reviewed publications (list provided). There are many more projects still ongoing. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | GS in currently recruiting more volunteers, and has applied for an extension of the previous approval. There is still demand for access to GS resources from the research community, and access to linked data is an integral part of the resource. |

## 1819-0270 Su-Gwan Tham

**Suicide by middle-aged men**

**End of Project Summary**

Aims

What did the study set out to achieve?

The study aimed to examine the characteristics of middle-aged men who die by suicide, determine how frequently suicide is preceded by factors often associated with suicide by men, examine the role of support services and to make recommendations to strengthen suicide prevention for middle-aged men.

Public Benefit Impact

How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered.

Our findings identify factors associated with suicide in middle-aged men, and could help inform changes to policy and safer practice in all front-line agencies. This includes the identification of barriers to accessing services to reduce suicide in middle-aged men.

Findings could inform national suicide prevention strategies in the UK and local suicide prevention plans for middle-aged men. Reducing risk in men in one of the main priority areas identified in the national suicide prevention strategy.

Findings could also feed into NHS England and NHS Improvement’s national suicide prevention programme – a nationally recognised suicide reduction priority.

Public Benefit and Privacy Panel for Health and Social Care

End of Project Declaration and Summary

End of Project Declaration and Summary Report V0.1 - Suicide by middle-aged men

Data

What data were received/processed/collected?

Was it as expected? Please give brief details.

We collected data about men aged 40-54 who died by suicide (including probable suicide) in England, Wales and Scotland between 1st January 2017 and 31st December 2017. We combined available data from official bodies: coroner inquest hearings/police sudden death reports, criminal justice reports, safeguarding adult reviews, NCISH data and Serious Incident reports. We sought to collect data on 200 suicide deaths by middle-aged men. Data collection proceeded as expected. 4

Methodology

How did you collect the data?

Suicides and probable suicides (undetermined deaths) were identified from general population mortality data received by the NCISH from the Office of National Statistics (ONS; for deaths registered in England and Wales) and National Records of Scotland (NRS; for deaths registered in Scotland). Stratified sampling was used to select a sample representative of each age in England, Wales and Scotland.

We sought data from official bodies for men who had been sampled for additional data collection. These data sources were coroner inquest hearings/police sudden death reports, criminal justice reports, safeguarding adult reviews, NCISH data and Serious Incident reports.

How did you process the data?

We extracted data from these data sources using a proforma designed to elicit relevant information for the purposes of the study.

How did you provision/publish the information?

Findings from the study will be published in a free, publically-available report on the NCISH website. Additional outputs will include academic papers in peer-reviewed journals and presentations at academic conferences.

Public Benefit and Privacy Panel for Health and Social Care

End of Project Declaration and Summary

End of Project Declaration and Summary Report V0.1 - Suicide by middle-aged men

Did your study scope change from its original aims? Please give brief details.

Outcomes:

The outcomes / results of your proposal. Please give brief details.

The provisional publication date for this report is May/June 2021. This will be made available on our NCISH website. The results are under embargo until this report has been published. Therefore, we are unable to provide details on the study results until then. However, we will provide the PBPP with a copy of the report and an updated Public Benefit Impact Summary when this has been published. 6

Future Questions:

Have the processes / results raised further questions for future exploration? Please give brief details.

The provisional publication date for this report is May/June 2021. This will be made available on our NCISH website. The results are under embargo until this report has been published. Therefore, we are unable to provide details on the study results until then. However, we will provide the PBPP with a copy of the report and an updated Public Benefit Impact Summary when this has been published.

## 1819-0315 Helen Colhoun

**SDRN Type 1 Bioresource Data Linkage**

**The Public Benefit Impact Summary**

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| 1 | **Aims** |  |
| What did the study set out to achieve? | | The overall aim of the study was to maintain a pseudonymised research bioresource of blood and urine samples linked to pseudonymised data for the study of Type 1 diabetes mellitus (DM), which was originally created with patient consent in a previous application ref: 15/13; XRB13113.  The resource was used for the study of causes, pathogenesis and preventability of type 1 DM and MODY, diabetes characteristics, complications and treatment response, including:  1. Genetics of type 1 DM, monogenic diabetes, and LADA;  2. Identification and assessment of appropriate treatment of patients with monogenic diabetes;  3. Environmental determinants of type 1 DM and their interaction with genetic factors;  4. Genetics of diabetic complications;  5. Pathogenesis of diabetic complications;  6. Biomarkers of diabetic complications. |

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| 2 | **Public Benefit Impact** |  |
| How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | | Type 1 DM, along with Latent Autoimmune Diabetes of Adulthood (LADA) and Maturity Onset Diabetes in the Young (MODY), affect tens of thousands of 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 outcomes. Research into and, ultimately, the prevention of the disease and its complications has been previously hampered by the small size of the existing cohorts of type 1 DM patients that have been studied (typically hundreds of patients). Following the establishment of this novel bioresource, including collation of various genetic data and biomarker data from laboratory analyses of the available samples, along with linkage of e.g. retinal screening images, we wished to use this resource to undertake specific analyses of the disease and associated complications. The genetic and environmental determinants of the disease are not understood completely and we currently do not know how to prevent the disease or associated complications. The linked dataset will be updated and utilised in this study will aid our knowledge across a wide number of areas from better understanding of the pathogenesis of disease through to improved strategies for clinical management. For example, increased knowledge of the genetic basis of type 1 DM and MODY will help the effort to design preventive immune-based interventions, and will improve diagnosis and clinical management of MODY. Genetic and biomarker data with respect to complications can increase our understanding of how these complications arise, help design better clinical intervention trials, and aid clinical prediction and development of targeted treatment strategies. |

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| 3 | **Data** |  |
| What data were received/processed/collected?  Was it as expected? Please give brief details. | | Data were requested from several different sources, including SCI-Diabetes, Public Health Scotland, Community Health Index database, NHS Central Registry (National Records of Scotland), Scottish Renal Registry, and Diabetic Eye Screening (DES) service. This data was then linked with existing study (Scottish Diabetes Type 1 Bioresource; SDRNT1BIO) data, which was derived from biological samples stored in the tissue biorepository, such as genotype and biomarker data. The linked data provided by SCI-Diabetes and eDRIS were only provided in pseudonymised format, and then linked by the DMIE group administrators to the existing data. All patients in the study cohort consented to genetic and biomarker testing of provided samples, and ongoing linkage with their past and future clinical and NHS data records.  The data received and processed were as expected and specified in the original application and subsequent amendments. |
| 4 | **Methodology** |  |
| How did you collect the data? | | All requested data were provided from existing datasets/sources, including SCI-Diabetes (approval provided for both provisioning of SCI-Diabetes data variables and data linkage), Public Health Scotland (e.g. A+E records, Scottish Morbidity Records- SMR, prescribing data, Scottish Renal Registry, Scottish birth records, Scottish stillbirth and infant deaths survey), National Records of Scotland (Registry Office birth, death and infant death/stillbirth records, quarterly updated cancer registrations, deaths and embarkations) and Diabetic Eye Screening (DES) retinal images. Existing Type 1 Bioresource derived genotype and biomarker data from stored biological samples were subsequently linked with the requested external datasets.  The data was provided via annual pseudonymised data extract, with quarterly updates from NHS Central Registry (NHSCR; via National Records of Scotland) for cancer registrations, deaths and embarkations and occasional updates of retinal images from DES as required. |
| How did you process the data? | | The data linkage process is described briefly here:  A set of CHIs defining the cohort, along with dummy IDs, have previously been securely sent to SCI-Diabetes and eDRIS at PHS, along with NHSCR and DES. A list of these CHIs, along with a map to each person’s pseudonymous ‘dummy ID’ and other identifiable data such as names and addresses is kept encrypted by the DMI&E group, as consented by persons participating in the study, only accessible to the PI and DMI&E systems administrators. eDRIS, SCI-Diabetes, NHSCR and DES will link identifiers (CHIs) provided at the start of the study. During data linkage on the datasets, they pseudonymise them by replacing the CHIs with the dummy IDs. The pseudonymised data is then securely transferred to the DMI&E systems administrators, who run the files through the extensive cleaning process before linking the pseudonymised data from SCI-Diabetes, eDRIS, NHSCR and DRS to the existing study research database, along with biochemical and genetic data from analysis of blood and urine samples. During data transmission and subsequent research, individuals are only referenced by their dummy IDs.  CHI number was processed for linkage purposes only- Public Health Scotland remove the CHI number and only retain the unique pseudonymised study identifier when transferring extracted data to the DMIE group. All data handling was of de-identified (pseudonymised) data, with the original study participant identifiers kept encrypted in a separate and secure server environment. |
| How did you provision/publish the information? | | Data from this research has been presented at various national and international conferences and a number of manuscripts have been published:  <https://doi.org/10.2337/db19-1695-P>  <https://doi.org/10.1186/s12916-019-1392-8>  <https://doi.org/10.1007/s00125-019-4915-0>  <https://doi.org/10.1007/s00125-019-05052-z>  <https://doi.org/10.2337/dc19-1582>  <https://doi.org/10.1007/s00125-019-05081-8>  <https://doi.org/10.2337/dc20-0567>  <https://doi.org/10.1093/glycob/cwaa106>  <https://doi.org/10.1177/1352458520963937>  <https://doi.org/10.1038/s41598-022-08429-0>  <https://doi.org/10.1016/j.ajhg.2023.04.003> |
| Did your study scope change from its original aims? Please give brief details. | | There was no change in scope over the duration of the study. |
| 5 | **Outcomes:** |  |
| The outcomes / results of your proposal. Please give brief details. | | * We have identified two novel loci with genome wide significance for eGFR and three suggestive eGFR loci when assessing the genetic determinants of diabetic kidney disease. The results can be used for future research into potential biomarkers in these pathways for DKD * An assessment of the relationship between detectable C-peptide secretion in T1D to clinical and genetic features of diabetes found that persistence of C-peptide secretion varies widely in people clinically diagnosed as T1D. C-peptide persistence is influenced by variants in the HLA region that are different from those determining risk of early-onset T1D. Known risk loci for diabetes account for only a small proportion of the genetic effects on C-peptide persistence * We identified a sparse panel of biomarkers for improving the prediction of renal disease progression in type 1 diabetes. * Our data on the rates and predictors of decline in renal function (decline in eGFR) in a type 1 diabetes cohort, including prevalence of chronic kidney disease (CKD), end-stage renal disease (ESRD), and micro-/macroalbuminuria, showed much lower levels of kidney disease than historical estimates. However, early identification of those likely to have significant decline in eGFR remains challenging. * An assessment of the prevalence of diabetic peripheral neuropathy (DPN) in people with T1D in Scotland showed that prevalence was higher in the most socioeconomically deprived, and that those with clinically manifest neuropathy were much more likely to have diabetes complications. * We found that a minor number of candidate biomarkers in serum, easily measurable along with serum creatinine, can improve the prediction of renal disease progression in type 1 diabetes, compared to urinary albumin/creatinine ratio (ACR). * Even minimal residual C-peptide secretion could have clinical benefit in T1D (e.g. reduced baseline insulin dosing, lower HbA1c levels, hazard ratio for follow-up diabetic ketoacidosis or incident retinopathy, and risk of serious hypoglycaemic episodes), which is in contrast to a follow-up study of the Diabetes Control and Complications Trial (DCCT) cohort, where an effect on hypoglycemia was seen only at C-peptide levels >130 pmol/L. * We showed that elevated HbA1c and worsening ACR is associated with an altered N-glycan profile in type 1 diabetes, while lower eGFR was associated with higher absolute N-glycan levels. However, we could not establish peak N-glycan levels to be prognostic of future renal function decline independently of HbA1c. * As part of a meta-analysis of the genetic pathogenesis of T1D, we showed that a mutation in the PRF1 gene is associated with increased lymphocyte levels in cytotoxic T-cells (leading to a reduced interleukin-7 receptor expression on these cells). This has a protective effect (reduced risk) of developing T1D. * Using a novel methodology termed Genome-wide association of *trans* effects, we have discovered potential causal (‘core’) genes involved in the pathogenesis of T1D. |
| 6 | **Future Questions:** |  |
| Have the processes / results raised further questions for future exploration? Please give brief details. | | Following expiration of NHSCR approvals, we have successfully renewed our application for further research using the linked data and biological samples from this cohort for the continued study of causes, pathogenesis and preventability of type 1 DM and MODY, diabetes characteristics, complications and treatment response. |

## 1819-0340 George Ramsay

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

**End of Project Report**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | We aimed to describe the epidemiology of Emergency General Surgery in Scotland. Specifically we had three aims: 1. In those patients who are discharged home after EGS care, of what do they subsequently die? 2. Do the long term mortality rates change with admission volume of institution? 3. Is long term mortality linked to the distance between home and hospital? |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | Emergency General Surgery (EGS) is an understudied aspect of General Surgery. Indeed most works in this field have explored the outcomes in those individuals who have had an operation. However, this accounts for only around a quarter of the patients in this group. We aimed to determine what the outcomes are for this whole group.  By further understanding the survival and cause of deaths in this cohort, as well as the impact of hospital volume and distance from hospital to home abode (manuscript in draft), we hope to have provided key stakeholders in workforce planning and service design within the NHS information which is useful for future care delivery. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | All patients who were admitted in an unscheduled manner to a hospital under the care of a General Surgeon in Scotland between 01/04/1997 and 01/04/2019 were included. Anonymised data on admission and operative diagnosis and codes were included. Co-morbidity indices, age, Gender and demographic details were also processed. This was linked to death data (including cause and date of death) as well as readmission rates.  The data were kept on the safehaven throughout the analysis and there was a very low rate of missing data. Furthermore, this is, to our knowledge, the largest scale project of its type in this field |
| 4 | **Methodology** |  |
|  | How did you collect the data? | Data already collected and stored by NSS was used |
| How did you process the data? | All analysis was undertaken in the safehaven |
| How did you provision/publish the information? | Our results were published in 2 peer reviewed manuscripts |
| Did your study scope change from its original aims? Please give brief details. | During this study we managed to address the three questions laid out in the aims section. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | Our results demonstrated that of the patients who died within one year of Emergency General Surgical (EGS) admission, around a half had a cancer diagnosis. Furthermore, the mortality rate was high after this type of surgery. EGS admission therefore highlights a relatively high risk cohort of patients. We proposed closer links between oncology, palliative care and emergency surgery as a result of this work.  EGS outcome is also improved upon by being admitted under a surgeon who has not had excessive numbers of patients managed in this manner each month. Rurality does not appear to negatively affect outcome in this group |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | The key next question would be what can be done to improve the mortality rate in EGS care? |

## 

## 1819-0251 Steve Turner

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

**End of Project Report**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | To determine whether to public health initiatives aimed at reducing children’s exposure to second hand smoke were associated with beneficial health outceoms in chidlren |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | Our research suggests that the “Take it right outside” and “Car smoking ban” may have directly improved the health of young children in Scotland. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | SMR01 data  Yes. The data initially provided were exactly as expected. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | From SMR01 (2000-2018) |
| How did you process the data? | Interrupted time series analyses |
| How did you provision/publish the information? | Usual peer review process |
| Did your study scope change from its original aims? Please give brief details. | We initially aimed to consider the association with Take it right outside (2014) but with approval also considered the association with the car smoking ban (2016) as |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | Both initiatives were associated with reduced asthma admissions in under five year olds. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | No |

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## 1819-0356 Dr Will Atkinson

**MR110 UKAEA Mortality & Morbidity Study**

**End of Project Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | The aim of the proposal was to continue the assembly of data pertaining to the health effects of low-level protracted exposure to ionising radiation |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | Studies of the MR110 cohort will influence, the development of the Ionising Radiation Regulations (IRRs) which regulate the exposure of people at work and of the public. The correct regulation of doses benefits the health not only of nuclear workers, but anyone else who works with radiation, such as medical radiographers and members of the public exposed as a result of medical x-rays or radioactive discharges to the environment. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | Death and Cancer Registration data was collected from NHS Scotland and linked to employment and radiation exposure data provided by the employers. The data provided was as expected and suitable for the study purposes. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | The data was received from NHS Scotland and the employers as electronic downloads. |
| How did you process the data? | The data was loaded into the Nuvia epidemiology database, SHIELD. |
| How did you provision/publish the information? | Some 20 publications have resulted from this study previously. No publications have resulted from the recent phase covered by this PBPP, but the data will continue to be used by the UK Health Security Agency in its new National Radiation Epidemiology Database. |
| Did your study scope change from its original aims? Please give brief details. | No |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | At the end of the period covered by this PBPP we had recorded 45,082 deaths and 18,083 cancer registrations in the UKAEA cohort. During the period we had added 2,110 deaths and 1,464 cancer registrations. This increases the statistical power of the study |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | No |

## 1819-0235 Lee Barnsdale

**Scottish Public Health Drug Linkage Programme**

**End of Project Report**

**The Public Benefit Impact Summary**

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| --- | --- | --- |
| 1 | **Aims** |  |
|  | What did the study set out to achieve? | By processing and linking routinely collected drug-related health data, to establish a cohort database of problematic drug users, which can be used for the purpose of public health surveillance. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | The work benefits members of the public by generating public health intelligence in relation to problematic drug use and its consequences for surveillance and monitoring purposes.  Benefits will be realised across three main themes which align closely with Scottish Government strategic priorities and research interests:   1. Size and composition of the population with problematic drug use 2. Mortality and morbidity among people with problematic drug use 3. Impact of Specialist Drug Treatment and Care |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | * NRS deaths database (SMR99) * NRS drugs implicated data * SMR01 * SMR04 * Scottish Drug Misuse Database (SMR25A/B) * Prescribing Information System * Drug and Alcohol Treatment Waiting Times database * National Drug-Related Death Database * Blood Borne Virus Testing/Diagnosis database   All data sources conformed to expectations. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | Via authorised access to routinely held PHS datasets or via internal PHS inform.ation request. |
| How did you process the data? | Data were CHI seeded where necessary and deterministically/probablistically linked via person identifiers |
| How did you provision/publish the information? | Data access restricted to those with access to confidential server area.  No publications yet |
| Did your study scope change from its original aims? Please give brief details. | No. However, work is ongoing. Ended PBPP process in order to manage project via PHS BAU. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | Work is ongoing. Ended PBPP process in order to manage project via PHS BAU. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | Work is ongoing. Ended PBPP process in order to manage project via PHS BAU. |

## 1819-0287 Christopher McGovern

Mortality and long term morbidity in survivors of burn injuries and acute pancreatitis

End of Project Report

**The Public Benefit Impact Summary**

|  |  |  |
| --- | --- | --- |
| 1 | **Aims** |  |
|  | What did the study set out to achieve? | To investigate the long-term health affects of sustaining a burn injury. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | Survivors of burn injury are at increased risk of various detrimental outcomes. Recognition of various risk factors will aid in targeting interventions towards groups at highest risk. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | Healthcare administrative data of acute and psychiatric hospital admissions, death certification data and drug prescription data. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | Linked available administrative healthcare data |
| How did you process the data? | Via eDRIS |
| How did you provision/publish the information? | Detailed above |
| Did your study scope change from its original aims? Please give brief details. | No |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | Survivors of burn injury are at increased risk of death, increased opioid use and perhaps cancer than individuals of similar age, sex and socioeconomic deprivation. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | What physiological processes are contributing to these outcomes and are they related to the burn injury specifically. |

## 1819-0183 Lucy Irvine

“The transfer, use, and retention of anonymised cancer data from the Scottish Cancer Registry, Population Health to enable the National Cancer Registration and Analysis Service (NCRAS), NDRS, NHS digital (formerly Public Health England (PHE)) to collate a UK dataset and carry out analysis needed for the

“UK Children, Teenage and Young Adults (CTYA) cancer statistics” report”

**The Public Benefit Impact Summary**

|  |  |  |
| --- | --- | --- |
| 1 | **Aims** |  |
|  | What did the study set out to achieve? | The aim of the “UK Children, Teenage and Young Adults (CTYA) cancer statistics annual report” is to provide standardised national data relevant for the distinctive spectrum of cancers that occur for this age group. Previously there was limited CTYA statistics available of this nature.   * To produce statistical analysis by detailed cancer diagnostic subgroups relevant to the CTYA age group. * To present CTYA cancer incidence, both case counts and rates over a 20-year period. * Survival of CTYA diagnosed with cancer, both case counts and rates over a 20-year period. * Mortality of CTYA diagnosed with cancer, both death counts over a 20-year period. |
| 2 | **Public Benefit Impact** |  |
|  | How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered. | The statistics in the report are an important source for clinicians and the NHS, scientists, researchers (both domestic and international) and charities. The report provides evidence for CTYA with cancer, by providing granular and up to date statistics on cancer incidence, mortality and survival, which is relevant to healthcare planning, interventions and care. It will be used as key point of reference for epidemiology and research for this age group. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | NCRAS (National Cancer Registration and Analysis), NDRS, NHSD/NHSE (previously Public Health England) collated cancer registration data extracts from each UK nation (Scotland, Northern Ireland, Wales and England) to create a UK dataset cases registered with cancer at the age of 0-24 during 1997-2016 and deaths up to the end of 2018, using the agreed data specification. The anonymised data extracts were provided to and collated by named analysts in the National Cancer Registration and Analysis Service, NDRS. NCRAS produced the statistical analysis of anonymised data for theUK-wide analysis of cancer in CTYA, as agreed by all the 4 UK countries. The data was used to produce a national report and related outputs containing the most recent UK statistics for cancer incidence, mortality and survival – so that the report provides a valuable overview of CTYA (0-24 year olds) cancer statistics. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | In order to run the UK analysis, the Scottish Cancer Registry, Population Health provided an anonymised data extract for their country to NCRAS, NDRS, NHSD/NHSE (previously PHE) for cancer cases diagnosed with cancer at the age 0-24 between 1997 and 2016. NCRAS collated these data with extracts (based on the same data specification) from Wales and Northern Ireland as well an extract of their English data from the National Cancer Registration and Analysis Service (NCRAS) ENCORE/CAS database, in order to create a UK dataset in Excel ready for analysis for the report. The data are held securely on the NCRAS network, under the secure environment used for the English cancer data. Only authorised NCRAS analysts accessed and analysed the data. The analysis was reviewed by each UK nation before release.  Process:   1. ISD Scottish Cancer Registry identified and extracted cases registered with cancer at the age of 0-24 during 1997-2016 and deaths up to the end of 2018, using the data specification. 2. ISD Scottish Cancer Registry, Population Health pseudonymised the data extract ready for secure transfer to NCRAS. 3. The data was transferred using secure file transfer processes (SFTp) between ISD Scottish Cancer Registry, Population Health and PHE. |
| How did you process the data? | NCRAS, NHSD/NHSE securely stores thepseudonymised Scottish dataset with equivalent cancer registration datasets from Wales, Northern Ireland and for England.  NCRAS, NHSD/NHSE collated the data extracts in excel to create a UK dataset and run the analysis statistical analysis for the report.  The project was be overseen/carried out with the project team which included David Morrison and analysts from ISD. We also worked in consultation with the PHE CTYA Expert Advisory Group (EAG), which includes charities and patient/parent representatives. They did not see case level data, only summary statistics. |
| How did you provision/publish the information? | The report was published on this website  [Cancer in children, teenagers and young adults (CTYA) - NDRS (digital.nhs.uk)](https://digital.nhs.uk/ndrs/our-work/ncras-work-programme/cancer-in-children-teenagers-and-young-adults) |
| Did your study scope change from its original aims? Please give brief details. | We were planning to produce more detailed cancer mortality analysis but we did not do this as we discovered there are slight differences in the way cause of death data is collected in each nation therefore we did not feel the data was comparable. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | The report has had excellent feedback. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | We did not include detailed trends analysis in our report, but this is something that may be explored further in the future. |