HSC-PBPP End of Project Reports – January 2024

Application Reference (click on reference for EPR Summary)	Applicant	Applicant Organisation	Title and Purpose of study	Date of Approval
1617-0060	Paul Gallagher	NHS Greater Glasgow & Clyde	Multiple sclerosis Outcomes after Disease modifying treatment Evaluating Regional differences After TimE (MODERATE) – Phase 1	30/08/2016
1617-0202	Dr Alistair McNarry	NHS Lothian	Evaluation of First Generation Supraglottic Airways (and Anaesthetic Face Masks) to Inform the Decisions of the Clinical Advisory Panel for National Procurement Exercise 178 (2016)	08/03/2017
1617-0215	William Urquhart	NHS Tayside	Use of copy of SCI-Diabetes Application for end-to-end test of replacement Diabetic Retinal Screening application	09/03/2017
1617-0226	Professor Laura H. Goldstein	King's College London	CODES	19/03/2019
1617-0275	Ms Linsey Galbraith	NHS National Services (NSS) Scotland	Estimating the Prevalence of Problem Drug Use (among individuals aged 15-64) in Scotland in 2015/16	25/08/2017
1617-0011	Dr Diane S J Lindsay	Glasgow Royal Infirmary	Genomic sequencing and epidemiology of Legionella pneumophila in Scotland	07/11/2017

1617-0221	Kirstin Leslie	University of Glasgow	Scotland-wide study of adherence with cardiovascular medication	09/02/2017
1617-0233	Dr Andrea E Williamson	University of Glasgow	Serially missed appointments in the NHS: a PILOT linkage project to inform future interventions.	17/12/2016
1617-0233	Dr Andrea E Williamson	University of Glasgow	Serially missed appointments in the NHS: a PILOT linkage project to inform future interventions.	20/03/2017
1617-0069	Steve Turner	University of Aberdeen	Using hospital admission data to study associations between early life conditions and later outcomes	13/07/2016
1617-0259	Professor Jill Pell	University of Glasgow	Trends in the health and healthcare of children with learning disabilities and children with autism	07/02/2017
1617-0179	Dr Caroline Jackson	University of Edinburgh	Assessing the impact of major mental illness on the outcomes and complications of cardiovascular disease and diabetes: a national data linkage project	24/04/2017
1617-0327	Prof Harry Campbell	University of Edinburgh	RESCEU data linkage	20/06/2017
1617-0116	Rebecca Barr	University of Dundee	TIME Study	
1617-0247	Joanne Given	Ulster University	Metformin for diabetes in pregnancy – an analysis of health outcomes in Scotland as part of a UK wide study	19/03/2018

1617-0338	Professor Colin Palmer	University of Dundee	SHARE - Central data transfer to SHARE in the accredited safe-haven, Health Informatics Centre (HIC).	

Appendix: End of Project Report Summaries

1617-0011 Dr Diane S J Lindsay

Genomic sequencing and epidemiology of Legionella pneumophila in Scotland

End of Project Summary

Public Benefit Impact
The increased resolution provided by whole genome sequening (WGS) and accessing the coresponding epidemiological data has revealed clusters among the Scottish Legionella isolates that were previously unrecognised. Scottish isolates were represented among all major global pathogenic clones. They were located in 70 distinct clusters, 48 of which contained more than one Scottish isolate. Seventeen were linked to travel both within and out with the UK, nine of which were previously unrelated travel clusters. Six hospital acquired clusters and nine community acquired clusters were also identified. 14 clinical and 8 environmental isolates were not linked to other Scottish isolates but clustered with sequences from the global data. Only six Scottish isolates (2 clinical and 4 environmental) were entirely singletons. Overall, these data demonstrate the benefit of WGS for identifying persistent sources of infection related to foreign travel and both the hospital and the community setting.

Aims
Examine the evolutionary history of clinical *Legionella* in Scotland since 1984 and the diversity of *Legionella* spp. populations within environmental and patient samples by WGS to identify clusters and apply the information to inform improved measures for tracing outbreaks and clusters of Legionnaires' disease.

Data: Information gained from the complete genetic code in conjunction with epidemiological data was used to identify links between patients and the environment.

Methodology: Whole genome sequencing (WGS) was performed on three hundred and ninety-seven historic *Legionella pneumophila* isolates from Scotland, collected for national surveillance of Legionnaires' disease (LD) and environmental monitoring. This included all clinical isolates and a snap shot of environmental isolates. Core genome multi-locus sequence typing (cgMLST) was used to cluster strains with the wider *L. pneumophila* WGS dataset. For the clusters containing Scottish isolates, epidemiological analysis of metadata was carried out in the context of the genetic relatedness of strains. The initial findings were part of oral communications with the European study group on Legionella infections (ESGLI).

Outcomes: This study has resulted in the largest and most diverse collection of the genetic code of *Legionella*, the causative agent of Legionnaires' disease that is currently available. This dataset also provides unparalleled resolution into relationships of *Legionella* strains that have caused infections in Scotland.

1617-0060 Paul Gallagher

Multiple sclerosis Outcomes after Disease modifying treatment Evaluating Regional differences After TimE (MODERATE) – Phase 1

End of Project Summary

Public Benefit Impact
This study has identified variation in the treatment of Relapsing Remitting Multiple Sclerosis (RRMS) within Scotland beyond factors related to disease characteristics alone. It is important for doctors and patients to be aware of factors influencing the use of treatments, which should largely be driven by scientific evidence, disease characteristics and patient choice, and this study suggests that 'non-disease' factors may be relevant to the decision to start disease-modifying therapies (DMTs) in RRMS. Whether this is always appropriate cannot be concluded from this study alone and further work is needed to determine the benefits and risks of early DMT use in this cohort but evidence from other sources suggest benefit overall with early treatment. Demonstrating this within a Scottish cohort may benefit patients by standardising the approach to treatment where appropriate and to the wider public by reducing costs associated with MS-related disability or treatments.

Aims
The aim of this study was to identify whether patients with RRMS had different treatment strategies despite similar disease severity i.e. were some patients with similar disease treated with DMTs and some not? We then planned to determine the impact of these differing strategies on retrospective efficacy and safety outcomes.

Data
We collected data on patients diagnosed with RRMS between 2010 and 2011 using the Scottish Multiple Sclerosis Register (SMSR). The SMSR stores each patient's Community Health Index (CHI) number which is unique for each patient in Scotland and allowed access to the medical records of these patients with RRMS. Medical records (electronic) were then accessed to determine disease characteristics and treatments for patients and compare outcomes where possible.

Methodology
Data were collected and stored using an online database stored by a protected NHS website [Scotland's Health On the Web (SHOW)]. Each patient was assigned a unique study identification number to anonymise their data for analysis. The headline results of the study were published in a poster presented at the largest worldwide annual MS conference, held jointly by the European and American MS Committees, in Paris in 2017. Additionally, an abstract summary of the study was published in an international MS scientific journal.

Outcomes
We identified 245 patients diagnosed with RRMS, of which 130 (53%) started a DMT

within the first year of their diagnosis. Using specialised statistics to match patients based on the severity of their disease at diagnosis, we identified that 124 (55%) of these 225 patients were treated or not despite comparable disease severity on many measures. This statistical matching process did not take account of all possible reasons which may have dictated treatment choices (or not) however and unfortunately detailed safety and effectiveness outcomes, related to treatment or not, could not be accurately determined due to limited follow-up information within patient records.

Further details from
We are hoping to begin the next phase of this study and determine whether the treatment differences identified in this first phase translate into differing clinical or safety outcomes for these patients over time**.**

1617-0202 Dr Alistair McNarry

Evaluation of First Generation Supraglottic Airways (and Anaesthetic Face Masks) to Inform The Decisions of the Clinical Advisory Panel for National Procurement Exercise 178 (2016)

End of Project Summary

Public Benefit Impact
Clinical evaluation of supraglottic airway devices by clinicians experienced in their use allowed patient-centred purchasing decisions to be made most cost-effectively

Aims
To determine the clinical effectiveness of various devices widely available to facilitate the administration of anaesthesia safely

Data
The effectiveness of four devices was assessed and the characteristics of the devices recorded.

Methodology
Centres across Scotland who already used a variety of devices assessed the four devices in a systematic way.

Outcomes
The overall performance of the devices were ranked to allow the most appropriate devices to be used with patients

1617-0069 Steve Turner

Using hospital admission data to study associations between early life conditions and later outcomes

End of Project Report

The Public Benefit Impact Summary

Aims
Public Benefit and Privacy Panel for Health and Social Care
End of Project Declaration and Summary
End of Project Declaration and Summary Report ST 16-08-21.docx
What did the study set out to achieve?
To use routinely acquired hospital admission data to answer the question what is the relationship between conditions in early life (e.g. bronchiolitis) and conditions in later childhood (e.g. asthma) 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.
There are undoubtably links between early illnesses and later non communicable diseases (chest infections and asthma are a good example of this). The evidence available comes from relatively small populations cohorts, what is unknown is whether these associations are seen on a whole population basis.

Data
What data were received/processed/collected?
Was it as expected? Please give brief details.
Yes
Yes

Methodology
How did you collect the data?
Routinely acquired from SMR01
How did you process the data?
By comparing risk for later condition (outcome variable) as a factor of an earlier condition with adjustment for covariates.
How did you provision/publish the information?
Not done
Did your study scope change from its original aims? Please give brief details.

Outcomes:
The outcomes / results of your proposal. Please give brief details.
Unfortunately there was no staff available to lead on this project and Dr Turner did not have time to undertake the analysis and write up papers. 6 Future Questions:
Public Benefit and Privacy Panel for Health and Social Care
End of Project Declaration and Summary
End of Project Declaration and Summary Report ST 16-08-21.docx
Have the processes / results raised further questions for future exploration? Please give brief details.

Rebecca Barr

TIME Study

End of Project Summary

Benefit Impact Summary

1 Aims What did the study set out to achieve? The Treatment in Morning and Evening (TIME) Study is a British Heart Foundation funded study, endorsed by the British Hypertension Society. It was to determine if morning or evening dosing of antihypertensive medications is more effective in the prevention of heart attacks and strokes. A small study conducted in Spain found that participants randomised to taking at least one antihypertensive medication at bedtime suffered significantly fewer adverse cardiovascular events compared with those taking all their medication at a single morning dosing time. Since the publication of the study there were several calls for a large scale randomised trial to determine if evening dosing is better at preventing heart attacks and strokes. The TIME study tested the hypothesis that nocturnal dosing of antihypertensive medications reduces the risk of cardiovascular events compared with conventional morning dosing. Secondary questions examined whether there were any downsides to nocturnal dosing. For example would patients accept evening dosing? The TIME study collected data on this and other adverse effects of dosage time. Data on rates of falls and fractures were also collected.

2 Public Benefit Impact Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary TIME PBPP End of Project Declaration and Summary (final - signed 13-10-22).docx How will these outcomes directly result in benefit for the public? Please give details.

This should be the main section answered. High blood pressure is a significant cause of heart attacks, strokes and deaths worldwide. Blood pressure-lowering medications reduce the chance of having a heart attack or a stroke. They also reduce the chance of dying from diseases of the heart or blood vessels. Some scientists have previously reported that taking medications for blood pressure at night is better than taking them in the morning. If this were the case, it would have been a simple and effective way to improve the management of high blood pressure. The findings of the TIME study will help doctors advise patients how best to take blood pressure medications in a way that maximises adherence and minimises side effects.

3 Data What data were received/processed/collected? Was it as expected? Please give brief details. Data came from two sources – self-reported participant information on changes in their health, and electronic reporting of events and deaths via the record linkage process. Record linked data received was SMR01, SMR04, SMR06, CHI database and NRS mortality. The data was as anticipated.

4 Methodology How did you collect the data? Participant reported events and record linkage How did you process the data? Data was processed in accordance with the study protocol and Statistical Analysis Plan (SAP) Public Benefit and Privacy Panel for Health and

Social Care End of Project Declaration and Summary TIME PBPP End of Project Declaration and Summary (final - signed 13-10-22).docx How did you provision/publish the information? The study was presented at the European Society of Cardiology in Barcelona, August 2022 with a subsequent paper published in The Lancet. All participants, participating GP practices and Research Networks will be informed by email of the result and with information on the study website Did your study scope change from its original aims? Please give brief details. The scope did not change from its original aims.

5 Outcomes: The outcomes / results of your proposal. Please give brief details. We carried out a parallel-group randomised controlled trial in adult patients with hypertension in the UK. Participants were enrolled through a secure study website. After consenting to participation, using an electronic signature, participants were randomised (1:1) to take their usual antihypertensive medication in the morning or the evening. All participants were followed up for the composite primary endpoint of hospitalisation for non-fatal myocardial infarction, hospitalisation for non-fatal stroke, or vascular death. Endpoints were identified by participant-report or record-linkage to national health service datasets and adjudicated by an end-point committee blinded to allocation. Between December 2011 and June 2018, 21 104 participants (mean age 65 years, 58% male, 13% with a history of previous cardiovascular disease) were randomised to evening (n=10 503) and morning (n=10 601) dosing groups. By the end of study follow-up, in March 2021, 529 participants randomised to evening dosing and 318 to morning dosing had withdrawn from all follow-up. The median follow-up time was 5.2 years. The primary endpoint occurred in 362 (3.4%) participants randomised to evening (0.69 events per 100-patient Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary TIME PBPP End of Project Declaration and Summary (final - signed 13-10-22).docx years) and 390 (3·7%) participants randomised to morning dosing (0.72 events per 100-patient years) (Unadjusted HR 0.95 [95%CI 0.83 -1.10], p=0.53). This finding did not vary by pre-specified subgroup analyses and no safety concerns were identified. In this large, prospective, randomised study, evening dosing of usual antihypertensive medication was not different from morning dosing in terms of major cardiovascular outcomes. Patients can be advised that they can take their regular antihypertensive medications at a convenient time that minimises any undesirable effects. 6 Future Questions: Have the processes / results raised further questions for future exploration? Please give brief details. There are four sub-studies still to be analysed – Sleep, Mood, Cognitive function and chronotype. In addition to these there is a large amount of home blood pressure and medication data to be analysed which might yield further insights.

1617-0179 Dr Caroline Jackson

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

End of Project Summary

1	**Aims**	

	What did the study set out to achieve?	The study aimed to investigate how severe mental illness relates to outcomes from, and receipt of clinical care for, heart attack, stroke and diabetes
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 work has highlighted various mental health disparities in care and/or outcomes of stroke, heart attack and diabetes in Scotland. This work informs the urgent need for new initiatives to improve retinopathy screening uptake in people with mental illness. It also raises critical questions about the acute hospital care of heart attacks in people with severe mental illness which we are investigating further in a new research study. This work will identify whether these vulnerable patients are disadvantaged at particular points of the care pathway, or whether health care providers need to be better supported to provided optimal clinical care to these patients. The findings from the present study have therefore highlighted key mental health disparities in physical disease outcomes and delivery of some clinical care. Through informing subsequent ongoing research, this work will ultimately inform strategies to improve physical disease outcomes and delivery of clinical care to people with severe mental illness.
3	**Data**	
	What data were received/processed/collected? Was it as expected? Please give brief details.	We received datasets which linked records from general and psychiatric hospital admissions and mortality records. We received linked data for a cohort of patients who had a hospital record for stroke and for patients with a record of heart attack. There were some errors in the original stroke dataset provided. Diabetes data were accessed separately through the SCI-Diabetes dataset.
4	**Methodology**	
	How did you collect the data?	We requested pseudonymised data through eDRIS
	How did you process the data?	We manipulated and analysed the provided datasets provided by eDRIS within the National Safe Haven using R software
	How did you provision/publish the information?	We published the methods within the peer-reviewed journal articles
	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.	We found that compared to people with no mental illness, people with severe mental illness: - had increased risk of mortality within 30, days, 1 year and 5 years of a heart attack, but were less likely to receive procedures to unblock arteries - had increased risk of mortality within 30 days, 1 year and 5 years of a stroke - were just as likely to receive key acute stroke care items (although relatively small numbers of events could not exclude possible differences) - had increase risk of all-cause mortality, cardiovascular disease mortality and cancer mortality following diabetes onset - were equally or more likely to receive routine diabetes care monitoring (apart from retinopathy screening) - were less likely to receive retinopathy screening
6	**Future Questions:**	
	Have the processes / results raised further questions for future exploration? Please give brief details.	The results raised additional questions for further research. The findings on severe mental illness and heart attack care has led to a further CSO-funded research study focused on comparing receipt of heart attack care using national heart attack audit data in England. The diabetes findings have raised additional questions relating to why people with severe mental illness and diabetes have poorer diabetes outcomes despite similar or better levels of diabetes monitoring. We are in the process of setting up new research projects to compare values of monitored care indicators in people with and without severe mental illness and to examine whether lower retinopathy screening translates into higher rates of retinopathy in people with mental illness. Further research using larger datasets is needed to further investigate receipt of stroke care in people with versus without severe mental illness, since analyses of the Scottish

		data couldn't exclude the possibility of small, but potentially important, differences in receipt of acute stroke care.

1617-0215 William Urquhart

Use of copy of SCI-Diabetes Application for end-to-end test of replacement Diabetic Retinal Screening application

End of Project Summary

Public Benefit Impact
This audit looked at outcomes following small bowel obstruction in the UK. We found that patients with small bowel obstruction were at a high risk of death, complications and identified risk factors for these. We also found that current clinical practice varies significantly, with some patients receiving operations faster than others and some centres opting for more invasive approaches than others. Interestingly, we found that there's a lot of work that is required in a relatively evidence-free zone. We will use the data generated by the NASBO audit to test hypotheses and translate these into clinical trials which can identify effective interventions to reduce mortality and morbidity following small bowel obstruction

Aims
To assess outcomes following small bowel obstruction and adherence to current clinical guidelines

Data
Clinical, prospective dataset on management, aetiology and risk factors.

Methodology
Prospective, multicentre, clinical audit. No divergence from aims.

Outcomes
We have presented this data and the NASBO project reported its findings in a formal report. Several publications are being written.

1617-0221 Kirstin Leslie

Scotland-wide study of adherence with cardiovascular medication

End of Project Summary

1	**Aims**	
	What did the study set out to achieve?	Utilise national prescribing data to investigate the epidemiology of adherence to cardiovascular medications in Scotland, and its subsequent association with outcomes.
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.	Contributes to the understanding of drug utilisation and treatment management. This is an important feature of Public Health, as drugs with proven efficacy in trials are widely available in Scotland and improving management of these may be more important to improving health outcomes for cardiovascular patients than the introduction of new medications. This is the first study to provide a population-level perspective of adherence across a range of CVD drug-classes in Scotland. Previous studies using these datasets have provided an in depth analysis of individual classes, including statins and anticoagulants, whereas this study provided a much broader epidemiological approach across ten different CVD drug-classes. Adherence to cardiovascular medication across Scotland broadly replicated that which has been previously seen in literature review. This provides a greater understanding of adherence in this particular context, and also highlights the validity of using PIS as a tool for estimating population level adherence. This replication of similar findings suggests that PIS is comparable to other validated databases as a tool for conducting adherence research. The methods reported in the published PhD thesis associated with this study also may be of value to future research in this area/ with these data.
3	**Data**	

	What data were received/processed/collected? Was it as expected? Please give brief details.	SMR01, SMR04, PIS, NRS deaths. Data largely as expected, though some extra quality control/ data cleaning was required (e.g. 'dispensed date' variable missing in a percentage of PIS records; some disagreement between formulation and dosage instructions; death date recorded prior to hospitalisation date etc.)
4	**Methodology**	
	How did you collect the data?	Data provided by eDRIS following PBPP application.
	How did you process the data?	Data linkage performed by eDRIS and provided with pseudo-anonymised patient ID to allow linkage between datasets.
	How did you provision/publish the information?	All data released from National Safe Haven as per eDRIS user agreement (following disclosure controls etc.)
	Did your study scope change from its original aims? Please give brief details.	Aims largely unchanged. Slight narrowing in scope/ refining of aims.
5	**Outcomes:**	
	The outcomes / results of your proposal. Please give brief details.	Adherence tends to be associated with traditional cardiovascular risk factors (male sex, older age, higher deprivation, etc.) across the drug-classes and patient groups studied. This replicated results observed in literature review so, while it may not have provided any substantial new findings, it did prove validity of using Scottish administrative datasets for studying cardiovascular adherence with respect to wider literature.
6	**Future Questions:**	
	Have the processes / results raised further questions for future exploration? Please give brief details.	Future project building on this work looking at comparative effectiveness of cardiovascular medication. Methods used for quality controls, analysing adherence etc. may be carried forward. New PBPP in progress (2021-0299).

1617-0226 Professor Laura H. Goldstein

CODES

End of Project Summary

Public Benefit Impact
Understanding health service use by adults with dissociative seizures (DS) and its associated costs and drawing comparisons between self-reported and centrally-recorded health service use. DS are paroxysmal events that are superficially similar to epileptic seizures and syncope but which are distinguishable from these and other medical disorders. It is thought that service use in this group may be high. Understanding health service use is important for planning services and evaluating treatments.

Aims
To investigate health service use in adults with DS taking part in a pragmatic, parallel arm, multi-centre randomised controlled trial (RCT) in Scotland, England and Wales comparing DS-specific Cognitive Behaviour Therapy (CBT) plus standardised medical care (input from neurologists and psychiatrists following certain guidelines) compared to standardised medical care alone and to use Hospital Episode Statistics (HES) data as an objective measure as opposed to self-reported health service use by trial participants.

Data
HES data on out-patient, in-patient and accident and emergency (A&E) department visits were obtained from eDRIS as well as from NHS Digital and NHS Wales Informatics Service for the 6 months prior to randomisation in the RCT and for months 7-12 post randomisation.

Methodology
Common data categories across the data sets were used to merge data so that only one set of data combined across England Scotland and Wales was analysed. No data were linked to any other variable than the treatment group to which patients had been assigned in the trial. Nationally applicable unit costs were applied to the HES data based on in 2017/18 £s. The same unit costs were applied to self-reported health service use in the same categories.

Outcomes
The HES-based costs of A&E care were lower prior to randomisation than costs derived from self-reported attendance. However, at follow-up the costs derived from each method were similar. The HES data showed that overall In the 6 months prior to being randomised in the study, over 80% of each treatment group had outpatient contacts, and this fell substantially for the follow-up period. In terms of outpatient care costs, pre-randomisation costs were similar for both groups and costs were lower for both groups in the follow-up period. Without directly combining data from the same participants, there was relatively good agreement between the HES and self-reported data for

outpatient care. In-patient costs showed a decline in both groups from pre-randomisation levels. However while the percentages reporting inpatient care prior to randomisation were similar between groups, and broadly similar for the HES and self-report data, the HES data cost estimates were lower, suggesting that DS patients may have overestimated the time they spent in hospital, but not the type of care received.

Further questions
Some issues may have arisen with the HES data in that not all participants were recorded as having had appointments that they would have to have attended in order to be in the trial, raising the possibility of some inaccuracy in local data recording.

1617-0247 Joanne Given

Metformin for diabetes in pregnancy – an analysis of health outcomes in Scotland as part of a UK wide study

End of Project Summary

1	**Aims**	

	What did the study set out to achieve?	The original aim and objectives were: Aim A UK wide study to use administrative data to explore the effect of metformin on maternal and infant health. Objectives 1) Determine how much metformin is being prescribed to women in pregnancy and for what conditions 2) Find out if metformin use in early pregnancy increases the risk of birth defects 3) Find out if metformin effects the risk of developing complications during pregnancy 4) Find out if metformin effects the growth of children who were exposed in the womb 5) Find out if a mother's diabetes during pregnancy affects their child's achievement in school and explore any effect metformin may have on this 6) Test the potential of using routinely collected administrative data in the UK in order to determine the long term safety of drugs in pregnancy
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.	It was originally planned that by providing information on the risks and benefits of metformin use in pregnancy this project would allow women, and their health care practitioners, to make more informed decisions about their treatment. Specifically, it will inform personalised evidence based decisions relating to contraception, pregnancy planning and management of diabetes during pregnancy. This will improve the service provided by the health care system and has the potential to improve both the short and long term outcomes of women and their children. The nature of the benefits arising from this work will depend on the results. If the use of metformin in pregnancy is found to be beneficial, or to have minimal risks, there is the potential to improve the quality of life of a significant number of pregnant women. This would be possible as those with diabetes tend to prefer metformin to the multiple daily injections required as part of insulin therapy. However, if risks are identified there is the potential to benefit the health of women, as well as the long term health of their children, by decreasing the use of metformin in pregnancy.
3	**Data**	

	What data were received/processed/collected? Was it as expected? Please give brief details.	**No Scottish data was made available.** In Scotland by the end of 2018 while some data was available it became clear that a further application was needed to access the required census data. By this stage the PI had moved to a new post and it was not feasible to undertake more work applying for data. Further, in May 2019 the PI was informed that this project was no longer going to be supported by the ADRC-S due to limited funds.
4	**Methodology**	
	How did you collect the data?	N/A
	How did you process the data?	N/A
	How did you provision/publish the information?	N/A
	Did your study scope change from its original aims? Please give brief details.	It was not possible to conduct the study.
5	**Outcomes:**	
	The outcomes / results of your proposal. Please give brief details.	It was not possible to conduct the study. There were severe problems with access to data. It was not possible to get data from Northern Ireland due to legal gateway issues and from England due to data availability issues. In Scotland by the end of 2018 while some data was available it became clear that a further application was needed to access the required census data. By this stage the PI had moved to a new post and it was not feasible to undertake more work applying for data unless additional staffing became available. Further, in May 2019 the PI was informed that this project was no longer going to be supported by the ADR-S due to limited funds.

		The only region where data was made available was Wales but staffing issues meant that it has not been possible to work on the analysis. Staff time for analysis was potentially available in Spring 2020 but then the Covid-19 epidemic hit. This meant that the safe haven was closed to researchers and it was not possible to work on the Welsh data. When the safe haven reopened there was no staff availability to work on the project. Only 6 months were left in the original project permissions. As staff time to work on the project was not available, the sample size had been severely reduced from that originally planned (limiting the power of the study), and the data was now becoming dated, it was decided to close the project.
6	**Future Questions:**	
	Have the processes / results raised further questions for future exploration? Please give brief details.	N/A

1617-0327 Prof Harry Campbell

RESCEU data linkage

End of Project Summary

1	**Aims**	

	What did the study set out to achieve?	This study within the larger RESCEU project focused on assessing the healthcare burden of Respiratory Syncytial Virus (RSV) in at least six EU countries (Denmark, Netherlands, Finland, UK / Scotland, Italy, France, and Norway. It also estimated the association between RSV and subsequent childhood illnesses such as wheeze, asthma, pneumonia, and whooping cough and the resulting economic costs.
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.	This study has provided the first estimates for the Scottish population, of RSV disease burden and the impact on subsequent ill health in children, such as wheeze, asthma, and pneumonia. The findings contributed to estimating the burden of RSV disease in Europe and thus made a significant contribution to improved health and wellbeing both in Scotland and in Europe. The findings helped raise awareness amongst healthcare staff of the risks of RSV infection in adults with chronic health conditions. The RESCEU data is forming the platform for future actions on RSV, which is identified as a health priority for action in Europe. It has currently generated interest in understanding the interaction between COVID-19 and RSV and the impacts on healthcare burden during and after the COVID-19 pandemic. This includes policy decisions on setting up future vaccine programs for RSV prevention and informing change to clinical treatment guidelines. The RESCEU baseline burden data is helping to assess future vaccine effectiveness (post-RSV vaccine). The project was timely given the many RSV vaccines currently under development.
3	**Data**	
	What data were received/processed/collected? Was it as expected? Please give brief details.	We analysed anonymised, linked routine healthcare datasets processed by the eDRIS team Yes, the data we received were as expected
4	**Methodology**	
	How did you collect the data?	Data were data collected by extracting data variables from national routine health datasets/registers by the eDRIS staff authorised to work with patient identifiable data and appropriately trained to the standards required by their national authorities to comply with Data Protection legislation.

	How did you process the data?	eDRIS extracted and linked the datasets using a CHI number. Once completed and any derived variables calculated, the CHI number was removed and a random identity number attached to each record. The random ID was consistent across all datasets to allow record linkage of several datasets. Date of birth contained month/year of birth and admission and discharge dates were also limited to month and year only. Full Dates of death were required to calculate age by month at death for babies up to age 1 year.
	How did you provision/publish the information?	The eDRIS disclosure control policy (ISD disclosure control policy) was followed to prevent any potential identification of any individual in the aggregated outputs. This included suppression of small numbers in any tables or statistical output etc. All summary tables, statistical output exported from the safe haven to the research team were subject to the eDRIS disclosure control policy.
	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.	The results of this study have provided key insights into the healthcare burden of RSV in young children and older adults, especially with comorbidities and/or in a high-risk group
6	**Future Questions:**	
	Have the processes / results raised further questions for future exploration? Please give brief details.	The results from this study have led to further partnerships to explore the RSV epidemiology and impact of COVID-19, conduct additional studies in preparation for future RSV product assessment, conduct clinical trials to clinically validate and update RSV bronchiolitis severity scores already in use and build RSV laboratory surveillance networks in Europe.

1617-0233 Dr Andrea E Williamson

Serially missed appointments in the NHS: a PILOT linkage project to inform future interventions.

End of Project Summary

1	**Aims**	
	What did the study set out to achieve?	To determine the relationship between general practice appointment attendance, health care utilization, preventive health activity, health
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 epidemiological evidence about health care use, health outcomes, social vulnerability and missingness in health care means that this is now an issue of concern and attention in health care policy and practice. Some individual GP practices have changed their practice policy about 'DNAs', one NHS health board is actively considering how this work impacts on their tackling health inequalities policy going forward, and there is work in development to incorporate improved 'DNA' management into general practice delivery more widely at a national (Scottish level) which will hopefully lead to sustained policy and practice change.
3	**Data**	
	What data were received/processed/collected? Was it as expected? Please give brief details.	Routine administrative general practice patient record data was transferred to the Safehaven by the Trusted Third Party, and this along with linked secondary care health data, mortality data and education data (provided by ScotXEd). The quality of the data was as expected. What was challenging was quite significant interruptions to Safehaven access at times and delays in disclosure checks. Staff were always very helpful when they were able to, but they seemed to struggle with available time.
4	**Methodology**	

	How did you collect the data?	This was already collected data available in patient's GP clinical record or from secondary care or from pupil records which were then processed either by the TTP, eDRIS or ScotXEd.
	How did you process the data?	This was done by colleagues in the teams above.
	How did you provision/publish the information?	In peer reviewed papers, some media work, some conference presentations and seminars to key stakeholders. All summarised on the webpage: https://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/research/serialmissedappts
	Did your study scope change from its original aims? Please give brief details.	Not substantively. We were unable to conduct further analysis on missingness to look at its association with health prevention and screening which we had hoped to do. This was due to the PI being off work due to serious ill health for 2018; we opted to prioritise other aspects of the workplan.
5	**Outcomes:**	
	The outcomes / results of your proposal. Please give brief details.	• **Patients** at high risk of missingness are characterized by poor health, higher treatment burden, complex social circumstances and have higher premature mortality • **General practice appointment scheduling** and context is important • **Patterns of missingness persist across secondary care** outpatients and inpatient 'irregular discharges'; patients are NOT seen in ED instead • **Missingness is a strong risk marker for a poor outcome** so needs urgent attention from health service planners and practitioners
6	**Future Questions:**	

	Have the processes / results raised further questions for future exploration? Please give brief details.	Having demonstrated that missingness in health care is a risk marker for very poor outcomes we are now working on interventions to reduce missingness in health care. A reconvened research team led by Andrea Williamson have submitted an National Institute of Health Research grant to continue the research to identify interventions for future testing.

1617-0259 Professor Jill Pell

Trends in the health and healthcare of children with learning disabilities and children with autism

End of Project Summary

1 Aims What did the study set out to achieve? To investigate antipsychotic prescribing in children and young people with autism and in children and young people with other children; the health and educational outcomes and relationship of potential confounding maternal, obstetric and lifestyle factors.

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. This projects within this programme of work were undertaken by the Scottish Government funded Scottish Learning Disabilities Observatory and the department of Public Health in the Institute for Health and Wellbeing, in support of key national policy and legislative priorities, including The Keys To Life (learning disabilities strategy), The Scottish Strategy for Autism, the new Mental Health Strategy for Scotland, Children and Young People's Act, and Getting It Right For Every Child. Healthcare professionals need to know the extent of prescribing, health and mortality outcomes for these children. It is important for parents and for all staff who work with children with learning disabilities and/or autism in order to direct action to address health and care inequalities experienced by this population group.

3 Data What data were received/processed/collected? Was it as expected? Please give brief details. Data received were as expected. (see below) Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary End of Project Declaration and Summary Report.docx

4 Methodology How did you collect the data? As described in pbpp 1617-0259 How did you process the data? As described in pbpp 1617-0259 How did you provision/publish the information? Following analysis all information was published in peer reviewed journals and presented at relevant conferences. Did your study scope change from its original aims? Please give brief details. The main change from the original aims of the proposal was that due to small numbers we were unable to report any geographical variation in prescribing or health outcomes.

5 Outcomes: Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary End of Project Declaration and Summary Report.docx The outcomes / results of your

proposal. Please give brief details. The outcomes of the proposal and published results have been significant. Through the Scottish Learning Disabilities Observatory, we implemented a programme of impact generation, which included roundtable discussions with policy makers, health professionals and self-advocates to agree implications and next steps for research in this field. These studies have been presented to a wide range of groups including: the Scottish Learning Disabilities Observatory steering committee, the Cross Party Group of Epilepsy, People First Scotland, Down Syndrome Scotland, the Scottish Commission for Learning Disabilities Evidence panel, the Scottish Government's Disabled Children and Young People's advisory group, the national hub for Child Deaths review group. Evidence from the study on children and young people's mortality was included in the latest SG Learning Disabilities and Autism strategy – Towards Transformation https://www.gov.scot/publications/learningintellectual-disability-autism-towards-transformation/ Researchers on the study also contributed to the development of the national postural care strategy.

6 Future Questions: Have the processes / results raised further questions for future exploration? Please give brief details. This study raised important questions in relation to the inequalities experienced by children and young people with learning disabilities and/or autism. It enabled quantification of outcomes for this group in terms of psychotropic prescribing and mortality. These studies have helped to raise important areas for further investigation. Including the need to better understand the factors leading to these inequalities. As a result of this work the Scottish Learning Disabilities Observatory Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary End of Project Declaration and Summary Report.docx completed a systematic review and meta-analysis of deaths from respiratory disease.

1617-0275 Ms Linsey Galbraith

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

End of Project Summary

Public Benefit Impact
Provide a more complete picture of problem drug use in Scotland. Support the planning and delivery of services to people affected by problem drug use. Monitor delivery of the national drug strategy and ensure Scottish Government funding allocations for drug treatment are based on accurate local needs assessment.

Aims
The primary aim was to produce robust modelled estimates of the prevalence of problem drug use (PDU) and injecting drug use (IDU) in Scotland during 2015/16.

Data
Clients registering with/receiving specialist drug treatment services; drug related hospital admissions and; criminal justice social work reports. Police data on individuals detained or arrested under the Misuse of Drugs Act was to be the fourth data source, but data unavailable.

Methodology
Capture-recapture in conjunction with a maximum likelihood modelling method

Outcomes
PDU estimates produced for Scotland, local authorities , alcohol and drug partnerships and NHS boards. Data not available to produce estimates of IDU.

Future Questions
Future studies may wish to look to alternative data sources, including improvements to routine, centrally held data, supplemented by new data collection where necessary

1617-0338 Professor Colin Palmer

SHARE - Central data transfer to SHARE in the accredited safe-haven, Health Informatics Centre (HIC).

End of Project Report

The Public Benefit Impact Summary

1	Aims	

	What did the study set out to achieve?	The Scottish Health Research Register and Biobank (SHARE) is a database of volunteers consenting to be contacted by SHARE and invited to participate in research projects. SHARE has two main aims which it is achieving currently: to offer the public opportunities to participate in studies (building the SHARE register), and to assist researchers in finding suitable and willing participants for their studies. SHARE's main ongoing objectives (which are being achieved) are to facilitate research, by providing researchers with: • suitable and willing volunteers, blood samples and health-related information for their trials. This is done by the consented use of the SHARE health records dataset to identify and provide researchers with eligible volunteers for their projects. • anonymised phenotypic data (via the consented use of the SHARE health records dataset) which can be linked to the blood samples stored as part of the SHARE biorepository for ethically approved projects.
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 benefit of using health data for cohort building is to facilitate research in a timely manner and allow researchers to connect with potential willing and eligible participants and complete the projects with time and money saved, thereby increasing capacity to take on further projects. The benefit to the public is that more studies can be completed, leading to faster developments in health care. SHARE has facilitated over 160 studies to date, ranging from the testing of new apps, treatments, and medications along with biomarker studies for early cancer detection. • The benefit of using data for research is to save the NHS time and money and to reduce the trauma to patients of having to 'trial' several different drugs until the right one is found. • The SHARE Biobank is growing steadily and is a valuable resource for Scotland. SHARE samples were instrumental in enabling the game changing development of sensitive, rapid, and high-throughput antibody assays for COVID-19 https://www.cso.scot.nhs.uk/wp-content/uploads/COVABN2002-1.pdf
3	Data	

	What data were received/processed/collected? Was it as expected? Please give brief details.	Data received as expected
4	Methodology	
	How did you collect the data? How did you process the data? How did you provision/publish the information? Did your study change from its original aims? Please give brief details.	SHARE, The Scottish Health Research Register and Biobank, is a register of adults and children aged 11 years and over, who are willing to be invited to take part in medical research projects and have also consented to allow researchers to use any leftover blood following routine clinical testing, for approved research. When participants register for SHARE, they give permission for Health Informatics Centre (HIC) to search your NHS health information to see if your characteristics match those needed by researchers for their studies. This may include genetic profile if permission was given for blood to be stored. The SHARE Team contacts individuals identified, to ask if they are interested in speaking to the researchers who are carrying out a particular study. Nothing on SHARE changed within this time-period.
5	Outcomes:	
	The outcomes / results of your proposal. Please give brief details.	SHARE continues as a research register.
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	SHARE continues as a research register.