

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
2021-0051	Kyle Gibson	NHS Lothian	Pulmonary Embolism in COVID-19 Patients requiring Critical Care	10/06/2021
2021-0054	Thomas Manship	NHS Lothian	Scottish study on the impact of COVID-19 on chronic liver disease	16/07/2020
2021-0049	Dr Michael McGettrick	General Medical Council	Pulmonary Thromboembolism in Covid-19 pneumonia	15/06/2021
2021-0064	Frederick Ho	University of Glasgow	COVID-19 Infection and Subsequent Thromboembolic Events	27/08/2020
2021-0124	Dr Agnes Tello/Prof Frank Sullivan	University of St Andrews	Characterisation of COVID-19 outcomes in a high-risk cohort: Assessment of background levels of autoantibodies as a prognostic marker for severe COVID-19 infection	14/09/2021
2021-0148	Albert King	Scottish Government	The Scotland Coronavirus Model (Regression Modelling)	04/08/2021

2021-0111	Sarah Wild	University of Edinburgh	Association of British Clinical Diabetologists (ABCD) audit of in-patients with diabetes and Covid-19	27/08/2021
2021-0229	Professor Simon Davies	Keele University	BioImpedance Spectroscopy to Maintain Renal Output: the BISTRO Trial	
2021-0071	Professor Andrea Doeschl-Wilson	University of Edinburgh	Data extraction to inform Scottish COVID-19 Response Consortium: epidemiological modelling and Data-driven now-casting & forecasting of health-care resource requirements associated with COVID-19	
2021-0255	Hazel Dodds	Public Health Scotland	Scottish Cardiac Audit	
2021-0236	Hazel Dodds	Public Health Scotland	Scottish National Audit Programme – Case Note Validation	
2021-0187	Nathaniel Quail	NHS GG&C at time of application Currently NHS Lanarkshire	How does advance care planning and palliative care input affect the place of death of motor neurone disease patients in the West of Scotland	
2021-0290	Dr Jodie Westhead	University of Manchester	Suicide in former service personnel: rates, antecedents, and prevention	
2021-0180	Jill P Pell	University of Glasgow	Defining and understanding the longer-term effects of COVID-19: A mixed methods study exploring the frequency, nature, and impact of 'long COVID' in the Scottish population	

Pulmonary Embolism in COVID-19 Patients requiring Critical Care

End of Project Summary

1	Aims	
	What did the study set out to achieve?	<ol style="list-style-type: none"> 1. Compare the number of patients admitted to Scottish Critical Care Units with Pulmonary Embolism during the COVID-19 pandemic with the same months of previous years. 2. Understand the clinical features, risk factors, diagnostic findings, management and outcomes of patients admitted to Scottish Critical Care Units with Pulmonary Embolism during selected months of the COVID-19 pandemic.
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.	These outcomes may improve understanding of the identification, diagnosis, management and outcomes of patients with Pulmonary Embolism requiring admission to Critical Care.
3	Data	
	What data were received/processed/collected? Was it as expected? Please give brief details.	Public Health Scotland, using the WardWatcher database, provided data to compare patients admitted to Scottish Critical Care Units with Pulmonary Embolism in pre-COVID years compared with during the COVID pandemic (selected months in 2020). In addition, local clinicians reviewed the case notes of patients admitted to their Critical Care Units with Pulmonary Embolism during selected months of 2020 and completed a data collection pro-forma.
4	Methodology	
	How did you collect the data?	Public Health Scotland securely transferred comparative (aggregate) data and local case note reviewers completed a password protected spreadsheet which was transferred securely for central data analysis.
	How did you process the data?	Public Health Scotland undertook statistical analysis for comparative data and local case note review data was analysed by the central audit team.
	How did you provision/publish the information?	Key findings have been shared as an oral presentation at the Scottish Intensive Care Society (online) Annual Scientific Meeting in January 2021. A manuscript is currently being finalised for submission to a journal.
	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 number of patients admitted to Scottish Critical Care Units with Pulmonary Embolism increased in March-June 2020 compared with the same months in previous years. Patients who had Pulmonary Embolism <u>and</u> COVID-19 were more unwell,

		required more organ support and had poorer outcomes compared with patients who had Pulmonary Embolism and no confirmed COVID-19.
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	Not at present

2021-0049 Dr Michael McGettrick

Pulmonary Thromboembolism in Covid-19 pneumonia

End of Project Summary

1	Aims	
	What did the study set out to achieve?	To establish if Covid-19 increased the risk of developing pulmonary thromboembolism.
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 has been increase in the rate of thrombosis in Covid-19, it suggests that more aggressive prophylactic measures should be taken in order to minimise the risk. In addition, where there have been reported increased risk of thrombosis with some of the vaccines, we have been able to show that Covid-19 puts patients at a much higher risk of thromboembolism compared to vaccines.
3	Data	

	<p>What data were received/processed/collected? Was it as expected? Please give brief details.</p>	<p>Numbers of cases of Covid-19 associated venous thromboembolism and demographic data and biomarkers from those patients. A higher number of patients than were expected presented with venous thromboembolism. We have been able to show that the biomarkers in patients with Covid-19 are different from those without.</p>
4	Methodology	
	<p>How did you collect the data?</p>	<p>This was a retrospective data collection using the NHS Scotland imaging database and using Scottish Care Information platform to collect biomarkers and demographic data.</p>
	<p>How did you process the data?</p>	<p>The data were collected and compared to control patients with pulmonary embolus prior to Covid-19 and published data from Scotland on the incidence of thromboembolism. Statistics package Graphpad Prism 9 were used to calculate non-parametric data comparisons</p>
	<p>How did you provision/publish the information?</p>	<p>Data has been presented at the National Pulmonary Hypertension Forum in the UK in November 2020 and a manuscript has been submitted to BMJOpen for peer review.</p>
	<p>Did your study scope change from its original aims? Please give brief details.</p>	<p>No.</p>
5	Outcomes:	
	<p>The outcomes / results of your proposal. Please give brief details.</p>	<p>We established that Covid-19 does increase the risk of thromboembolism in hospitalized patients in Scotland, both in critical care and in ward environments.</p>
6	Future Questions:	

	Have the processes / results raised further questions for future exploration? Please give brief details.	No.
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2021-0054 Thomas Manship

Scottish study on the impact of COVID-19 on chronic liver disease

End of Project Summary

1	Aims	
	What did the study set out to achieve?	To determine the effects of the COVID-19 pandemic on patients with chronic liver disease compared to previous years
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.	To assess the need for alteration in the provision of care for patients with chronic liver disease in the event of additional "COVID-19 waves" to prevent poorer outcomes such as increased mortality.
3	Data	
	What data were received/processed/collected? Was it as expected? Please give brief details.	Patient demographics (age, sex, deprivation score) disease characteristics (aetiology, bloods at admission, severity scoring), admission characteristics (diagnosis, length of stay, inpatient mortality) We were unable to collect data on observations at admission as these were universally poorly recorded in patient records.
4	Methodology	
	How did you collect the data?	Accessing patient records from across several Scottish trusts
	How did you process the data?	On Microsoft Excel and analysed on SPSS
	How did you provision/publish the information?	At an international conference with a plan to publish an article in a journal.
	Did your study scope change from its original aims? Please give brief details.	Yes. We were unable to get data from NHS Grampian/Highlands/Ayrshire & Arran/Borders
5	Outcomes:	

	The outcomes / results of your proposal. Please give brief details.	Compared to the previous 3 years patients with chronic liver disease admitted during the COVID-19 pandemic were not more unwell at presentation, weren't demographically different and didn't have significantly worse outcomes.
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	These results were unexpected however it is felt that the study was too soon after the start of lockdown and the pandemic to assess its effects. We are considering analysing a further study period, perhaps after the current third lockdown, to see if there has been more of an effect.

COVID-19 Infection and Subsequent Thromboembolic Events**End of Project Report****The Public Benefit Impact Summary**

1	Aims	
	What did the study set out to achieve?	To determine whether people infected with COVID-19 infection are at higher risk of thromboembolic events
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 will inform public policy and clinical guidelines on early detecting and preventing thromboembolic events among people with Covid-19
3	Data	
	What data were received/processed/collected? Was it as expected? Please give brief details.	ECOSS, SMR01, deaths. The data was received and processed as expected.
4	Methodology	
	How did you collect the data?	N/A
	How did you process the data?	Linking data between datasets
	How did you provision/publish the information?	Publish the regression analysis results
	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.	Across Scotland, 1,449 individuals tested positive for Covid-19 and experienced a thromboembolic event. The risk of thromboembolism was significantly elevated over the whole risk period but highest in the 7 days following the positive test (IRR 12.01, 95% CI 9.91-14.56) in all included individuals. The association was also present in individuals not originally hospitalised for Covid-19 (IRR

		4.07, 95% CI 2.83-5.85). Risk of MI, stroke, PE and DVT were all significantly higher in the week following a positive test. The risk of PE and DVT was particularly high and remained significantly elevated even 56 days following the test.
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	No.

2021-0071 Professor Andrea Doeschl-Wilson

Data extraction to inform Scottish COVID-19 Response Consortium: epidemiological modelling and Data-driven now-casting & forecasting of health-care resource requirements associated with COVID-19

End of Project Report

1	Aims	
	What did the study set out to achieve?	We aimed to develop models and analyses that would quantify key aspects of disease spread from available data and then use this information to enable data-driven assessment of potential public health interventions such as the impact of lockdowns, wider testing and track and trace programmes and the impact of potential vaccines. We also aimed to generate evidence-based data-driven predictions of the effect of COVID-19 on short-term demands on primary health care and hospital resources 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.	During the pandemic detailed estimates and predictions of various Covid statistics on an online dashboard which was available to members of the public. These included detailed interactive maps showing statistics for each 1km square of Scotland, and predictions of hospital bed requirements. The information was an aid to members of the public for making informed decisions on their behaviour while taking into account government guidelines. The novel approaches developed may be used in future real-time systems for new infectious outbreaks, which would again assist members of the public with their personal decision making.
3	Data	
	What data were received/processed/collected? Was it as expected? Please	Weekly updates of individual records relating to Covid on testing, vaccination, hospital stays, NHS24 calls, NRS deaths. Yes.
4	Methodology	
	How did you collect the data?	Data were supplied weekly by eDRIS to Edinburgh University by secure transfer.
	How did you process the data?	Using the statistical packages SAS and R. A description of the statistical methods and models is provided on the dashboard.
	How did you provision/publish the information?	Via an online dashboard: https://theiteam.shinyapps.io/COVID19Scotland_TrackandModel/

	<p>Did your study scope change from its original aims? Please give brief details.</p>	<p>For the benefit of the public, we focussed primarily on developing models and analyses that quantify key aspects of disease spread from available data, and to generate evidence-based data-driven predictions of the effect of COVID-19 on short-term demands on primary health care and hospital resources in Scotland, and towards making the results accessible to the public on the interactive dashboard.</p> <p>As originally envisaged statistical inference for models was used for data-driven quantification of changes - in part attributable to public health interventions - during the outbreak and in particular to quantify hard to measure aspects such as the real-time reproduction number and changes in age-related contact patterns driven by the pandemic. The intention had been to apply these methods to the data shared under this agreement. However, initial analysis suggested this data was likely insufficient to estimate such effects and subsequent analysis then focussed on data from the outbreak in England. Nonetheless access to the Scottish data was useful in understanding these limitations. Similarly work was conducted at BioSS with RESAS, SEPA and staff from the Scottish Government COVID Hub and at UK level with JBC to analyse COVID-19 wastewater sampling data for its potential to inform on COVID-19 cases and control, but it turned out that data under this agreement was not needed for these purposes. In the emergency context of the pandemic we could not anticipate either of these changes which were made in response to the evolving situation, our developing understanding and with a view to maximising the benefit to the public.</p>
5	<p>Outcomes:</p>	
	<p>The outcomes / results of your proposal. Please give brief details.</p>	<p>Using the data shared under this agreement the project has demonstrated the enhanced use of routinely collected health records to generate novel real-time statistics, which have the potential to be incorporated into future real-time systems and assist in the management of new outbreaks of infectious disease (including new strains of Covid). The main outcome was the development of novel statistical and computational methods to process Covid-19 data and compute statistics in near real-time and publish the results on an interactive online dashboard.</p> <p>The approaches developed included:</p> <ul style="list-style-type: none"> - Method to estimate local statistics for each 1km grid square of Scotland and display these on detailed interactive maps. - Methods to adjust for variations in testing practice. - Method to estimate prevalence of Covid (i.e. number of people expected to have Covid in a given place at a

		<p>given time) from PHS testing data and ONS survey data taking account of: variations in testing practice, and the expected duration of infection.</p> <ul style="list-style-type: none"> - Short term prediction of hospital bed requirements taking into account: the current age breakdown of cases, the estimated effect of vaccination, the expected length of hospital stay. - Short term predictions of Covid infection rates within data zones, and from these flexibly defined areas ranging from 1km grid squares up to local authorities and the whole of Scotland. - A measure of the effect of vaccination for specified locations and age groups (e.g. 10 year age bands within data zones) at a given time, taking account of the time since last vaccination of all included individuals and the expected effectiveness of vaccines received. - Technology to process the data, compute the statistics in near real-time and publish on an interactive online dashboard.
6	Future Questions:	
	<p>Have the processes / results raised further questions for future exploration? Please give brief details.</p>	<p>Yes, key questions to be addressed for future exploration are:</p> <ul style="list-style-type: none"> - Whether and how the tools developed in this project complement the information provided by other Covid-19 dashboards or alternative platforms. - Scope for integration of the tools developed in this project into existing dashboards / alternative platforms. - More detailed evaluation of the potential of NHS24 call data to monitor and assist in the management of an infectious outbreak. - Alternative access to this information via e.g. mobile apps. - Use of the tools developed into future epidemic preparedness initiatives / programmes. - How model-based inference for epidemic models could be applied to data from jurisdictions of different sizes and how these limit what could be estimated.

Covid-19

End of Project Report

1	Aims	
	What did the study set out to achieve?	To describe factors that affect severity of illness among people admitted to hospitals in the UK with diabetes and COVID-19.
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 findings were used to provide clinicians and their patients about prognosis and to assess whether guidelines for treating people admitted to hospitals in the UK with diabetes needed to change during the COVID-19 pandemic. Please see below for detailed findings
3	Data	
	What data were received/processed/collected? Was it as expected? Please give brief details.	<p>This multi-centre audit project used existing infrastructure and clinical expertise to collect data from hospitals across the UK (including Forth Valley Royal Hospital and Queen Elizabeth University Hospital Glasgow) using an electronic tool specifically designed and piloted by the steering group members. Data were collected more than 3,500 admissions for people with diabetes and Covid in the UK. For some analyses summary UK data were combined with those from other countries.</p> <p>Data were collected on patient characteristics related to admission including blood test results, anthropometry, diabetes and comorbidity history including drug treatment, outcomes during and at the end of hospital stay. Data for the first wave of data collection were as expected (with some missingness) but the second wave of data collection requesting longer term data described in the amendment had limited uptake.</p>
4	Methodology	
	How did you collect the data?	Data collection took place on an Excel spreadsheet. Participating hospitals retained identifiable data in accordance with local data governance rules.
	How did you process the data?	Centres sent pseudonymised data to Oxford University Hospital where data were collated and analysed. For studies with international collaborators analysis of individual level took place in each country and aggregated results were pooled.

	How did you provision/publish the information?	Please see list of publications.
	Did your study scope change from its original aims? Please give brief details.	No (other than planned extension to include longer term outcomes was not feasible).
5	Outcomes:	
	The outcomes / results of your proposal. Please give brief details.	<p>In summary we used data on 3,179 people with diabetes from over 40 hospitals between March and October 2020 to risk stratify this groups of patients, provide information to support primary and secondary prevention and reassurance about the safety of some commonly used drugs in this population.. Various sub-groups of the dataset were used for different research questions. Key findings were as follows:</p> <ol style="list-style-type: none"> 1. In people with type 1 diabetes and COVID-19 who were admitted to hospital in the UK, higher body mass index, poorer kidney function and presence of microvascular complications were associated with greater risk of death and/or admission to an intensive care unit. Risk of severe COVID-19 was reassuringly very low in people with type 1 diabetes who are under 55 years of age without microvascular or macrovascular disease. 2. In meta-analysis of UK, French and US studies microvascular disease burden was associated with an increased risk of death in patients with diabetes hospitalized for COVID-19. Systematic search for microvascular complications in patients with diabetes and COVID-19 is recommended to identify those at high mortality risk. 3. Our large multicentre, multinational study found no evidence of an association between mortality from COVID-19 infection in people with diabetes and use of either renin-angiotensin-aldosterone system inhibitor (RAASi), statin or combination therapy. This provides reassurance that clinicians should not change their RAASi and statin therapy prescribing practice in people with diabetes during the COVID-19 pandemic. 4. We demonstrated a low risk of diabetic ketoacidosis (DKA) and high mortality rate in people with T2D admitted to hospital with COVID-19 and limited power, but no evidence, of increased risk of DKA or in-hospital mortality associated with prescription of sodium-glucose co-transporter-2 inhibitor drugs 5. Our large multinational study of people with diabetes mellitus hospitalized for COVID-19 demonstrated that previous macrovascular disease was associated with higher mortality and lower proportions admitted to an intensive care unit and treated with invasive mechanical ventilation during a hospital stay suggesting selective admission criteria. Our findings highlighted the importance of correctly assessing the

		<p>prognosis and intensive monitoring in this high-risk group of patients and emphasize the need to design specific public health programmes aimed to prevent SARS-CoV-2 infection in this subgroup</p> <p>6. Hospitalization with COVID-19 and adjudicated diabetic ketoacidosis is four times more common than with hyperosmolar hyperglycaemic state but both are associated with substantial mortality. There was a strong association of previous insulin therapy with survival in type 2 diabetes-associated DKA.</p>
6	Future Questions:	
	<p>Have the processes / results raised further questions for future exploration? Please give brief details.</p>	<p>We had hoped to extend the work to include longer term follow-up but this was not feasible. The collaboration is continuing to collate data on other topics of mutual interest and we hope to develop approaches to use routinely collected data to partially complete data collection forms to minimise the manual data collection for future audits.</p>

Characterisation of COVID-19 outcomes in a high-risk cohort: Assessment of background levels of autoantibodies as a prognostic marker for severe COVID-19 infection

End of Project Report

The Public Benefit Impact Summary

1	Aims	
	What did the study set out to achieve?	To investigate whether the production of high levels of autoantibodies, as measured by the EarlyCDT-Lung test in the ECLS trial, leads to more severe disease in patients who then develop a SARS-CoV-2 infection.
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 EarlyCDT-Lung test is a blood-based biomarker panel that measures seven autoantibodies that can be found in patients with lung cancer up to four years before symptomatic presentation. The antigens the test targets are p53, NY-ESO-1, CAGE, GBU4-5, HuD, MAGE A4 and SOX2. We posit that patients who produce higher levels of these autoantibodies, measured by the EarlyCDT-Lung test in the ECLS trial, may develop more severe disease if they develop a SARS-CoV-2 infection. If our hypothesis is right, then EarlyCDT-Lung could be used as a prognostic marker for COVID-19 and could aid in the stratification of patients with regards to the level of monitoring and course of treatment. Particularly in cases of severe COVID-19, an early prognostic marker, such as EarlyCDT-Lung, could help to ensure that patients receive a more intense course of treatment early, before symptoms worsen and require critical care.
3	Data	

	<p>What data were received/processed/collected?</p> <p>Was it as expected? Please give brief details.</p>	<p>ECLS cohort</p> <p>Updated data was requested for the ECLS cohort from routine NHS service use and was linked with (1) existing ECLS trial data held at the Dundee Health Informatics Centre Safe Haven and (2) the raw EarlyCDT-Lung blood test results.</p> <p>Yes</p>
4	Methodology	
	<p>How did you collect the data?</p> <p>How did you process the data?</p> <p>How did you provision/publish the information?</p> <p>Did your study scope change from its original aims? Please give brief details.</p>	<p>Updated data was requested for the ECLS cohort from routine NHS service use and linked with (1) existing ECLS trial data held at the Dundee Health Informatics Centre Safe Haven and (2) the raw EarlyCDT-Lung blood test results.</p> <p>Data travelled from eDRIS to the Dundee Health Informatics Centre Safe Haven. Data provided by eDRIS was pseudo-anonymised using the HIC participant ID before transfer to HIC, and linked through participant ID by HIC to anonymised data collected during the ECLS trial. No member of the ECLS team will have access to identifiable data. All data was accessed via the HIC Safe Haven and will be subject to the SOPs for access, backup and disaster recovery.</p> <p>The Data Processor is the Dundee Health Informatics Centre, who will provide data cleaning, linkage, hosting, and secure access according to their local governance processes.</p> <p>We have already published a preprint and plan a peer reviewed publication,</p> <p>No</p>
5	Outcomes:	
	<p>The outcomes / results of your proposal. Please give brief details.</p>	<p>This hypothesis generating study demonstrated no clinically valuable or statistically significant associations between EarlyCDT positivity in 2013-15 and the likelihood of SARS-CoV-2 positivity in 2020, ICU admission or death in all participants (current or ex-</p>

		smokers with at least 20 years pack history) or in those with COPD or lung cancer
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	No

2021-0148 Albert King

The Scotland Coronavirus Model (Regression Modelling)

End of Project Report

The Public Benefit Impact Summary

1	Aims	
	What did the study set out to achieve?	The study set out to determine model parameters which best predict higher risk of Covid-19 cases, with the aim to use these parameters to identify which areas of Scotland are at higher risk of Covid-19 cases.

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 analysis which has been carried out is informing historical regional impacts and drivers of the pandemic to support our policy stakeholders.
3	Data	
	What data were received/processed/collected? Was it as expected? Please give brief details.	Data on cases, tests and deaths were received. These were used together with data on SIMD, population, commuter journeys, and geographic data.
4	Methodology	
	How did you collect the data?	The data, which had been collected by SIGSAG and ECOSS teams, and was encrypted and transferred into the National Safe Haven, was extracted via R Studio Server.
	How did you process the data?	We processed the data using R Studio.
	How did you provision/publish the information?	We used R Studio to produce graphs and maps which were then included in summary reports.
	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 have interrogated the data and tested that it is fit for purpose within the model requirements. We have looked at how the modelling can inform local prevalence. This work has underpinned the approach to local modelling at local authority and IZ level.
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	

2021-0187 Nathaniel Quail

How does advance care planning and palliative care input affect the place of death of motor neurone disease patients in the West of Scotland

End of Project report

The Public Benefit Impact Summary

1	Aims	
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What did the study set out to achieve?

The primary outcomes were to investigate whether there was an:

- Association between community palliative care and death in preferred place.
- Association between advance care planning and death outside of hospital.
- Association between unscheduled hospital attendances in last year of life and palliative care

Secondary outcomes involved analysis of multiple variables in relation to the above primary outcomes.

2	Public Benefit Impact	
	<p>How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered.</p>	<p>The findings of this study will help inform palliative care input and advance care planning in the West of Scotland for persons with Motor Neurone Disease, suggesting a possible role for earlier intervention to help achieve preferred place of death. The demographics of the cohort suggest that the results may be generalisable to populations outside of the West of Scotland. As a result, further research questions, such as why non-invasive ventilation increases the odds of dying in hospital and why having a gastrostomy increases the odds of having unscheduled hospital admissions in the last year of life, may be subsequently investigated to prevent unnecessary hospital admission in patients with Motor Neurone Disease and help achieve their preferred place of death.</p>
3	Data	
	<p>What data were received/processed/collected? Was it as expected? Please give brief details.</p>	<p>Data was collected and processed from the CARE-MND register, Clinical Portal, and local West of Scotland hospices.</p>
4	Methodology	
	<p>How did you collect the data?</p>	<p>Data was collected from the CARE-MND audit register, local Clinical Portals, and local hospices by the named researchers.</p>
	<p>How did you process the data?</p>	<p>Data was processed by the named researchers. Community and Hospital Index (CHI) numbers were changed to project numbers in the active dataset when no longer needed for data collection. Postcodes were converted into Scottish Index of Multiple Deprivation rankings.</p>

	How did you provision/publish the information?	The results are awaiting publication after being collated into a manuscript.
	Did your study scope change from its original aims? Please give brief details.	Edinburgh Cognitive and Behavioural ALS Screen results were sparse for the cohort of patients and therefore not used in the final analysis. A lack of documentation regarding preferred place of death impaired analysis of this outcome. Evidence from the literature and from our cohort suggests most patients prefer to die outside of the hospital setting and this was therefore taken as the preferred outcome.
5	Outcomes:	
	The outcomes / results of your proposal. Please give brief details.	<p>Binary logistic regression, a form of statistical analysis that considers how multiple variables interact in relation to an outcome, was used to examine the data. The statistically significant results from this are shown below, subject to peer review.</p> <p>Community palliative care input and advance care planning increased the odds of death outside of hospital. Non-invasive ventilation decreased the odds of death outside of hospital.</p> <p>Patients with a gastrostomy had increased odds of having one or more unscheduled hospital admissions in the last year of life compared to those without. This effect persisted with removal of admissions related to gastrostomy complications from the analysis. The health board that the patients lived in also had a statistically significant effect on odds of having one or more unscheduled hospital admission in the last year of life. Understanding this observation will require further study.</p>

6	Future Questions:	
	<p>Have the processes / results raised further questions for future exploration? Please give brief details.</p>	<p>Community palliative care input and advance care planning increased the odds of patients dying outside of hospital in our study. Will considering advance care planning options and community palliative care input at an early stage for patients with MND lead to more patients dying outside of a hospital setting? This would require prospective investigation and may have resource implications.</p> <p>Patients with non-invasive ventilation were more likely to die in hospital in our study. Was this due to carer/primary care confidence in using the equipment and managing the deterioration of a patient who already has impaired respiratory function at baseline? Qualitative investigation of this may prove useful going forward.</p> <p>Why were patients with gastrostomy more likely to have unscheduled hospital admissions in our study? This was still the case even when relevant variables, such as rate of deterioration, were included in the analysis and when admissions with gastrostomy complications were removed from the analysis. This would warrant further qualitative and quantitative investigation.</p> <p>The health board that the patients lived in also had a statistically significant effect on odds of having one or more unscheduled hospital admission in the last year of life. Understanding this observation will require further study.</p>

BioImpedance Spectroscopy to Maintain Renal Output: the BISTRO Trial

End of Project Report

1	Aims	
	What did the study set out to achieve?	To establish the clinical and cost effectiveness of using bioimpedance (a bedside body composition measurement device) in the management of haemodialysis patients in the preservation of their native residual kidney function after commencing treatment.
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 results following publication will be examined by NICE and lead to recommendations on the use of bioimpedance devices in kidney units throughout the UK (by updating their current advice published in 2017, https://www.nice.org.uk/guidance/dg29 which falls short of a recommendation due to lack of clinical and no health economic data). This will maximise the benefits to patients while ensuring that the cost of delivering dialysis represents value for money. Dialysis is a very expensive treatment that consumes 0.5% of the NHS budget, so it is in the public interest that every attempt be made to maximise its cost effectiveness.
3	Data	

	<p>What data were received/processed/collected?</p> <p>Was it as expected? Please give brief details.</p>	<p>From the patients we collected data on the primary outcome – native kidney function decline over 2 years, patient reported outcomes and quality of life, blood pressure and bioimpedance data. From HSC we collected data on their hospital episodes (inpatient and outpatient episodes, planned and unplanned).</p> <p>The data obtained was what we requested. It demonstrated that a significant proportion of the medical costs for dialysis patients is not directly related to their dialysis treatment.</p>
4	Methodology	
	How did you collect the data?	The clinical data (outcomes, symptoms and measures of quality of life) were collected from patients during this course of the trial. This was combined with the HSC data on hospital episodes to enable calculation of quality adjusted life years and the incremental cost effectiveness of the intervention.
	How did you process the data?	The HSC data was linked electronically to the clinical data obtained from the trial participants which was then fully anonymised prior to analysis.
	How did you provision/publish the information?	The primary analysis has been submitted for publication to the NIHR Journal Health Technology Assessment, and will also be summarised in the BISTRO trial synopsis, again to be published in the NIHR HTA journal (submission date 27 th October, 2023)
	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 Health Economic Evaluation found that there was a modest cost effectiveness benefit to the intervention,

		due to a combination of small cost savings and slightly more quality adjusted life years. The probability of the intervention being cost-effective was 76% and 83% at commonly cited willingness-to-pay threshold of £20,000 and £30,000 per QALY gained.
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	Yes. Our findings raise the possibility that the slightly better quality of life and cost effectiveness was associated with better preservation kidney function. We propose to undertake an analysis from this data from the whole BISTRO cohort.

2021-0255 Hazel Dodds

Scottish Cardiac Audit

End of Project Report

1	Aims	
	What did the study set out to achieve?	<p>To develop an audit structure for cardiac disease in Scotland. The Scottish Cardiac Audit Programme (SCAP) will provide an evidence-based framework to ensure the delivery of safe, effective and person-centred care for people with cardiac disease across Scotland.</p> <p>This work will support the identification of unwarranted variation in the delivery of secondary and tertiary care for people with cardiac disease and support quality improvement through the Scottish National Audit Programme (SNAP) of Public Health Scotland (PHS) Governance process.</p>
2	Public Benefit Impact	

	<p>How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered.</p>	<p>Cardiac disease is a significant burden on NHS Scotland and on people across the country. Its impact is expected to grow with the pressures currently facing the health service alongside Scotland's aging population.</p>
3	Data	
	<p>What data were received/processed/collected?</p> <p>Was it as expected? Please give brief details.</p>	<p>Data relating to clinical staff: Surname, forename, GMC number (doctors only), NHS email addresses (all provided by staff).</p> <p>Data relating to patients: Forename, surname, CHI number, full post code, sex, date of birth, medical history, current diagnosis, ethnicity. The majority of the data are already collected in local systems within the cardiac units across Scotland (individual patient paper/ electronic case-notes/ patient records).</p> <p>A significant amount of work was done with local NHS Boards to ensure accurate collection or appropriate data.</p>
4	Methodology	
	How did you collect the data?	<p>Data for SCAP were extracted from local systems or collected via research electronic data capture (REDCap) tool.</p> <p>Data will be transferred via secure electronic transfer, i.e. via secure email or Submission with Internet File Transfer (SWIFT/ Globalscape) from cardiac units to PHS.</p>
	How did you process the data?	<p>Data was analysed using R on the PHS secure Posit server area and reports were presented in data visualisation, for example via Tableau/ RShiny and access to these is managed following the current PHS protocols.</p>
	How did you provision/publish the information?	<p>As noted above - the first publications utilising these data were published here on the PHS website on 14th March 2023 by PHS.</p>

	Did your study scope change from its original aims? Please give brief details.	Recently added linkage: Linking to the unscheduled care data to help with data completeness in working out how long it took people from the point of call for help to receive a PCI. Using the Scottish Stroke Care Audit (SSCA) as a linkage resource we are able to further enhance the data collection around complications following cardiac intervention as the data surrounding this for certain procedures is often completed at the time of procedure with no further checks subsequently carried out.
5	Outcomes:	
	The outcomes/ results of your proposal. Please give brief details.	All outcomes and results can be viewed in the recent publications - here .
6	Future Questions:	
	Have the processes/ results raised further questions for future exploration? Please give brief details.	The Scottish Cardiac Audit Programme continues to collect data. Following this year's publications various stakeholder meetings were held to assess if the clinicians and others wanted to change or add anything to future publications. As noted above the next iteration of publications are currently being developed and are due for publication in January 2024. Further analysis is now included in the DPIA e.g. Total End to End Report (TEER) on the mitral valve, tricuspid mitral valve repair (TMTV) and cardiac rhythm management as well as other device information.

2021-0236 Hazel Dodds

Scottish National Audit Programme – Case Note Validation

End of Project Report

1	Aims	
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	What did the study set out to achieve?	The aim of this application was to fulfil the service provided by the data quality assurance function of the Scottish National Audit Programme (SNAP), in the Clinical and Protecting Health Directorate of Public Health Scotland (PHS), which involves having rolling access to patient level data to complete data quality assurance assessments. This ensures that these data are accurate, consistent and comparable across time, and between hospitals and for the credibility of clinical audit data.
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.	PHS has an obligation to demonstrate that the statistics that it publishes are trustworthy, of high quality and of public value.
3	Data	
	What data were received/processed/collected? Was it as expected? Please give brief details.	<p>Data relating to clinical staff: Surname, forename, designation, NHS email addresses (all provided by staff).</p> <p>Data relating to patients: Surname, forename, CHI number, health data, ethnicity</p> <p>All of the data that are checked as part of this process are already collected in local systems within the various units/ hospitals across Scotland (individual patient paper/ electronic case-notes/ patient records).</p> <p>During the pandemic and continuing now, we are carrying out CNV virtually, i.e., using MS Teams, this has caused some issues when connectivity has been slow or the user has difficulty sharing the screen and/ or showing the patient records, in particular when using paper records. We are now doing face-to-face visits again, when needed.</p>
4	Methodology	
	How did you collect the data?	Lists of patients were extracted from the various audits/ registers using SPSS/ R and shared with the relevant NHS Board. Data for CNV are collected during virtual/ face-to-face visits to the NHS Boards and are stored on secure PHS servers.

	How did you process the data?	Data were analysed using excel and reports were presented in word documents.
	How did you provision/publish the information?	As noted above - the results of CNV are not publicly available other than when summarised within annual national reports of the various audits/ registers or in the SNAP annual publication.
	Did your study scope change from its original aims? Please give brief details.	Only due to the pandemic when we had to adopt a virtual mechanism of doing CNV. Also, during the time noted we have moved from utilising SPSS to R.
5	Outcomes:	
	The outcomes/ results of your proposal. Please give brief details.	Outcomes of CNV are discussed with the local teams and the central audit/ register team. As noted above a summary is included in annual national reports.
6	Future Questions:	
	Have the processes/ results raised further questions for future exploration? Please give brief details.	Nil to date.

2021-0290 Dr Jodie Westhead

Suicide in former service personnel: rates,

antecedents, and prevention

The Public Benefit Impact Summary 1 Aims Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary Ref2021-0290 PBPP End of Project Declaration and Summary Report Final What did the study set out to achieve? This study set out to examine rates of suicide and characteristics of individuals who had left the UK Armed Forces, and to update our earlier work – firstly, by examining a 20 year (1997-2018) compared to a 10 year (1996-2005) period. We also sought to build on earlier findings by collecting coroners' and police death report data on approximately 200 veterans who died by suicide. This was a new data source compared to our previous study, and allowed us to examine factors related to suicide in veterans in detail. The findings of this study provided an estimate of the burden of suicide in UK veterans and identified key characteristics that could be the focus of preventative efforts in the veteran population. 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 findings of this study provided an estimate of the

burden of suicide in UK discharged personnel (veterans). By describing these individuals (and comparing them with those serving in the Armed Forces and those in the general population) the study was able to identify key characteristics that could be the focus of preventive efforts in the veteran population. A report of the findings was prepared for the MoD and NHS England, together with supporting materials, e.g. infographics, short videos of the key messages, and academic publications providing a mechanism by which findings can be shared amongst those responsible for delivering services to both serving and military veterans, ensuring relevant initiatives/action plans are put in place to address any adverse findings.

3 Data Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary Ref2021-0290 PBPP End of Project Declaration and Summary Report Final

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

This study was conducted in two phases. Phase 1: We conducted a retrospective UK-wide cohort study linking data held by the Ministry of Defence (MoD) on all suicide deaths amongst serving personnel and all personnel discharged from the Armed Forces (from 1996 to 2018). The MoD provided NCISH with an extract of information from the Service Leavers Database (SLD) - a database of all service personnel who have left service since the mid-1970s (from 1996 to 2018), and the MoD Deaths Database - all in-service suicide deaths amongst serving personnel from 1997-2018. These were linked with two databases held by NCISH at the University of Manchester; The general population suicide database (1997-2018) – consisting of general population mortality data previously supplied by national data providers - National Records of Scotland (NRS; for deaths registered in Scotland) and the database of suicide deaths in people in recent (i.e. 12 month) contact with mental health services (1997-2018). Phase 2: In phase two, we collected data on the factors related to suicide from coroners' records in England and Wales, and police reports in Scotland on veterans who have died by suicide. We collected data on 145 suicide deaths by veterans who died in a 10-year period (1st January 2007 to 31st December 2018). These veterans were identified through the linkage in Phase 1. Data collection proceeded as expected.

Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary Ref2021-0290 PBPP End of Project Declaration and Summary Report Final

4 Methodology

How did you collect the data? In Phase 1, the datasets were provided by the MoD and transferred using an encrypted USB memory stick and linked to existing data already held by NCISH. In Phase 2, data was obtained from coroners' records in England and Wales and police reports in Scotland on veterans who had died by suicide during the study period. How did you process the data? In Phase 1, data received from the MoD was linked using the identifiers provided to NCISH's general population database to identify those former service personnel who have subsequently died by suicide or probable suicide in the study time period. In Phase 2, coroners records (for deaths that occurred in England and Wales) were obtained from the senior coroner in the jurisdiction where the death occurred. For deaths that occurred in Scotland, police sudden death reports were obtained. Information was extracted from these records and reports onto a data collection proforma and entered into a database for aggregate analysis. How did you provision/publish the information? Reports were provided to stakeholders and an article has been published in an academic journal. Information and data included in these outputs adhered to disclosure control guidance. Did your study scope change from its original aims? Please give brief details. The study scope did not change from its original aims.

5 Outcomes: The outcomes / results of your proposal. Please give brief details. A final report was prepared for stakeholders. One academic paper has already been published on Phase 1 of the study, which reports that overall, the suicide risk in veterans is slightly lower than in the Public Benefit and Privacy Panel for Health and Social Care End of Project Declaration and Summary Ref2021-0290 PBPP End of Project Declaration

and Summary Report Final general population. However, the risk was 2 to 3 times higher in male and female veterans aged under 25 years than in the same age groups in the general population. Male sex, Army service, discharge between the ages of 16 and 34 years, being untrained on discharge, and a length of service under 10 years were associated with higher suicide risk. Factors associated with reduced risk included being married, a higher rank, and deployment on combat operations. A second paper is being prepared for publication on Phase 2. There will also be further publications and presentations at academic conferences. 6 Future Questions: Have the processes / results raised further questions for future exploration? Please give brief details. One key question raised for potential exploration is the risk factors specific to female veterans which unfortunately we could not examine in detail from coroner records due to a small sample size.

2021-0180 Jill P Pell

Defining and understanding the longer-term effects of COVID-19: A mixed methods study exploring the frequency, nature, and impact of 'long COVID' in the Scottish population

The Public Benefit Impact Summary

1	Aims	
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	<p>What did the study set out to achieve?</p>	<p>The COVID in Scotland Study (CISS) aimed to determine the extent, severity, and impact of long-COVID at a population level. Specific objectives were:</p> <ul style="list-style-type: none"> • To determine the proportion of people with confirmed COVID-19 infection who have longer-term sequelae. • To determine the nature of these sequelae. • To determine the factors associated with them. • To determine the extent to which they impact quality of life and activities of daily living. • To understand the experiences of living with long-COVID.
2	Public Benefit Impact	

<p>How will these outcomes directly result in benefit for the public? Please give details. This should be the main section answered.</p>	<p>Study outcomes included measures of the prevalence and nature of long-COVID in the Scottish population. This can inform service provision bringing patients direct benefits.</p> <p>We found that self-reported long-COVID was very common. Following symptomatic infection 42% of participants reported that they had only partially recovered and an additional 6% said they have not recovered at all. The condition was associated with worse quality of life, impairment across all aspects of daily living and a wide range of symptoms. However, the true frequency (taking into account individual characteristics and current symptoms in people who did and did not have COVID infection recorded) of long-COVID was much lower than the self-reported frequency. Apart from altered taste and smell, the symptoms of long-COVID are non-specific and therefore may occur irrespective of infection. Therefore, whilst 64.5% of the people in this study reported at least one symptom 6 months following SARS-CoV-2 infection, this was also true of 50.8% of those never infected. The 'true' prevalence of long-COVID (percentage of people who had one or more symptom that would not have occurred anyway) was 6.6%, 6.4% and 10.3% at 6-, 12- and 18-month follow-up.</p> <p>Between 6- and 12-month follow-up the overall percentage of people with one or more symptom did not change, but there were changes in specific symptoms. Altered taste, smell and confusion improved over time in the post infection group when compared to the never infected group. Conversely, late onset dry and productive cough, and hearing problems were more likely following SARS-CoV-2 infection than among those never infected.</p>
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		<p>Interviews identified the devastating impact of long-COVID on people’s lives. Participants spoke about its catastrophic effects on finances, careers, relationships and mental health. The desire to have ‘their life back’ was universal. Many spoke of attempts to access healthcare as ‘fragmented’. Some felt ‘dismissed’ by GPs; others described an arduous cycle of undergoing various investigations, receiving normal test results, organising more consultations and more tests, all adding to the burden of life with long-COVID. This made some reluctant to seek further healthcare.</p> <p>At follow-up interviews six months later a diverse picture emerged where for some symptoms had gradually improved while others experienced no improvement or worsening symptoms. Effective treatment remained elusive – people were even more reluctant to consult after being previously dismissed by healthcare professionals or because previous consultations and investigations proved fruitless. An exception to this is treatment from physiotherapists, in the form of breathing exercises and advice on pacing to manage fatigue, which was well received.</p>
3	Data	
	<p>What data were received/processed/collected?</p> <p>Was it as expected? Please give brief details.</p>	<p>Questionnaire and interview data were collected exploring participants’ health and wellbeing following their COVID-19 PCR test. This was as expected.</p>
4	Methodology	
	<p>How did you collect the data?</p>	<p>We used the Scottish polymerase chain reaction (PCR) test result database to identify and invite every adult in Scotland who had had a positive PCR test for COVID-19 and a comparison group of people who had a negative test only. 4,049,590 invitations were sent by SMS (text message). We included existing cases and added new cases as they occurred, and a total of 257,341 unique people participated fully. Study participants completed questionnaires at 6, 12, 18, and 24 month follow-up.</p>

		<p>Participants also consented, if they wished, to recruitment to a qualitative study. Forty-five people were interviewed; eighteen were reinterviewed 6 months later.</p>
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<p>How did you process the data?</p>	<p>Public Health Scotland uploaded a file containing the contact numbers of all eligible participants along with a study ID, on a quarterly basis, onto a secure web-based administration suite set up by STORM-ID. The administration suite automatically sent SMS text messages to potential participants, both positive cases and negative matched controls, inviting them to participate in the study. Participants who consented entered their data via a progressive web-based app questionnaire. The questionnaire data were stored on the Lenus Health Platform on the NHS controlled Azure infrastructure.</p> <p>eDRIS received one file from PHS, for all invitees regardless of whether they consented to participate or not, containing the study ID, the test date/result, age, sex, and SIMD quintile of the eligible participants. eDRIS was sent a second file by the Lenus platform containing the study ID and questionnaire responses but no other identifiers. This initial merged file, containing questionnaire responses, covid test information, age, sex, and SIMD quintile, was stored in the National Safe Haven for responders who consented to linkage to medical records. The merged file was then linked to SMR01, SMR04, A&E, SICSAG, COGUK Metadata, PIS, vaccination database and deaths via CHI. eDRIS then stripped off the CHI number before the file was put into the safe haven.</p> <p>eDRIS provided aggregated outputs of sociodemographic data (age, sex, SIMD quintile) and test result (positive/negative) for non-responders and for those who did not consent to data linkage.</p> <p>Following completion of the questionnaire participants were informed that the researchers would like to conduct interviews with some people. Participants were asked to consent to be contacted to participate in this further part of the study. Potential participants for interview were selected, by University of Glasgow investigators, from those who consented based on sociodemographic characteristics and their Covid test result held in the National Safe Haven. An ID list was extracted from the National Safe Haven by eDRIS and passed to approved PHS staff who extracted the person's name and mobile phone number from the PHS Test and Protect system. These contact details were then passed to study investigators.</p>
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	<p>How did you provision/publish the information?</p>	<p>Data were stored and analysed in the National Safe Haven. Results were disseminated to the University of Glasgow long-COVID Patient and Public Involvement and Engagement group, Public Health Scotland, the Scottish Government, Chief Scientist Office, to the general public via press releases and social media, and (to date) in three peer reviewed publications.</p>
	<p>Did your study scope change from its original aims? Please give brief details.</p>	<p>No</p>
<p>5</p>	<p>Outcomes:</p>	
	<p>The outcomes / results of your proposal. Please give brief details.</p>	<p>Key findings</p> <ul style="list-style-type: none"> • At 6 months or more after symptomatic infection, 48% of participants reported not being fully recovered. • The symptoms of long-COVID vary, but the most common are tiredness, headache, muscle aches/weakness, difficulty sleeping, and breathlessness. • The risk of long-COVID is greater in people who had to be hospitalised for their COVID infection, women, people living in deprived areas and those with pre-existing health conditions (especially multimorbidity), and absent following asymptomatic infection. • The 'true' prevalence of long-COVID (percentage of people who had one or more symptom that would not have occurred anyway) was 6.6%, 6.4% and 10.3% at 6-, 12- and 18-month follow-up. • Interviews with participants living with long COVID identified the devastating effect it has on lives, with detrimental impacts on finances, careers, relationships and mental health

		<ul style="list-style-type: none"> Repeat interviews 6 months later identified fatigue, breathlessness, and brain fog as common enduring symptoms and effective treatments elusive.
6	Future Questions:	
	Have the processes / results raised further questions for future exploration? Please give brief details.	Questions were raised regarding effective treatment options for people with long-COVID. This requires exploration.