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

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| **Application Reference**  **(click on reference for EPR Summary)** | **Applicant** | **Applicant Organisation** | **Title and Purpose of study** | **Date of Approval** |
| [2122-0054](#_2122-0054_Duncan_Buchanan) | Duncan Buchanan | Research Data Scotland | Equality Protected Characteristics Dataset | 10/06/2020 |
| [2122-0018](#_2122-0018_Anna_Santarsieri) | Anna Santarsieri | Cambridge University Hospitals NHS Foundation Trust | Toxicities and strategies to reduce them in blood cancer patients treated in the non-trial setting | 12/08/2021 |
| [2122-0225](#_2122-0225_Dr._Holly) | Dr. Holly Marissa Tibble | University of Edinburgh | Short-Term Adult Asthma Attack Prediction using Electronic Health Record Data in the Primary Care Setting | 11/06/2022 |
| [2122-0132](#_2122-0132_Michelle_Oliver) | Michelle Oliver | NHS | An exploration of the experiences of identity and resilience in adolescents assigned female at birth (AFAB) with Autism Spectrum Disorder (ASD) and Gender Dysphoria (GD) who have not surgically transitioned: An Interpretative phenomenological analysis (IPA) study |  |
| [2122-0197](#_2122-0197_Lucy_Cureton) | Lucy Cureton | Primary Care Clinical Trials Unit, University of Oxford | PANORAMIC |  |
| [2122-0102](#_2122-0102_Ms_Jan) | Ms Jan Mackenzie | University of Edinburgh | Transfusion Medicine Epidemiology Review (TMER) |  |

**Appendix: End of Project Report Summaries**

# 2122-0018 Anna Santarsieri

**Toxicities and strategies to reduce them in blood cancer patients treated in the non-trial setting**

**End of Project Report**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | To investigate whether a modified chemotherapy protocol (escalated BEACOPDac) is as effective as standard chemotherapy (escalated BEACOPP) in Hodgkin lymphoma therapy for younger adults (16-60y) |
| 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 project has generated evidence for the clinical and genomic health benefits of escalated BEACOPDac, compared with escalated BEACOPP. As a result of presentation of our research at international conferences, many centres across the world (in the UK, France, Switzerland, the whole of Sweden, Australia) have switched from using escalated BEACOPP to escalated BEACOPDac. This has benefitted hundreds of patients with Hodgkin lymphoma across the world. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | Retrospective data were collected on month/year of diagnosis, vital status at last follow-up, month/year of relapse and death (where applicable) and on specific toxicities (e.g. haematological, biochemical), we will be able to assess how efficacious and how toxic modified therapies are compared with standard treatment.  Data collection was as expected. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | Eligible patients were identified by Principal Investigator (Haematologist) at local NHS hospital. Patient identifiers removed. Assigned unique study ID and data collected in spreadsheet. Pseudonymised data from participating NHS Health Board were sent in password-protected file from nhs.scot to nhs.net account at Cambridge University Hospitals. |
| How did you process the data? | Data were stored at Cambridge University Hospitals. Data were collated and analysed to compare efficacy and toxicity endpoints. Data analysis was performed using R software. Statistical tests used included Mann-Whitney U, Fisher and T-tests. A survival analysis was performed using Kaplan-Meier estimators. |
| How did you provision/publish the information? | The data has been presented at international conferences as detailed above. We plan to write up and publish the data in 203. |
| Did your study scope change from its original aims? Please give brief details. | The study scope has changed from its original aims in that it has focused predominantly on the treatment of Hodgkin lymphoma in younger adults. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | With 27 months median follow-up, escalated BEACOPDac (modified treatment) appears as effective as escalated BEACOPP (standard treatment) in terms of curing younger adults (16-60y) with Hodgkin lymphoma. Patients who received escalated BEACOPDac required significantly fewer units of blood transfusion and spent significantly fewer days admitted to hospital. All women under 35y who received escalated BEACOPDac recovered their menstrual periods after treatment and had a significantly earlier return of their menstrual periods than those who had escalated BEACOPP. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | Reduced toxicity was observed in patients who received the modified treatment, escalated BEACOPDac. In this modified regimen dacarbazine has been substituted for procarbazine, which is known to be a relatively stem cell toxic drug. The results have raised the question whether this toxicity may reflect an excess somatic mutation burden in stem cells exposed to this drug. To explore this hypothesis further we have examined the mutational burden and mutational spectrum in haematopoietic stem and progenitor cells following treatment with either escalated BEACOPP or escalated BEACOPDac. |

# 2122-0054 Duncan Buchanan

**Equality Protected Characteristics Dataset**

**End of Project Report**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | The overall aim of the project proposal is to develop a securely held population-wide equalities dataset based on linking data on individuals across a number of administrative databases. This reference dataset would then be available to provide equalities data in future projects looking to report on the equality of outcomes and service provision for specific services where equality data is not available or adequate.  This current application covers the first phase of the project to build and test the dataset  The reference dataset collates data related to the protected characteristics listed under the Equality Act 2010, such as age, sex, ethnicity, religion, national identity, maternity/pregnancy, marital status and disability. The new dataset and the data are pseudonymised multiple times making it difficult to identify where data originated. |
| 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 data held on protected characteristics in administrative and clinical databases, such as ethnicity was found to be incomplete and often of low quality. This hindered attempts to produce timely evidence on how the pandemic impacted on different groups and communities within the population. This lack of complete data and evidence has the potential to discriminate groups due to lack of evidence on which to base interventions and actions. While there are attempts to address data quality in administrative and clinical databases these may take time to be realised. One approach to mitigate the risks of lack of complete data is to make maximum use of the data that is already collected by different public organisations. The current project aims to address this by linking datasets with a wide coverage across the demography and geography of Scotland and combining records on protected characteristics to aid future research projects provide timely evidence on equality of public services.  The public benefit will be in assisting public sector organisations with evaluation of their services to ensure they are inclusive and equitable. Where inequalities in service provision or outcome are identified by research, providers can consider improvements to be made to address them. |
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| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | Data that were processed came from the following sources:   1. Scottish Census 2011(from NRS) 2. School Pupil Census for 2011-19 (from SG) 3. SMR00/SMR01/ SMR02/SMR04 for 2011-22 (from PHS)   Only the following variables were collated from these sources and combined using on a set of business rules: Date of birth, sex, ethnicity, religion (census only), national identity (census/pupil census only), maternity episodes (SMR02 only), marital status (census/SMR only), disability (Census only) and disability-related student support needs (pupil census only).  In addition, a pseudonymised index number was provided by NRS, who retained master index file that links this index number to the population spine.  The data received and processed were as expected and specified in the original application. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | All data was sourced from existing national datasets collected and maintained by Scottish Government (pupil census), National Records of Scotland (Census) and Public Health Scotland (SMR records) |
| How did you process the data? | The source datasets from the original data controllers were pseudonymised by National Records of Scotland which involved replacing person identifying information on the source datasets with an anonymous index number. These pseudonymised datasets were then linked separately by EPCC within the National Safe Haven and combined to create a single value for each protected characteristic using pre-agreed business rules. Analysis and testing were carried out on the final dataset within the NSH to test the application of the business rules and create summary statistics of the distributions of values. |
| How did you provision/publish the information? | A Summary report describing the Dataset has been prepared (and is attached). This has been shared with researchers and others who may have an interest in using the dataset or for reviewing and providing feedback in relation to research requirements. |
| Did your study scope change from its original aims? Please give brief details. | The study scope did not change from the original aims. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | The final dataset has captured a wide range of data on many of the protected characteristics of over 6.2 million individuals across the full distribution of age. This includes individuals who have been born or moved to Scotland since the 2011 census. It was not possible to capture information on sexual orientation or gender reassignment since these were not captured in any of the data sources. The dataset can be linked to data on individuals from public sector organisations to allow analysis of equality issues such as uptake and outcomes across a range of characteristics and is sufficiently large to allow analysis of minorities at a granular level as well as intersectional analysis. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | Future issues to be addressed from the first phase of the project are:   * Fitness for purpose for use as a reference dataset by public sector organisations and researchers * Retention of data on different protected characteristics sourced from varying data sources at different times, included some heavily reliant on census 2011. * Frequency and efficient methods of updating the values to reflect changing population and identities. * Methods of suitable public engagement on the use of the as a dataset as a standing resource for research. * Ensuring consistency and lack of duplication with other data improvement initiatives, especially around ethnicity data. |

## 2122-0102 Ms Jan Mackenzie

Transfusion Medicine Epidemiology Review (TMER)

**The Public Benefit Impact Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | The TMER project was set up with the aim of investigating whether Creutzfeldt Jakob Disease (CJD) and its variant form (vCJD) is transmissible through blood transfusion. |
| 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 identification of transfusion transmission of vCJD through the TMER study has had profound implications for public health nationally and internationally and has resulted in policies aimed at minimising the risk of further transmission, for example the deferral of transfusion recipients as donors in the UK. It is crucial to determine whether there are further cases of transfusion transmission as this will inform public policy and serve the wider public interest. There are many unresolved questions including the risk to recipients, the level of infectivity of blood and the potential for a large population of infected donors that could lead to further cases. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | Collected were details of CJD/vCJD cases and their blood donation and blood transfusion status. Processed and received were details of recipients from/donors to, these CJD/vCJD cases. This was as expected. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | Cases of CJD/vCJD were identified by NCJDRSU as part of their UK CJD surveillance programme. |
| How did you process the data? | Cases of CJD/vCJD were sent to NHSBT to check their blood donor status and cases of CJD/vCJD who had previously received blood transfusion(s) were sent to NHSBT to identify potential donors. Details of recipients from, and donors to, CJD/vCJD cases were sent back to NCJDRSU to check |
| How did you provision/publish the information? | Several articles were published in peer-reviewed journals and abstracts/posters shown at national and international conferences. |
| Did your study scope change from its original aims? Please give brief details. | The scope changed in 2017 after an audit on the reliability of surrogate witnesses where it was found that some cases where the surrogate witness had denied a history of blood donation in the case were found to be registered as blood donors in the past. From 2017 all cases of CJD were sent for donation status checking regardless of their reported history of blood donation. Previously only cases with a reported donation history were sent for checking. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | Three cases of vCJD and one sub-clinical infection have been linked to transfusion transmission through this study. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | Risk to recipients, the level of infectivity of blood and the potential for a large population of infected donors that could lead to further cases. |

## 2122-0132 Michelle Oliver

**An exploration of the experiences of identity and resilience in adolescents assigned female at birth (AFAB) with Autism Spectrum Disorder (ASD) and Gender Dysphoria (GD) who have not surgically transitioned: An Interpretative phenomenological analysis (IPA) study**

**The Public Benefit Impact Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | This study aimed to explore experiences of Gender Dysphoria in Autistic adolescents assigned female at birth. It also set out to have a particular focus on identity and resilience. |
| 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 research gives free access to all who wish to understand more about the experiences of Gender Dysphoria in autistic adolescents assigned female at birth. It was hoped that this would promote parent and healthcare staff understanding; particularly around gender-affirming care to foster positive mental health outcomes. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | Name, preferred name, address, postcode, date of birth, age, ethnicity, employment status, gender identity, sexuality, age at autism diagnosis, length lived in current gender, age of onset of gender dysphoria, family prevalence of gender dysphoria, level of parent support, experience of gender and gender dysphoria, gender dysphoria with autism experience, group identity, self-concept and resilience/coping factors.  Yes, data was collected as expected. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | “We recruited through both health services and the community. Posters of advertisement were sent to two NHS Scottish health board teams...Posters were also displayed on social media (namely Facebook, Twitter and Discord) and those interested could contact the researcher directly.” (Oliver et al., 2025) |
| How did you process the data? | Data was kept within the NHS Shared drive with restricted access given to the clinical lead and applicant. Recordings were deleted as soon as transcripts were completed. |
| How did you provision/publish the information? | The research was published in the Journal of Autism and Developmental Disorders |
| Did your study scope change from its original aims? Please give brief details. | The only change was that there were no participants from the community who opted to take part. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | “In conclusion, this study explores the unique phenomenological experiences of assigned female at birth autistic adolescents who are experiencing GD. In summary, this includes dealing with socially gendered expectations and internal conflicts, whilst trying to manage menstruation and sensory sensitivities (e.g. which may make binding more challenging), struggling to express this distress, asking for help and showing resilience by trying to cope, but having to wait a considerable time for support. This is on top of experiencing transphobia, mis-gendering, bullying and other life difficulties, such as bereavements.  This paper highlights this as a much-needed conversation and contributes to the growing knowledge about how healthcare staff can support the mental health outcomes of assigned female at birth autistic adolescents. This includes the importance of reducing waiting times, considering the meaning of repetition and utilising key therapeutic and gender-affirming strategies such as acceptance, empathetically listening and co-constructing an individual’s story and goals. In addition, it contributes to recent theory developed to explain experiences within this population (e.g. Coleman-Smith et al., [2020](https://link.springer.com/article/10.1007/s10803-024-06688-6#ref-CR10)). This paper also shines a light on areas of social and individual identity forming in assigned female at birth autistic adolescents, as well as levels of resilience, validation and acceptance; which can positively impact upon mental health outcomes. Proceeding studies should take stock of the current literature to highlight future areas to explore.” (Oliver et al., 2025) |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | “Future studies should also give a voice to those assigned female at birth autistic adolescents who identify as non-binary, as well as quantifying the impact of waiting times upon psychological wellbeing - and given current demands on services - striving to find out what waiting “*well*” could look like.” (Oliver et al., 2025) |

## 2122-0197 Lucy Cureton

PANORAMIC

**The Public Benefit Impact Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | Primary objective:  To determine whether antiviral treatment in the community safely reduces non-elective hospitalisations/deaths in high risk symptomatic patients with confirmed COVID-19.  Secondary objectives:  To explore whether antiviral treatment affects:  1) Time to recovery (defined as the first instance that a participant report of feeling recovered from the illness)  2) Participant reported illness severity, reported by daily rating of how well participant feels, enabling identification of sustained recovery.  3) Duration of severe symptoms and symptom recurrence  4) Contacts with the health services  5) New infections in household  6) To investigate the safety of antiviral agents  7) Longer term effects  8) Cost effectiveness  Sub-study primary aim:  To determine whether antiviral treatment in the community reduces viral load to undetectable levels more quickly than untreated patients and to explore antiviral treatment on potential development of antiviral resistance. |
| 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 currently very limited treatment options for people who are infected with COVID-19 in the community. Recently, a couple of treatments such as molnupiravir and paxlovid have shown to be effective in reducing hospitalisation/death rate in people with COVID-19. However, the evidence of these treatments has been very much focusing on unvaccinated population and therefore not entirely relevant to the UK population when a high proportion of the population has been vaccination. Therefore, this trial is important to demonstrate (1) if the treatment should be given to a high risk group in the UK; (2) if the trial could reduce hospitalisation so that the pressure to the hospital in UK can be reduced; (3) if the treatment could reduce viral load that would also lead to lower transmission of infection within the community. The results of the study will able to provide a definitive evidence to the government and members of the public as whether the tested antiviral treatments should be used as standard treatment for COVID-19 in this high risk population in UK.  In order to ensure the trial is conducted at high quality, we must collect good quality data so that we can be sure all hospitalisation/death events are captured and kept any missing data to its minimal (under 5%). Therefore, the NHS Scotland data will be a vital data source to achieve this target (at least for the population in Scotland).  The other reason for the request is to conduct health economics evaluation, which almost all the resource use data are not captured in the trial. This is because we do not want to put too much burden in terms of data collection to participants. We have requested similar resource data from NHS England for participants living in England but since health services in Scotland is different from England, we would like to make sure the health economic evaluation will incorporate data from all four nations to give a true representation of cost-effectiveness of the treatments being used in the UK. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | All as expected as per application. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | Data are obtained directly from participants via a secured online platform that include screening, eligibility, informed consent, safety, and daily diary data. Other data are obtained from routinely collected data. |
| How did you process the data? | A data manager will conduct data cleaning. Statistical analysis will be carried out by statisticians who will process the data from a restricted access folder. In addition, anonymised data will be transferred to the statisticians in the USA (Berry Consultants) for interim and final analyses of the primary outcome. That will be no personal data such as date of birth, name, addresses, being sent to the USA. The statisticians in Oxford will remove participant identifier such as study ID to ensure data cannot be identifiable by any of the statisticians in Berry Consultants or anyone in the trial team. As for the primary outcome, Berry Consultants will only receive an indicator of whether the participants have an event or not (i.e. a binary data with 1 indicating hospitalisation/death, and 0 indicating alive). No date of hospitalisation or date of death data will be transferred to the US. Some baseline characteristics and diary data will also be transferred to Berry for analysis, but these data are collected directly from participants themselves who have already consented to the anonymised data being sent to the US for analysis. |
| How did you provision/publish the information? | Via journals, presentations and website |
| 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. | <https://www.panoramictrial.org/results>  All results so far are listed here, links publications listed above |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | None specified |

## 2122-0225 Dr. Holly Marissa Tibble

**Short-Term Adult Asthma Attack Prediction using Electronic Health Record Data in the Primary Care Setting**

**The Public Benefit Impact Summary**

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| 1 | **Aims** |  |
|  | What did the study set out to achieve? | * To evaluate the different methods of estimating asthma medication adherence, a major risk factor for asthma attacks, in prescribing data * To estimate the rate of asthma attacks from electronic health records * To train and appraise a selection of asthma attack risk prediction models in electronic health records * To test the final selected risk prediction model in electronic health records |
| 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. | Asthma attacks cause more than 25 deaths per week on average in the UK. Primary care consultations provide the opportunity for patients and clinicians to assess changes to asthma attack risk. Accurate prediction of risk can instigate timely primary care intervention, prompt more frequency primary care visits, promote risk-reducing lifestyle choices, and encourage patients to seek emergency care following symptom deterioration. Furthermore, highlighting periods when risk is lower can reduce lifetime steroid use and patient anxiety. |
| 3 | **Data** |  |
|  | What data were received/processed/collected?  Was it as expected? Please give brief details. | The study recruited over half a million patients from 75 general practices in Scotland, with primary care records linked to national A&E, hospital, and mortality datasets.  The primary care prescription data was of very high quality – including the dose direction notes from the GP which enabled estimation of adherence not possible in other UK datasets. However, as is the current status quo, there was no free-text doctor’s notes available, which capture a substantial amount of information which is never translated into coded records. |
| 4 | **Methodology** |  |
|  | How did you collect the data? | No new data collected |
| How did you process the data? | The analysis population for this study was adults (aged 18 and over) with at least one eligible primary care consultation related to either asthma or respiratory infection during their follow-up. Eligible individuals (psuedoanonymised) were identified from the primary care data, and then their A&E, inpatient admissions, and mortality records were linked.  The final analysis dataset was structured with each observation as a day on which a primary care encounter for asthma (diagnosis, management, or monitoring) or respiratory infections occurred for each member of the study population, without a steroid prescription or secondary care asthma encounter. The columns of the dataset were their clinical features as of that date, including demographics, prescriptions, lung function, and more. |
| How did you provision/publish the information? | No raw data was removed from the safe environment. Any analyses, figures, or summary tables which were released from the safe environment were aggregated to minimise the risk of confidentiality disclosure. |
| Did your study scope change from its original aims? Please give brief details. | No, although the analysis of the prescribing data took a lot longer than expected due to the complexity of the data, and became a substantive research component in its own right. |
| 5 | **Outcomes:** |  |
|  | The outcomes / results of your proposal. Please give brief details. | This study has had two main outcomes.  Firstly, we have created a set of analytic tools for using prescribing data, including comprehensive open-source R scripts.  Secondly, it has contributed towards our understanding of asthma attack prediction in primary care, including important model features for different prediction time windows, and best practices for modelling. |
| 6 | **Future Questions:** |  |
|  | Have the processes / results raised further questions for future exploration? Please give brief details. | Dissemination of the results to key partners, including patients, funders, and clinicians, has prompted a new collaboration towards joint decision making and co-design of new prediction modelling software. |