Privacy Notice for project:
Modelling risk of alcohol withdrawal (AW) in the acute hospital setting using Hospital Episode Statistics (HES) Data

This notice relates only to personal data obtained from NHS Digital in the above project. The project has the following NHS Digital reference: DARS-NIC-226185-B6C2J

A table of abbreviations is available in Appendix 2 of this document.

I have questions or want further information. Who do I talk to?

If you have any questions or concerns about how your data will be processed within this project please contact the Research Associate Rachel Coleman, BSc MSc, Society for the Study of Addiction (SSA) funded PhD Student, Institute for Clinical and Applied Health Research, Faculty of Health Sciences. Professor Thomas Phillips, University of Hull is supervising this project.

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If you are unhappy with the response, please contact the University of Hull Data Protection Officer (DPO):

Email: dataprotection@hull.ac.uk

Telephone: 01482 466594

Address: University of Hull, Cottingham Road, Hull HU6 7RX

What is this project about?

The aim of this project is to explore Hospital Episode Statistics (HES) Data to predict risk of patients experiencing alcohol withdrawal when admitted to acute hospitals.

Those with alcohol use disorders exert a disproportionate impact or burden on the NHS, usually accessing care via emergency departments (Phillips et al, 2019). Recent reports identify that the majority of patients experiencing alcohol dependence, including alcohol withdrawal (AW) receive treatment in acute hospitals – outside of specialist services where these skills and competencies are concentrated (Roberts et al, 2020a). During 2017/18 there were 5,887 planned admissions to specialist inpatient units for alcohol use disorders, and over 80,000 for alcohol dependence and AW across acute hospital trusts in England, with an estimated cost of £1,500 - £2,704 per admission (NICE, 2011; Phillips et al, 2019). There were 36,6000 more patients admitted for alcohol-related reasons in 2018/2019 compared with 2012/2013 (PHE, 2020).

Provision of specialist inpatient services for AW is reducing, with a concomitant increase in alcohol related hospital admissions in England (Robertson et al, 2017; Drummond, 2017; Roberts et al, 2020b; Phillips et al, 2020a). Roberts et al (2020b) conducted an examination of the relationship between alcohol related admissions, specialist alcohol treatment provision and deprivation levels

since 2012. They found that the national rise in alcohol related hospital admissions may associated with funding cuts to specialist alcohol services (Roberts et al, 2020b). They also highlighted that there is a statistically significant association between reduction in net expenditure for alcohol misuse treatment per 1000 people and increased rate of alcohol related hospital admissions (Roberts et al, 2020b). Phillips et al (2020a) assessed the relationship between specialist and non-specialist admissions for alcohol withdrawal and found a strong statistical association between increase in alcohol related hospital admissions and reduction in non-specialist admissions. They highlighted the displacement of cost reductions in specialist services to non-specialist settings, and the need for resource development for non-specialist staff to meet the care needs of this population (Phillips et al, 2020a).

Limited use of validated tools, together with poor identification and inadequate assessment of AW in non-specialist settings (Barnaby et al, 2003; Mitchell et al, 2012) is likely to result in deficient clinical management which has been associated with discharges against medical advice and subsequent readmission (Mullins et al, 2017). Barriers to the effective implementation of protocols to enhance the identification and assessment of AW within non-specialist settings relate to; nurses feeling inadequately trained, uncomfortable with regards to the high doses of medication patients often require, limited time to assess patients and the need for simpler assessment tools (Roberts & Drummond, 2019; Glann et al, 2019). There are a small number of limited studies which aim to improve identification and management of AW in non-specialist settings – one of which considered a symptom-based tool which is predictive of Alcohol Withdrawal Syndrome, the Prediction of Alcohol Withdrawal Severity Scale (PAWSS; Maldonado et al, 2014). However, the current standards of practice for identifying and managing AW in non-specialist settings has not been studied, and there are no tools which exist to identify and target individuals likely to experience AW. Therefore, the development of a series of tools to identify 'at risk' individuals would allow for targeted care and result in better outcomes.

The first step in developing these tools is the proposed new purpose which is a detailed analysis of Hospital Episode Statistics (HES) Data to predict risk of AW based on the information collected on admission to hospital. The findings of this study will underpin a wider programme of research which incorporates observational work, staff interviews and development of interventions/tools to support non-specialist staff in managing AW. It is important to understand the characteristics that place individuals at risk of AW prior to developing tools to support their care.

Who is working on the project?

Colleagues within the Institute for Clinical and Applied Health Research and Data Safe Haven, University of Hull with experience in epidemiology, clinical information systems and alcohol research are working with colleagues with experience in Health Service Research at the University of Kent.

What data are you using?

Hospitals collect lots of data about any visit you make. Data is collated nationally by NHS Digital and is referred to as Hospital Episode Statistics (HES data). Data is separated into a number of different datasets dependant on what interaction you have with the hospital. The two datasets we will use in this project are: Accident and Emergency data which records information about when you go to A&E and Admitted Patient Care records when you are admitted to hospital. This data is used for many purposes within the NHS but is also made available for research. More information on HES data can be found here.

Our research project looks at all data from both A&E and the Admitted Patient Care records for the reporting period 2017-2018.

Whilst the HES datasets contain many data items we have selected only the data items we need to answer our research question. These items are listed in Appendix 1 at the end of this notice.

Under GDPR we need to confirm to you if the data we receive will be used to inform automated decision making or profiling. We confirm that the data we receive as part of this project cannot and will not, be used for either automated decision making or profiling.

Am I in this dataset?

If you attended A&E or were admitted to hospital between April 1st 2017 and March 31st 2018 your data will be in this dataset. However, we have not requested any identifiable information so all researchers involved in this project, do not know and have no way of finding out who is in the dataset.

In the project we link people in A&E and Admitted records using an identifier generated for us by NHS Digital. This means we can match a person who both attended A&E and was admitted to hospital. The identifier we use is specific to this dataset so we cannot use it to link to any other record provided by NHS Digital or other data provider to identify you.

NHS Digital hold both the identifier and the full data. This means they can identify you from the data we hold. We would work with them to meet any request you might make using your rights under GDPR as described below.

How are you able to access this data?

NHS digital are very strict about who can have access to patient data. This is managed via a process called a Data Access Request (DARS). This means we need to meet very detailed data governance standards and can demonstrate we are able to look after it appropriately. More information about the DARS process can be found here.

Where will you store the data?

The University of Hull has a Data Safe Haven (DSH) where this data will be stored and analysed. The DSH is disconnected from the internet and can only be accessed by approved researchers at specific computers within specially secured rooms. The DSH is managed by the Hull Health Trials Unit who hold a Data Security and Protection Toolkit (DSP), which provides assurance that they are practising good data security and that personal data is handled correctly.

We also confirm that the data held for analysis will not be transferred outside of the HHTU to any third countries or organisations.

 More information about the DSP can be found here.

How long will you keep it?

We will keep the data within the Data Safe Haven for the period of our data sharing agreement contract with NHS digital. At the end of the contract all patient data must be deleted. We will retain summary data but this will not be individual data

The legal stuff - GDPR

Under the terms of our contract with NHS Digital we (the University of Hull) are the data controller and processor of your data for the time we hold it. As a data controller we have the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in

the EU General Data Protection Regulation (called "GDPR") and a new UK law, the Data Protection Act 2018. In particular University must:

> • Take steps to ensure that the data it processes is accurate and up to date;

> • Give you clear information about its processing of your data, in one or more privacy notices like this one and the participant information sheet (referred to together in this section as a "Privacy Notice");

> • Only process your data for specific purposes described to you in a Privacy Notice, and only share your data with third parties as provided for in a Privacy Notice; and

> • Keep your data secure.

More legal stuff – Lawful basis

The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. As we are processing your special category data we also must meet one of the conditions in Article 9 GDPR. Special Category data includes personal data which relates to your ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership. Under the data protection legislation we need to explain the legal basis for holding your data, i.e. which of these conditions apply.

For our research project the following conditions apply:

• Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that UoH performs in the public interest, as part of our core function as a university;

• Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes. This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests.

Your rights as a data subject

Under the data protection laws you have a number of rights in relation to the processing of your data. These are limited by the lawful basis under which we hold your data. Your rights are:

- Right to request access to your data as processed by UoH and information about that processing
- Right to rectify any inaccuracies in your data
- Right to place restrictions on our processing of your data

Please note that we are unable to identify you ourselves within the data we hold. As such we would need to work with NHS Digital to identify if you are in any of the datasets.

If you would like to exercise any of your rights as outlined above, you can contact the DPO as above or visit the Data Protection page on our website

https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

We will always aim to respond clearly and fully to any concerns you have about our processing and requests to exercise the rights set out above. However, as a data subject, if you have concerns about our data processing or consider that we have failed to comply with the data protection legislation, then you have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: https://ico.org.uk/concerns/

Email: casework@ico.org.uk

Tel: 0303 123 1113

Post: Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

Appendix 1 – Requested Variables

Hospital Episode Statistics - Admitted Patient Care

[ACPDISP_N Augmented care period disposal, [ACTIVAGE Age at activity date, [ADMIAGE Age on admission, [ADMIDATE Date of admission, [ADMIFLAG Admission episode flag, [ADMIMETH Method of admission, [ADMINCAT Administrative category, [ADMINCATST Admin category at start of episode, [ADMISORC Source of admission, [ADMISTAT Psychiatric history on admission, [AEKEY Record identifier, [ALCDIAG Principal alcohol related diagnosis, [ALCDIAG_4 4 character concatenated alcohol related diagnosis, [ALCFRAC Principal alcohol related fraction, [AT_GP_PRACTICE Area Team of GP Practice, [AT_RESIDENCE Area Team of Residence, [AT_TREATMENT Area Team of Treatment, [BEDYEAR Bed days within the year, [CARERSI Carer support indicator, [CATEGORY Administrative & legal status of patient, [CAUSE Cause code, [CAUSE_3 Cause code - 3 characters, [CAUSE_4 Cause code - 4 characters, [CCG_GP_PRACTICE CCG of GP Practice, [CCG_RESIDENCE CCG of Residence, [CCG_RESPONSIBILITY CCG of Responsibility, [CCG_TREATMENT CCG of Treatment, [CENWARD Ward type at psychiatric census date, [CHAPTER Primary diagnosis chapter, [CLASSPAT Patient classification, No cohort data will be provided by the customer to NHS Digital Standard Data Sharing Agreement Version 1.01 - Report run on 20/03/2019 10:59 PM Page 11 of 15 Application Summary and Additional Technical Detail DARS-NIC-226185-B6C2J-v0.5 [CR_GP_PRACTICE Commissioning Region of GP Practice, [CR_RESIDENCE Commissioning Region of Residence, [CR_TREATMENT Commissioning Region of Treatment, [DIAG_3_CONCAT 3 character concatenated diagnosis, [DIAG_3_NN Diagnosis - 3 characters, [DIAG_4_CONCAT 4 character concatenated diagnosis, [DIAG_4_NN Diagnosis - 4 characters, [DIAG_NN All Diagnosis codes, [DISDATE Date of discharge, [DISDATE_UNCLN Date of discharge - Uncleaned, [DISDEST Destination on discharge, [DISFLAG Discharge episode flag, [DISMETH Method of discharge, [DISREADYDATE Discharge ready date, [DOMPROC Trust derived dominant procedure, [ELECDATE Date of decision to admit, [ELECDUR Waiting time, [ELECDUR_CALC Calculation of Elecdur, [ELECDURD Waiting time - derived, [EPIDUR Episode duration, [EPIEND Date episode ended, [EPIKEY Record identifier, [EPIORDER Episode order, [EPISTART Date episode started, [EPISTAT Episode status, [EPITYPE Episode type, [ETHNOS Ethnic category, [FAE Finished Admission Episode, [FAE_EMERGENCY Finished Admission Episode, emergency classification, [FCE Finished Consultant Episode, [FCEFLAG Finished consultant episode flag, [FDE Finished In-Year Discharge Episode, [FYEAR Financial Year, [GORTREAT Government office region of treatment, [HESID_ORIG Patient ID - HES generated (original), [IMD04 IMD Index of Multiple Deprivation, [IMD04_DECILE IMD Decile Group, [IMD04RK IMD Overall Rank, [INTMANIG Intended management, [INYRFLAG In Year flag, [MAINSPEF Main specialty, [MARSTAT Marital status (psychiatric), [NUMACP Number of augmented care periods within episode, [OACODE6 Census Output Area, 2001 (6 character), [OPERTN_3_CONCAT 3 character concatenated procedure, [OPERTN_3_NN All secondary Operative procedure codes - 3 character, [OPERTN_4_CONCAT 4 character concatenated procedure, [OPERTN_4_NN All secondary Operative procedure codes 4 character, [OPERTN_COUNT Total number of procedures per episode, [PARTYEAR Year and month of data, [PCTCODE06 Primary care trust of responsibility - current, [PROCODE3 Provider code - 3 character, [PROCODE5 Provider code - 5 character, [PROCODET Provider code, [PROTYPE Provider type, [PURSTHA Commissioner's Strategic Health Authority, [RESGOR Government office region of residence, [RESGOR_ONS Government office region of residence (ONS), [RESLADST Local authority district, Standard Data Sharing Agreement Version 1.01 - Report run on 20/03/2019 10:59 PM Page 12 of 15 Application Summary and Additional Technical Detail DARS-NIC-226185-B6C2J-v0.5 [RESLADST_ONS Local authority district (ONS), [RTTPEREND RTT period end date, [RTTPERSTART RTT period start date, [RTTPERSTAT RTT period status, [RURURB_IND Rural/Urban Indicator, [SEX Sex of patient, [SPELBGIN Beginning of spell, [SPELDUR Duration of spell, [SPELEND

End of spell, [STARTAGE Age at start of episode, [TRETSPEF Treatment specialty, [WAITDAYS Duration of elective wait, [WAITLIST Method of Admission - Waiting List

Hospital Episode Statistics – Accident & Emergency

[ACTIVAGE Age at activity date, [AEARRIVALMODE Arrival mode, [AEATTEND_EXC_PLANNED Attendances excluding planned, [AEATTENDCAT Attendance category, [AEATTENDDISP Attendance disposal, [AEDEPTTYPE Department type, [AEKEY Record identifier, [AEKEY_FLAG AEKEY Flag, [AEPATGROUP Patient group, [AEREFSOURCE Source of referral for A&E, [ARRIVALAGE Age on arrival, [ARRIVALDATE Arrival date, [ARRIVALTIME Arrival time, [CARERSI Carer support indicator, [DEPDUR Duration to departure, [DEPTIME Departure time, [DIAG_NN A&E diagnosis, [DIAG2_NN A&E diagnosis: 2 character, [DIAG3_NN A&E diagnosis: 3 character, [DIAGA_NN A&E diagnosis - anatomical area, [DIAGS_NN A&E diagnosis - anatomical side, [DIAGSCHEME Diagnosis Scheme in Use, [EPIKEY Record identifier, [ETHNOS Ethnic category, [FYEAR Financial Year, [IMD04 IMD Index of Multiple Deprivation, [IMD04_DECILE IMD Decile group, [IMD04RK IMD Overall rank, [NODIAGS Number of Diagnosis values, ⬚WZKKKđŐĂŶŝƐĂⱡŝŽŶĐŽĚĞ;ĐŽĚĞŽŽĎđŽ|ŝĚĞđɈ [PROCODE3 3-digit provider code, [PROCODET Provider code, [PROTYPE Provider type, [RESLADST LA district of residence, [RESLADST_ONS Local authority district (ONS), [RURURB_IND Rural/Urban Indicator, [SEX Sex of patient

Appendix 2 Abbreviations

Abbreviation	Full description
A&E	Accident and Emergency (see ED)
APC	Admitted Patient Care – dataset related to inpatient care
DARS	Data Access Request Service – Online system hosted by NHS Digital
DPO	Data Protection Officer
DSH	Data Safe Haven
DSP	Data Security and Protection Toolkit
ED	Emergency Department (See A&E)
GDPR	General Data Protection Regulation
HES	Hospital Episode Statistics
ICAHR	Institute for Clinical and Applied Health Research, University of Hull