

lechyd Cyhoeddus Cymru Public Health Wales

SUBSTANCE MISUSE PROGRAMME

The Linked Environment for Alcohol Death Research (LEADR)

Overview and Initial findings

About Public Health Wales

Public Health Wales exists to protect and improve health and wellbeing and reduce health inequalities for people in Wales. We work locally, nationally and internationally, with our partners and communities.

The Substance Misuse Programme works to address both the current and emerging public health threats in Wales and in line with the overarching strategic objective to 'reduce health inequalities, and prevent or reduce communicable and non-communicable disease, wider harms and premature death related to drugs and alcohol'.

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LEADR – initial findings



I. Executive Summary

- The Linked Environment for Alcohol Deaths Research (LEADR), established in 2015, has been developed by Public Health Wales to support identification of factors that may reduce future non-communicable disease and mortality related to alcohol use in Wales
- The LEADR project utilises a 'linked environment' in which multiple datasets, are linked as required for analysis. All available data from core healthcare datasets including specialist substance misuse treatment, hospital admissions, emergency care, critical care and outpatients have successfully been linked to alcohol related death data for the 10-year period 2005 to 2014
- Further work to bring additional healthcare datasets including primary care records and datasets from non-healthcare organisations (e.g. employment and welfare data) is ongoing
- Initial analysis of the LEADR identified 4,732 cases in which death resulted from an alcohol related underlying cause, with a further 3,169 cases in which alcohol was listed as a contributory cause
- Of these 7,901 alcohol related deaths:
 - 93.8 per cent (n=7,408) of cases were found to have been previously admitted to hospital, accounting for 74,775 admissions, of which 34,820 (46.6 per cent) were related to alcohol consumption
 - 24.8 per cent (n=1,959) of cases were recorded as having been assessed by a substance misuse treatment service, with a total of 5,625 assessments recorded and a mean number of months between assessment and death of 32.1 months for women and 31.5 months for men
 - During the period 2010 to 2014, of the 3,943 individuals dying of an alcohol related condition, 79.5 per cent (n=3,138) had visited an emergency department with a total of 15,319 attendances identified and a mean time between last attendance and death of 15.4 months
- Of the 9,755 individuals admitted to hospital in 2005 with a condition related to alcohol consumption, 1,505 (15.4 per cent) died of an alcohol related condition within ten years

2. Introduction

This report provides a summary of progress in developing the Linked Environment for Alcohol Deaths Research (LEADR), details of next steps and headline analysis of the data.

LEADR, previously described as the Alcohol Deaths Database, has been developed to support the review of alcohol deaths in Wales in line with the key aims within the previous and current Welsh Government Substance Misuse Strategy Delivery Plans 2013-15 (Outcome 3.1) and 2016-18 (Outcome 3.10 iii).^{1,2}

In addition to the burden on health and mortality caused by alcohol consumption across the population, alcohol harms also represent an economic burden, with recent estimates putting the cost to the NHS at £3.5 billion per year in England alone.³ As described in the document 'Reviewing alcohol deaths to reduce future morbidity and mortality'⁴ the overarching purpose of this review process is to identify factors that may reduce future mortality related to alcohol use in Wales.

To achieve this, the aims of the review are to:

- Better understand and evidence the nature of alcohol deaths and the geographic, gender, age and socio-economic differences in alcohol deaths in Wales
- Provide a national framework for data collection, analysis and review of alcohol deaths in young people, working aged adults and older people in Wales, identifying trends over time
- Evidence the opportunities for better access, engagement and service treatment based upon historical contact with physical and mental health services and specialist substance misuse services
- Provide a mechanism for the ongoing review and development of recommendations, by a multi-disciplinary expert group, for local and national implementation bodies, to reduce future alcohol morbidity and mortality in Wales

The objectives of the review process are to:

- Provide review definitions for all individual-level and population-level alcohol deaths in Wales
- Utilising all available and robust datasets, establish a comprehensive database of alcohol mortality in Wales to include, where available, history of referral and/or engagement with specialist alcohol and other related health and mental health services

- Explore, alongside existing cross-cutting programmes e.g. child death review programme, fatal and non-fatal drug poisoning programme, a mechanism to better understand the role and impact of alcohol in deaths in young people (initially in those aged under 18 years and seeking to expand to those aged up to 24 years), and support collation of this evidence for a national thematic review of alcohol deaths in young people
- Identify and describe trends and patterns in causes of alcohol deaths, stratified by age, gender geographic area of residence and deprivation and publish findings along with recommendations for actions to reduce alcohol deaths in Wales
- Identify themes and patterns in relation to the dynamic relationship between alcohol and mental health and ensure findings are highlighted in order to promote effective engagement with those experiencing problems with both alcohol and mental health
- With Welsh Government, ensure the structures and mechanisms are appropriate and effective for the ongoing review of alcohol deaths and implementation of recommendations and interventions to reduce alcohol deaths in the future

3. Definitions and terminology

The figures most commonly used to report alcohol related deaths are those produced by the Office for National Statistics (ONS).⁵ The ONS selects cases based on codes for medical conditions (produced by the World Health Organisation and known as the International Classification of Diseases 10th edition, or ICD-10) that are included on all death records. The 'alcohol related' codes and conditions used by the ONS are provided in Appendix 1.

Every death record includes an 'underlying' cause of death, which is "the disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury".⁵ The record will also contain 'contributory' causes which were associated with the death. The ONS routinely reports cases in which an alcohol related condition was listed as the underlying cause of death. However, it has been estimated that there are a substantial number of additional deaths in which alcohol is recorded as a contributory cause and that these should be considered in reviewing and developing effective alcohol strategies.⁴

In this report the term 'alcohol related conditions' refers to those conditions within the ONS definition, provided in Appendix I. Unless otherwise specified, 'alcohol related deaths' refers to deaths in which an alcohol related condition was listed on the death record as an underlying or contributory cause. Note that where a distinction between cases with an alcohol related underlying cause and an alcohol related contributory cause are discussed, the cases with a contributory cause are additional to those with an underlying cause: there is no overlap between these categories.

Finally, it should be noted that further definitions of alcohol attributable deaths have been developed to reflect the wider impact of alcohol on morbidity and mortality.⁶ These definitions identify conditions which are 'wholly alcohol attributable' and those which are 'partially alcohol attributable' when considered across the population as a whole, and are commonly referred to as 'Alcohol Attributable Fractions' (AAF).⁶ The list of 'wholly alcohol attributable' conditions is comparable to, and overlaps with, the ONS definition of 'alcohol related' deaths. Appendix I includes details of AAF 'wholly attributable' conditions. AAF definitions are potentially of value in future analysis of the LEADR; however, in this report, for clarity, they are only briefly summarised in comparison with ONS figures in section 5.1.1. A complete list of 'partially alcohol attributable' conditions, including the relevant attributable proportions by age and gender can be accessed at http://www.cph.org.uk/wp-content/uploads/2014/03/24892-ALCOHOL-FRACTIONS-REPORT-A4-singles-24.3.14.pdf.

4. Development of the LEADR

4.1 Overview

As described in 'Reviewing alcohol deaths to reduce future morbidity and mortality',⁴ the alcohol review process is based on linking data on deaths related to alcohol to other person-level datasets, in particular those related to healthcare and substance misuse treatment.

4.2 Healthcare data

The following datasets are currently available within the LEADR to be linked to the Office for National Statistics (ONS) alcohol related death data:

- Admitted Patient Care (APC) dataset: data related to admission of residents of Wales to hospital, including date of admission, length of stay, mode of admission, conditions identified during admission and demographic details of the patient
- **Critical Care Dataset (CCD) dataset:** data related to patients resident in Wales who require intensive care and monitoring
- Emergency Department Data Set (EDDS): data relating to patients resident in Wales seen in emergency departments
- **Outpatient Dataset (OPD)**: data relating to appointments of patients resident in Wales in hospital outpatient departments

Given the purposes of the LEADR, historical hospital admission data is considered to be of sufficient quality from 1999 onwards, when assignment of valid NHS numbers to admissions consistently achieved required standards. Emergency data available for linking to the LEADR is available with a consistent level of data quality from 2009. In terms of current data quality for the recording of NHS numbers on patient records, the most recent report from NHS Wales Informatics Service (NWIS)⁷ indicated that all Welsh health boards had achieved the agreed standard of recording the patient's NHS number in for 95 per cent or more hospital admissions. For emergency department activity, the 95 per cent or greater standard had been achieved across all Welsh providers, although there was some variation by emergency department⁸. The standard of 98 per cent or greater recording of NHS number for outpatient appointments was achieved across all Welsh providers⁹ as was the standard of 95 per cent for data relating to critical care.¹⁰

4.3 Substance misuse treatment data

Substance misuse treatment data for Wales is held on the Welsh National Database for Substance Misuse (WNDSM). The WNDSM began gathering data in 2006, with data going back to 2005 available on the database. However, for the purposes of data matching, WNDSM data from 2014 onwards included NHS numbers whereas data prior to 2014 did not. As such, the agreed process of data matching, as defined by NWIS, was undertaken thereby enabling those records to be linked to the LEADR. The process for this is provided in Appendix 2.

4.4 Child Death Review Programme

As set out in the document 'Reviewing alcohol deaths to reduce future morbidity and mortality',⁴ the alcohol review process has engaged with the Child Death Review Programme (CDRP) within Public Health Wales, to explore how data relating to deaths from alcohol amongst young people from different sources is gathered and analysed. The CDRP team recognise the relevance of considering alcohol as a factor in deaths amongst younger people, with the recent review on deaths through drowning amongst children and young people aged up to 24 in Wales reporting that eight of the 26 cases were linked to alcohol consumption¹¹. The CDRP is evolving its approaches to analysing data and we will continue to engage with the CDRP over this period as we evaluate future opportunities for a detailed study of the role of alcohol in the deaths of young people.

4.5 Access to additional healthcare datasets

The recording of healthcare data continues to evolve across the NHS in Wales, and we have liaised extensively with organisations that produce and/or hold data relevant to the LEADR project. Ongoing work includes:

- Work with those who produce and hold primary care data with a view to gaining access to basic details of primary care attendance, alcohol advice provided and alcohol-related behaviour reported by patients. A proposal to gain access to this data was submitted to Data Quality System Governance Group, which manages access to primary care data, in July 2016. The LEADR project is scheduled to present to this group in January 2017
- Data from Community Mental Health Teams in Wales would be of clear value in delivering the objectives of the LEADR project. However, following engagement with relevant teams across the NHS in Wales, it has been established that these data are not nationally available at an individual level. However, work is ongoing to develop a consistent Wales-wide dataset, and we continue to monitor developments with a view to incorporating these data into the LEADR
- Discussion with the Welsh Ambulance Service Trust (WAST) to develop future methods of linking WAST data to death records

4.6 Access to non-healthcare datasets

A number of other datasets of potential value to the alcohol review process have been identified. Data from the Department for Work and Pensions (DWP) and the probation service are likely to have particular value in identifying key life transition points and potential intervention opportunities. We are in the process of developing an application to the DWP and have engaged with the Wales Probation Service via the Integrated Research, Analysis and Performance (IRAP) group to discuss further. Scoping work for these two data sources will continue through the final quarter of 2016-17, with the expectation that formal applications for data will be made in the first quarter of 2017-18, assuming data is available and linkable within the LEADR.

5. Initial analysis

5.1 Cases identified

5.1.1 Number identified and validated by different definitions

This section provides an overview of the number of cases accessible to LEADR and to validate that data in relation to figures produced by the ONS. The most recent year for which published ONS figures for the UK are available is 2014⁵ These figures include headline numbers of alcohol related deaths for Wales. A more detailed breakdown of the figures for Welsh residents is provided annually to Public Health Wales by formal arrangement with the ONS.

The ONS typically reports alcohol related deaths by year of registration rather than year of death. The median delay for these deaths to be registered is five days; however, 4 per cent of deaths registered in 2014 were registered after a delay of six months or longer. In this section of the report, figures are given for year of registration, in order to validate the numbers using ONS published data. In other sections of the report where specified, figures are given for year of death.

Using the ONS definition of an alcohol related condition (see Appendix 1) and considering the 'alcohol as underlying cause of death' data set only, a total of 4,732 cases were identified within the LEADR.^a When the analysis was extended to include cases in which an alcohol related condition was recorded as contributory, a further 3,169 cases were identified, increasing the total number of cases available to the LEADR by 67 per cent to a total of 7,901 alcohol related deaths for this period.

The annual proportion of all cases in which the alcohol related condition was listed as an underlying cause was stable, ranging from between 57.4 per cent (492 of 859) to 63.4 per cent (541 of 853) over the time period 2005-2014.

Men accounted for 64.2 per cent (n=3,039) of all cases over this period in which an alcohol related condition was listed as the underlying condition. For those cases where an alcohol related condition was recorded only as a contributory condition, the proportion was higher at 71.2 per cent (n=2,259 cases).

A brief analysis was carried out to compare cases using the ONS definition of an alcohol related condition and cases using the AAF definition of a 'wholly alcohol attributable' definition. As shown in Appendix 1, there is considerable overlap between the two definitions. A total of 7,977 cases in which an underlying or

^a There were some small anomalies with ONS published figures. The LEADR identified one additional case compared with the published ONS figures in 2005 (underlying cause coded as K746) and two additional cases in 2007 (also both coded K746). The ONS data counted one case not found on the LEADR in 2009 (code K739). The reasons for these small anomalies are not clear, but do not materially affect any analyses presented in this report.

contributory condition met either definition were registered between 2005 and 2014. Of these, 5,947 cases met both definitions, with a further 1,954 meeting only the ONS definition and 76 meeting the AAF definition only.

A comparison of the 7,901 cases identified using the ONS definition and the 6,023 cases identified using the AAF definition between 2005 and 2014 is shown by year of registration and underlying/contributory condition in Chart 1.



Chart I: Cases of ONS definition 'alcohol related' and AAF 'wholly alcohol attributable' deaths, underlying and contributory causes, 2005-14, by position of condition on death record

5.1.2 Deaths from underlying and contributory conditions by age and local authority

Of the 7,901 cases registered between 2004 and 2015 and meeting the ONS definition, the mean age of those dying from an underlying alcohol related cause

was 60 years and 9 months for women and 55 years and 8 months for men. For those cases where an alcohol related cause was listed as contributory, the mean was 58 years for women and 56 years and 8 months for men. The most frequently observed five-year age band at death was 55-59 where the alcohol related condition was listed as underlying cause (708 cases). The most frequently observed age band where the cause was contributory was 60-64 (365 cases). Deaths over the period 2005-14 from both underlying and contributory causes by age are shown in Chart 2.





Chart 2: Deaths from underlying and contributory alcohol related causes, 2005-14, by age band

The local authority with the highest European age standardised rate (EASR) of deaths from an alcohol related underlying cause registered in 2014 was Torfaen, with 24.4 deaths per 100,000 population. The lowest rate was recorded in Powys with 4.7 per 100,000. The highest rate for deaths from contributory alcohol related causes was seen in Caerphilly (17 per 100,000 population) with the Denbighshire recording the lowest rate (2.8 per 100,000 population).

EASRs of alcohol related deaths by underlying and contributory causes per 100,000 population are shown in Chart 3.



Chart 3: EASR of alcohol related deaths per 100,000 population in 2014 by local authority

5.2 Alcohol deaths and hospital admissions

5.2.1 Overview

The dataset for this analysis included deaths occurring between 2005 and 2014, allowing for ten years of data to be analysed. As before, in order to establish admissions relating to those dying in 2005, further assessment of hospital admissions data from 1991 onwards was included. 5,206 admissions of the 74,755 included in this analysis were recorded between 1991 and 1998, 7 per cent of the total.

Of the 7,901 cases of death from alcohol related underlying or contributory conditions between 2005 and 2014, 93.8 per cent (n=7,408) were recorded as having been previously admitted to hospital. For cases where the death was from an underlying alcohol related cause, the proportion admitted to hospital at any point was 95.7 per cent (n=4,526); where an alcohol related condition was a contributory cause, the proportion was 91.3 per cent (n=2,882).

The total number of admissions for these 7,408 cases was 74,775, a mean of 10.1 admissions per case. Of these admissions, 34,820 included an alcohol related condition recorded in any position on the admission record, meaning that each case was admitted to hospital a mean of 4.7 times for conditions related to alcohol consumption. The mean length of stay in hospital following admission was 5.4 days for all admissions and 6.2 days for alcohol related admissions.

The majority, 62.5 per cent (n=46,752), of all admissions were categorised as 'emergency' admissions. Where an alcohol related condition was recorded, the admission was substantially more likely to be categorised as an emergency accounting for 83 per cent (n=28,898) of all alcohol related admissions. Categorisation was unavailable for 10 admissions (<0.001 per cent).

Type of hospital was recorded for 90.5 per cent (n=67,701) of all admissions (both alcohol and non-alcohol related). The majority, 91.2 per cent (n=61,738), of all admissions were to a general hospital; 2.7 per cent (n=1,804) admissions were to a psychiatric hospital. Of the 32,915 alcohol related admissions for which the type of hospital was available, 2.8 per cent (n=922) were to psychiatric hospitals.

5.2.2 Date of hospital admission and date of death

Given the focus of the alcohol review process on identifying intervention opportunities, analysis of the temporal relationship between healthcare contact and alcohol related deaths is particularly relevant. Considering all 74,775 hospital admissions (both alcohol and non-alcohol related) for all 7,408 cases, the mean time between hospital admission and death was 44.7 months. Excluding those admissions during which the individual died, there were 70,230 admissions, with a mean time of 48.9 months between admission and death. For the 34,820 alcohol related admissions the mean time between admission and death was 29.3 months for all alcohol related admissions and 34.1 months for the 30,810 alcohol related remaining when admissions during which the individual died are excluded.

Chart 4 represents the time between admission and death for alcohol related and non-alcohol related admissions, excluding those admissions ending in death and including only those admissions occurring ten years or less prior to death:



Chart 4: Months between admission and death, by type of admission. All admissions for cases of death occurring 2005-14 in which an underlying or contributory alcohol related condition were recorded. Admission more than 10 years prior to death and admissions during which the patient died are excluded

In addition to looking back from the point of death, the data can also be analysed by looking forward from a cohort of patients admitted over a specific time period and considering their outcomes – survival analysis.

In 2005, 9,755 individuals were admitted to hospital with an alcohol related condition, as defined by the ONS, recorded in any position on the admission record.[†] These individuals accounted for a total of 14,670 admissions over the period. Of these 9,755 individuals admitted, 10.4 per cent (n=1,017) would go on to die of an underlying alcohol related condition within the next ten years, with a further 488 (5 per cent) dying in the next ten years with an alcohol related condition listed as a contributory cause. The number of deaths per year between 2005 and 2014 amongst those who were admitted to hospital with an alcohol related condition during 2005 are shown in Chart 5.



Alcohol related underlying cause

Chart 5: Deaths from alcohol related conditions, 2005-14, amongst those admitted to hospital with an alcohol related condition in any position in 2005

[†] No distinction is made here of whether it was the first admissions for each individual. Further analysis of this and future data will enable greater detail on survival from first admission.

5.3 Alcohol deaths and emergency department attendances

5.3.1 Overview

Given that emergency department (ED) data is only consistently available to the LEADR from 2009 onwards, the dataset for analysis in this report includes cases in which death from an alcohol related underlying or contributory condition occurred between 2010 and 2014.

Of the 3,943 cases over the period in which an alcohol related underlying or contributory condition was recorded, 79.5 per cent (n=3,138) were recorded as attending an ED at some point prior to death. There were 15,319 attendances recorded for these cases, a mean of 4.9 ED attendances per case. The majority, 65.9 per cent (n=10,091) of these attendances involved arrival by ambulance.

Details on what or who prompted the ED attendance were available for 92 per cent (n=14,101). Of these, self-referral was reported by 45.7 per cent (n=6,450) with a further 33.8 per cent (n=4,771) brought in / advised to attend by the emergency services. The attendances resulted in a total of 62,446 patient hours spent in EDs, a mean of 4 hours and 5 minutes per attendance.

There is a field in which Alcohol can be recorded under 'type of attendance' on ED datasets. However, this field was only completed for 37.7 per cent (n=5,768) of attendances and the low completion rate suggests that relatively little can be inferred from this data.

5.3.2 Outcomes recorded following emergency department attendance

Outcome of ED attendance was recorded for 15,062 attendances, 98.3 per cent of all attendances. Of these, 43.5 per cent of attendances was recorded as admitted to hospital (N=6,558 attendances); 25.3 per cent (n=3,806) were recorded for 'no follow-up', and 'self-discharge' was recorded for 8.1 per cent (n=1,22). In a total of 173 attendances (1.2 per cent) the individual was recorded as being dead on arrival or dying in the ED.

5.3.3 Date of emergency department attendance and date of death

As noted above, the aims and objectives of the alcohol review process mean that the capacity to analyse time between ED attendances and death from alcohol related causes is an important aspect of the LEADR. It should be noted again that ED data is available for a considerably shorter time period (since 1999) than data for hospital admissions.

Hospital admissions in which the individual died in hospital are particularly relevant to the aims and objectives of the alcohol review process. As noted above, only a very small proportion, 1.2 per cent, of those seen in ED were recorded as dying within that department and there is no data item within the ED dataset that indicates whether the individual subsequently died following hospital admission[‡]. Therefore, analysis here includes all attendances (15,319 attendances) and all attendances excluding those during which the individual was recorded as having died and those in which the individual died within the seven days following attendance (14,429 attendances).

[‡] Ongoing development of the LEADR may allow more sophisticated analysis including ONS, hospital admission and emergency department datasets to enable this

There was a mean of 15.4 months between ED attendance and death amongst those who died of alcohol related underlying or contributory causes between 2010 and 2014. Excluding those who died within the emergency department or within 7 days of attendance the mean was 16.4 months.

The mean age at which these individuals attended ED was 52 years and 4 months for men and 53 years and 9 months for women. This mean is the same for all attendances and attendances excluding those who died within seven days. However, analysis of the distribution of age of attendance shows that 4.4 per cent (633 attendances) of all attendances excluding those who died within seven days involved individuals under 30 years of age, with a total of 17.3 per cent (2,491 attendances) accounted for by individuals under 40. The most frequently recorded five-year age band was 45-49 accounting for 14.9 per cent (2,146 attendances). The distribution of ED attendances by age band is shown in Chart 6 below.



Male

Chart 6: Age band and gender at emergency department attendance for all attendances involving individuals who died of an alcohol related underlying or contributory cause between 2010 and 2014. Data excludes attendances of individuals who died during emergency department attendance or within seven days

The time in months between ED attendance and death is shown by age band at point of attendance in Chart 7.



Chart 7: Age band at emergency department attendance for all attendances involving individuals who died of an alcohol related underlying or contributory cause between 2010 and 2014, by month prior to death of attendance. Data excludes attendances of individuals who died during ED attendance or within seven days

5.4 Alcohol deaths by underlying cause

Over 66 per cent (3133 deaths) of the 4,732 deaths from an underlying alcohol specific cause in Wales registered between 2005 and 2014 were due to alcoholic liver disease. One in five (978 deaths) were due to fibrosis and cirrhosis of the liver, with deaths coded as 'mental and behavioural disorders due to alcohol' the third most frequently recorded underlying cause (340 deaths). Although the proportions of deaths amongst those aged 50-74 due to specified underlying causes were very similar between genders, a higher proportion of women aged 25-49 died with alcoholic liver disease recorded as the underlying cause (74.9 per cent) compared with men (68.9 per cent), but a lower proportion of women (5.1 per cent) were recorded with 'mental and behavioural disorders' or 'accidental poisoning by alcohol' as the underlying cause of death compared with men (11.8 per cent).



Chart 8: Deaths from underlying alcohol related causes, 2005-14, by age group, gender and cause of death

5.5 Alcohol deaths by deprivation

The Welsh Index of multiple deprivation (WIMD)[§] that allows for comparison of overall deprivation rank for small areas, comparing across 8 domains of deprivation including income, health employment, education and access to services. Utilising this data in relation to alcohol specific deaths between 2006-15, a clear picture emerges with the highest rates of death occurring in the 10% most deprived areas (16.3 per cent) and an almost linear decline in the percentage of all alcohol specific deaths to the 10% least deprived, with 4.7 percent of these deaths as shown in Chart 9.



Chart 9: Proportion of deaths from underlying alcohol related causes 2006-2015, by multiple deprivation decile in Wales

[§] Welsh Government. Welsh Index of Multiple Deprivation 2014. Available at: www.gov.wales/docs/statistics/2015/150812-wimd-2014-summary-revised-en.pdf

5.6 Alcohol deaths and treatment

All cases in which an alcohol related underlying or contributory condition was recorded on the death record between 2005 and 2014 are reported on here. Cases were matched to treatment records held on the WNDSM, which holds data for the same period. Therefore records of assessments prior to 2005 are not available. Of the 7,901 cases identified between 2004 and 2015, 1,959 (24.8 per cent) were recorded as having been assessed by a specialist substance misuse treatment service at some point prior to death. Of those assessed, 1,355 (69.2 per cent) were men and 604 (30.9 per cent) were women.

Of the 5,275 men who died of an alcohol related underlying or contributory condition between 2005 and 2014, 25.7 per cent were recorded as assessed by a substance misuse treatment service; for the 2,612 women who died of an alcohol related cause over this period, the proportion assessed was 23.1 per cent.

There were 5,625 assessments recorded for the 1,959 cases, with a mean number of 4.2 assessments per person. The mean age at assessment was 44 years and 2 months for men and 45 and 9 months for women. The mean number of months between assessment and death was 32.1 months for women and 31.5 months for men. All assessments are shown by gender and by the number of months prior to death in Chart 10.



Chart 10: Months prior to death of assessment by substance misuse service, all those dying of underlying or contributory alcohol related condition between 2005 and 2014, by age at death of individual

5.7 Further analysis

In addition to bringing in additional datasets, as described in Section 4.5 and 4.6 above, the next stage of analysis will be to bring together a wider range of data from multiple sources into a single dataset that will support more sophisticated analyses. This work is expected to include themes and questions such as:

- Analysis of subgroups within the datasets, in particular how the experiences of those of different age groups and who died of different categories of alcohol related deaths may vary systematically
- How do the trajectories of those in different age bands differ? Is there evidence of different levels of engagement with treatment services by area and what factors might explain any variation? Do women typically encounter serious/chronic health problems at an earlier age than men? Does deprivation mediate access to treatment?
- More complex investigation of the relationships between engagement with different forms of healthcare and outcomes
- What is the relationship between admission to hospital with an alcohol related condition and treatment assessment? Is frequency of hospital stay and/or emergency department attendance related to engagement with treatment?
- More detailed analysis of the experiences of individuals with benefits, employment and criminal justice services

As one of the key aims of this work is to evidence the opportunities for better access, engagement and service treatment based upon historical contact with physical and mental health services and specialist substance misuse services, further analysis and recommendations will be published to highlight opportunities and current gaps and inequity in services. In particular, the LEADR anticipates looking in some detail at the trajectories and service engagement of those under 50, as deaths amongst this demographic represent a particular opportunity to address alcohol related premature mortality.

In addition, focus will be given to early identification and prevention of noncommunicable disease and premature deaths related to alcohol and, following economic evaluation of the current costs associated with care as identified by the LEADR, recommendations for commissioning and service restructure and provision.

Appendix 1: Alcohol related and wholly alcohol attributable conditions

Table I sets out the medical conditions and their associated ICD-10 codes that are defined as 'alcohol related' by the ONS and/or 'wholly alcohol attributable' by the Alcohol Attributable Fractions. Note that the AAF definition is applicable to both mortality and morbidity and therefore may include conditions that would not typically be included on death records.

Table 1: Conditions considered to be 'alcohol related' or 'wholly alcoholattributable' as defined by the ONS and the Alcohol AttributableFractions respectively

Condition	Code	Included in ONS definition?	Included in AAF definition?
Alcohol-induced pseudo- Cushing's syndrome	E24.4		\checkmark
Mental and behavioural disorders due to use of alcohol	F10*	√	✓
Degeneration of nervous system due to alcohol	G31.2	~	~
Alcoholic polyneuropathy	G62.1	\checkmark	✓
Alcoholic myopathy	G72.1		\checkmark
Alcoholic cardiomyopathy	142.6	\checkmark	\checkmark
Alcoholic gastritis	К29.2	\checkmark	\checkmark
Alcoholic liver disease	K70*	\checkmark	\checkmark
Chronic hepatitis, not elsewhere classified	K73*	~	
Fibrosis and cirrhosis of liver	K74 (Excluding K74.3-K74.5 - Biliary cirrhosis)	~	
Alcohol-induced acute pancreatitis	K85.2		~

Alcohol-induced chronic	K86.0				
pancreatitis		V	V		
Foetal alcohol syndrome	Q86.0		1		
(dysmorphic)			•		
	D 70 0				
Excess alcohol blood levels	K/8.0		V		
Ethanol poisoning	T51.0		✓		
			•		
Methanol poisoning	T51.1		\checkmark		
Toxic effect of alcohol,	T51.9		1		
unspecified			-		
A soldental soles ning hu and	V4F*				
Accidental poisoning by and	A43 ¹	\checkmark	\checkmark		
exposure to alconol					
Intentional self-poisoning by	X65*				
and exposure to alcohol		\checkmark	\checkmark		
Poisoning by and exposure to	Y15*		1		
alcohol, undetermined intent		v	v		
Evidence of alcohol	190				
involvement determined by			~		
blood alcohol level					
Evidence of alcohol	Y91				
involvement determined by			\checkmark		
level of intoxication					
*includes all four character codes falling under this three character code					

Appendix 2 - Development of the LEADR process

The majority of core healthcare datasets relevant to the aims of the alcohol review process are received and administered by the NHS Wales Informatics Service (NWIS). Following extensive discussion with NWIS, linking of relevant person-level datasets within the NWIS data warehouse environment was identified as the optimal solution capable of providing the most complete and detailed data whilst ensuring secure information governance arrangements and robust technical infrastructure. The 'alcohol deaths database' was therefore renamed the Linked Environment for Alcohol Deaths Research (LEADR) to reflect this evolution in its development.

NWIS provided access to a defined 'view' (essentially, a 'virtual table' within the data warehouse) that selects death data relevant to the alcohol review process from the Office for National Statistics (ONS) death data. This 'LEADR alcohol related death data view' allows the relevant death data to be linked to patient and treatment records via a pseudonymised patient ID derived from an individual's NHS number, but not traceable back to that NHS number by analysts using the LEADR. This creates a 'linked environment' in which detailed analysis can take place. Personal identifiable data, such as date of birth and home postcode, have been removed from this data, but relevant demographic details, such as local authority of residence or age at death are available for analysis.

The LEADR alcohol related death data view

The foundation of the LEADR is data on alcohol related deaths provided by the ONS. Details of all registrations of deaths of Welsh residents are held within the NWIS data warehouse. The LEADR alcohol related death data view lists all cases of alcohol related deaths at a person level and includes details of all conditions recorded on each death record, core demographic data including age, gender and area of residence at death, and a reference number allowing linkage to the Child Death Review database (see below). The LEADR alcohol related death data view will be updated monthly with new death registrations.

As briefly described above, individuals appearing on the ONS death data (and therefore on the LEADR alcohol related death data view) and on the healthcare datasets described below are identified by a unique pseudonymised person ID. This person ID is derived from, but not traceable to, an individual's NHS number. Data linkage therefore depends on accurate and reliable recording of NHS numbers on datasets. Note that in nine cases of alcohol related deaths between 2005 and 2014 (representing less than 0.01 per cent of all alcohol related deaths occurring or registered over that period), no record of the NHS number was available to the LEADR. These cases cannot therefore be linked with other datasets. Data quality in relation to NHS number availability for other datasets is discussed in Section 4.2.3 below. Data for analysis are created when a specific

query developed by the analyst links data via the person ID on each dataset. This linkage produces a temporary table to be used by the analyst. A representative schematic of the process is shown in Figure 1 below.



Process for all records from the Welsh National Database for Wales (WNDSM) without an existing NHS number to be data-matched:

- Identify records that currently include an NHS number
- Use other person identifiable data (e.g. initials, date of birth, gender) within the record to derive an NHS number from other NWIS data sources
- Check rate of matching of known NHS numbers against derived NHS numbers for different combinations of other person identifiable data
- Based on the proportions of NHS numbers correctly identified, incorrectly identified and not identified, identify the preferred combination of personal data from which to derive NHS numbers where one is not available

Analysis by NWIS on WNDSM data from 2010 onwards established that 48 per cent of all records contained a valid NHS number. Three different combinations of personal identifiable information were used to match these records to NHS numbers. These combinations matched records with (1) greater than 90 per cent probability of accuracy (2) 80-90 per cent accuracy and (3) 50-80 per cent accuracy. Applying each of these protocols in turn to the entire dataset from 2010 onwards produced the results summarised in Table 2.

NHS Number Status	Number	Percentage
Record includes valid NHS number	37,979	48%
NHS Number identified with probability >90%	33,893	43%
NHS Number identified with probability 80-90%	1,333	2%
NHS Number identified with probability 50-80%	3,618	5%
No NHS number identified	2,773	3%
Total	79,596	100%

Table2: number and percentage of WNDSM records (2010 onwards) with valid NHS number and additional records identified with different matching protocols

Based on the process outlined above and balancing the risks of losing relevant data with the probability of 'false positives', we have selected the matching protocol with 80-90 per cent probability of accuracy to identify those WNDSM records without a valid NHS number.

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