End of Life Care for people with alcohol and other drug problems

Report on Strand 2:

Scoping review of existing database evidence.

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Acknowledgements

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SUMMARY

The purpose of this study was to establish the prevalence and incidence of people with problematic substance use receiving or in need of end of life and palliative care. A strategic search for available databases, datasets and reports based on datasets was carried out, supported by consultation with key informants for further sources of data. The sources of evidence found, however, do not directly identify this population group. The findings indicate that data is not routinely recorded that specifies whether a person receiving hospital, hospice or community end of life care has, or has had, problems with substance use. Neither does data from substance use treatment populations include any record of end of life care.

In the UK, and more specifically in England, data on deaths, treatment episodes and diagnoses are routinely recorded by via Hospital Episode Statistics (HES), General Practitioner Records (GPRD) and coroner reports, all of which are collated by the Office for National Statistics (ONS). It is from these key sources that national, regional and specific Care Commissioning Group (CCG) data on patient care pathways can be examined. However, the reliance on medical diagnostics and reporting in this data collection, using international and standardised categories, restricts the identification of people with problematic substance use who are in need of end of life care. Additional sources of data exist which facilitate access to samples of patient groups, such as medical and organisational audits, but these resources do not specify this target population and consist of opportunistic or generic samples from which wider population estimates would be unreliable. In order to define and examine this target population more readily, dataset merging and access to patient records would be required.

This report focuses on what is known about people who are or have been in need of end of life care, and are likely to have a history of substance use problems. Estimates using disease type as proxy indicators to identify likely cases are currently the only viable approach but it needs to be recognised that use of proxy variables affects the accuracy of any estimates of frequencies.

Key Findings

- People with problematic substance use and end of life care needs cannot currently be directly identified in any single health or population database or dataset.

- Using freely available data, such target cases can only be estimated using proxy variables such as disease type, cause of death and place of death. This presents sensitivity and specificity problems for identification of all cases (sensitivity) and excludes non-cases (specificity).

- Data from the Office for National Statistics and Hospital Episode Statistics are currently the most reliable sources of freely available data from which to identify and calculate prevalence and incidence of end of life care for people with substance use problems, using cause of death and treatment episodes as indirect indicators of cases.

- Other direct sources of medical diagnostic data for this target population stem from end of life care records but these are currently poorly reported and do not facilitate accurate surveillance or monitoring.

- Reliance on medically determined diagnoses and cause of death excludes target cases where their end of life care need is unrelated or only indirectly related to substance use.

- People with problematic alcohol use may be easier to identify via morbidity and mortality diagnoses than people with problematic illicit drug use. This is because there is a narrower range of chronic diseases associated with alcohol use than drug use.

- For people with problematic illicit drug use, existing data relating to disease type are not useful for case identification because of the wide range of diseases associated with illicit drug use. As there is no 'typical' disease profile, it is not possible to extract these cases from others in which there is no illicit drug use (decreased specificity).

- Databases monitoring problematic illicit drug users receiving treatment for their substance use only identify cases within drug treatment services, and only record their substance use treatment and reason for treatment exit, such as 'died'. Therefore end of life care is not traceable via these databases, and such databases will not record people with problematic illicit drug use who do not use treatment services.

- To obtain more accurate and reliable prevalence and incidence of end of life care for people with problematic substance use it will be necessary to combine existing datasets and access patient records.

1. Introduction

This report identifies and explores existing prevalence and incidence data indicative of end of life care received by people with problematic substance use. The definition of the target population for this investigation included all people with existing problematic use of alcohol or illicit drugs. 'Illicit drugs' in this case refers to drugs listed under the Misuse of Drugs Act 1971. Use of tobacco as a substance is excluded as it goes beyond the remit of this scoping study.

According to the Office for National Statistics (ONS), just under half of all deaths in England and Wales take place in hospital (48%), with roughly a quarter at home (23%), or in care homes (22%), while only about 6% of people die in a hospice (ONS, 2016a). Place of death is a focus for a substantial amount of policy interest and is seen as indicative of the extent to which a dying person's wishes are met. However, commentators indicate that it is important to recognise that preferences are only known for a small proportion of the population and preferences can change, and meeting preferences may not be medically advisable for everyone (National Audit Office, 2008; Abel et al., 2009). Therefore *where* someone dies may be indicative of medical need as much as resource availability or social discrimination. Some evidence indicates that people with lower social economic status may find it harder to access good quality end of life care (Wilson et al., 2009), while people with non-cancer diagnoses are less likely to receive specialist hospice care (Dixon et al., 2015). There is therefore a recognised gap in provision of specialist end of life care, with reduced access and provision for people with non-cancer conditions. This gap in provision is not wholly explained by differences in clinical need or variations in local provision (Dixon et al., 2015). This scoping study aims to explore data that may reveal further discrepancies in provision for people with problematic substance use, and identify possible explanations for such discrepancies.

1.1. Background

The recent report from Public Health England on life expectancies indicates that life expectancy has increased in the last 30 years for older adults (at ages 65, 75, 85 and 95) and continues to rise incrementally for both genders (PHE, 2016a). At the same time, the demographic age profile of the UK is changing, with a disproportionate growth of people over 65 (Dixon et al., 2015). This ageing profile is mirrored in the population of drug users in the UK. According to Beynon and Lawson, (2010), evidence from sources such as the National Drug Treatment Monitoring System (NDTMS) and the British Crime Survey indicates that the average age of drug users accessing treatment is rising, with higher proportions of treatment admissions for people over 40. This is likely to be

explained by the reduction in younger people using drugs and needing treatment, and the cohort of users from the 1980s and 1990s surviving into older age. Among alcohol users, while the estimates for rates of alcohol use among young people have started to reduce (NHS Digital, 2015), older people still drink more frequently than younger people (Fuller, 2015) and alcohol is currently among the top three lifestyle risk factors of death, contributing 10% of the burden of disease and death in the UK (Baker, House of Commons Health Committee, 2017).

1.2. Overview: End of Life Care

People are regarded as in need of end of life care in the UK when they are considered to be in the last 12 months of life. Most end of life care in the UK is co-ordinated at primary care level: delivered through community care in which people receive care in their own homes, in a nursing home or a day or out-patient facility. End of life care is also provided through in-patient stays in specialist hospices, or during in-patient stay in hospital (NHS Choices, 2017). End of life care may be delivered by third sector specialist hospice providers, National Health Service end of life care staff or private healthcare providers.

End of life care is regarded as part of palliative care which is defined as holistic care applicable at both early and late stages of a terminal illness (Dixon et al., 2015). Each primary care provider is required to register patients in need of palliative care on a Palliative Care Register. Whilst Palliative Care Registers (PCRs) generally provide patients with access to better care through identification of need and coordination of the primary care team (Thomas et al., 2012; Collins, 2004; NICE, 2004), the lack of a standard working definition for a 'palliative patient' impedes the systematic inclusion of all patients (Mitchell et al., 2013; Shaw et al., 2010; Shipman et al., 2008). By 2009, only about 25% of patients who died were included on a palliative care register, over two-thirds being cancer patients (Omega, 2010). Therefore, initiatives such as The End of Life Care Strategy (Department of Health, 2008) and The NICE Quality Standard for End of Life Care (NICE, 2011) were introduced to improve care in the last year of life with improved recognition of end of life conditions and referrals to end of life care services. They also aimed to widen end of life care to people with a non-cancer diagnosis, and optimise people's choice of where they died. The degree to which these initiatives are successful in relation to a substance using population is discussed later in this report.

Approximately one per cent of the population in England and Wales die per year, equating to half a million deaths. The majority of deaths (85%) occur for people aged over 75. The main causes of

death are cancer (28%) and circulatory diseases (26%) (ONS, 2016a). Just under half of deaths take place in hospital (48%), with roughly a quarter at home (23%), or in care homes (22%), and only about 6% of people die in a hospice (ONS, 2016a). Place of death is a focus for a substantial amount of policy interest; seen as indicative of the extent to which a dying person's wishes are met. However, it is important to remember that: (1) preferences are only known for a small proportion of the population; (2) preferences can change; and (3) meeting preferences may not be medically advisable for everyone (National Audit Office, 2008; Abel et al., 2009). According to Hospice UK (2016), approximately 200,000 people received some form of support from hospices in the UK each year with approximately 48,000 of these receiving continued inpatient care, while 796,000 received some form of overnight hospice stay. Other forms of end of life care used include hospice service attendance in hospital settings, in the home or in a day centre. Data from the Public Health England End of Life Care Profiles (2017) indicate that, in 2015, 46.7% of end of life care patients died in hospital, 5.6% died in a hospice, 22.8% died in their own home, 22.6% died in a care home, and 2.2% died in 'other' places (not specified). The data illustrate the spread of end of life care delivery at the point of death, and it is not to be assumed from this data that there is a difference in quality of care associated with different localities of death, as they may be explained equally as clinical need, preference or lack or resources, but the differences need to be explored in the light of concerns over disproportionate delivery of care in hospices to cancer patients.

It is recognised that cancer is over-represented in hospice referrals. Over 80% of hospice inpatient cases in 2016 were cancer referrals, and people with other diagnoses were not referred even though potentially benefitting from hospice care (Hospice UK, 2016). Many non-cancer patients are referred later in the disease course than cancer patients (Zheng et al., 2013). Evidence from the Royal College of Physicians (RCP) and Marie Curie (2014) indicates that patients who die in hospital are more likely to be older and die from pneumonia (and slightly less likely to die from cancer) than the general profile of deaths. Their report (End of Life Care Audit – Dying in Hospital) surveyed up to 9302 patient cases, finding that although 93% of patients had been recognised as likely to die within five days after admission, for half of the patients this only occurred within 34 hours before death. Ninety-three per cent of patients whose death was predictable had documentation that they would probably die. A senior doctor was involved in the recognition of dying in 76% of cases. Only 25% of people recognised as being likely to die had a documented discussion about their death. This may reflect an error in documentation rather than care delivery, but 65% of these cases were reported to be unconscious or otherwise unable to understand at this stage of their end of life. This highlights the typically limited timespan for discussions around preferences for end of life care. This is also

illustrated by the median length of stay, being approximately eight days, with 17% of patients dying suddenly within four days.

The majority of patients included in the RCP audit died in medical (66%), intensive/critical care (13%) or surgical (8%) settings. It is notable that very few died in specialist palliative care units within the hospital (0.2%) or in a separate unit in hospital grounds (1%). The findings suggest a degree of unpredictability of deaths for hospital patients. This is supported by a recent UK study by Higginson et al. (2017) which finds that people with multiple morbidities and people who live in deprived areas were more likely to die in hospital than at home or in a specialist end of life care service. The implication for their study is that people with unstable or less predictable disease progressions are more likely to be taken to hospital during an acute symptom than people with predictable and controllable disease symptoms which can be managed in the community or in a hospice. A 14 year population study of over 300,000 respiratory disease deaths in the UK found that people with multiple morbidities and people who live in deprived areas and cities were more likely to die in hospital rather than at home or in a specialist end of life care service (Higginson et al., 2017). The authors suggest that the End of Life Care strategy is reducing the number of deaths in hospital for many, but where there is multi-morbidity or deprivation, a gap in the equality of care is widening. Deprivation aside, it appears that multi-morbidity may present unstable or less predictable disease progressions which are more likely to be addressed in hospital than in the community or hospice.

1.3. Overview: Substance use treatment

Records for 2015/16 from the National Statistics report 'Statistics on Drug Misuse: England 2017' (Office for National Statistics, 2017a) show an estimate of 8.4% of adults aged 16 to 59 (2.7 million people) had taken an illicit drug in the last year. Comparison with the 2005/6 survey of 10 years ago, this demonstrates a significant reduction in drug use in England (from 10.5% to 8.4%). The National Statistics report records that over 288,000 people were in contact with drug and alcohol services in 2015/16 with the majority needing treatment for opiates. Opiate users in treatment were on average older than people seeking treatment for other substances.

The Crime Survey of England and Wales 2013/14 (The Home Office, 2014) gives a breakdown of drug users by social status, finding that, in 2014,frequent drug users were more likely to be living in deprived areas (4% to 5%) compared with those in the least deprived areas (2.3%). According to the survey, males are more likely (11.8% of men) to take drugs than women (5.8% of women), and urban

living is more likely to be associated with drug use than rural living (9.3% of the urban population versus 6.5% of the rural population). These figures are supported by the National Statistics (2017a) estimates showing that, by employment status, people who were dependent on drugs were most commonly classed as economically inactive (males 9.6%, females 4.4%).

Treatment of substance use (illicit drugs and/or alcohol) in the UK takes many forms to meet multiple health and social care needs, types of substances used and different populations. Devolution of treatment service commissioning in the UK has resulted in a wide range of agency provision from statutory services, the third sector and private treatment providers. Treatment for drugs or alcohol dependence takes place in the community, in in-patient services and in prisons or in general secondary care (hospitals). Definition of treatment for substance use within the health service is regarded as both medical and psychosocial, and can consist of screening and assessment, substitute prescribing and managed dependence withdrawal, rehabilitation, psychological therapies and social support for individuals and families (Department of Health (England) and the devolved administrations (2007). It is likely that many community-based treatment providers, and even specialist in-patient drug treatment or rehabilitation services, are not equipped to manage multiple physical morbidities that people with end of life care needs are likely to present. Therefore, these physical needs are most likely to be provided by health care teams which are not specialists in substance use. Indeed, medical staff members are advised to prioritise health needs and refer substance-using patients with health needs to the relevant specialism following the general health assessment (Department of Health (England) and the devolved administrations (2007).

Details of people receiving treatment for substance use in the UK will be on the National Drug Treatment Monitoring System (NDTMS) (Public Health England, 2016b). The recent evidence from the NDTMS shows that 288,843 people were in contact with drug and alcohol services in 2015-16, with males making up 70% of the treatment population. Opiate dependent people made up the largest group of substance-dependent people in treatment at 52%. Alcohol use was the second largest treatment need with over 144,000 individuals presenting with problematic or dependent drinking. Fifty-nine percent of these required alcohol treatment only. This group is generally much older that people receiving treatment for drugs or drugs and alcohol. The median age for alcohol only treatment was 45 years, with 11% of these over 60 years old. Even so, despite the average age of drug users being 26 years old (Home Office, 2014), the median age of opiate users in treatment was 39 in the 2016 NDTMS report.

People with ongoing dependence or a history of dependence and substance use are recognised as being stigmatised and marginalised in society, with related issues such as low socio-economic status, health problems and housing needs contributing to the negative attitudes and labelling they receive (Room, 2005; Palepu et al., 2013). Reducing health inequalities is a key objective of the European Policy Framework for health and wellbeing (WHO Europe, 2012), which specifies non-communicable diseases such as alcohol-related harm as a key focus (WHO Europe, 2014).

1.4. Summary: Co-existing problematic substance use and end of life care

This study set out to explore whether or not incidence and prevalence of co-existing needs could be determined and if not, why not. People with both end of life care needs and alcohol/drug problems may present to both end of life care and substance use services. However, they are not currently being identified – neither as substance users in end of life care services, nor as in need of end of life care when accessing substance use services. This means that their co-existing needs cannot be systematically addressed. Whilst the healthcare settings and health conditions described above give some indication as to where to look for data sources, it is important to remember that an unquantifiable number of people with alcohol/other drug problems may not approach services at all.

2. Methodology

The aims of this scoping study were to:

i) Identify key sources of quantitative data on prevalence and incidence of end of life care delivered to people who have substance use problems;

ii) Identify end of life care needs of people with substance use problems;

iii) Identify the prevalence and incidence of people with co-existing problematic substance use and end of life/palliative care needs.

The main objectives were to:

- Identify and appraise key sources of patient data indicative of end of life treatment received and disease type;

- Identify and appraise key data sources of end of life care delivery;

- Identify key sources of care delivery to people with substance use morbidity;

- Critically analyse the value of the data, relating to end of life care and substance user care needs and identify anomalies and gaps in the evidence;

- Identify possible service gaps that indicate poor access or uptake of end of life care for people with substance use problems;

- Make recommendations for the improvement of data collection and availability;

- Make specific recommendations for more detailed interrogation of existing data.

2.1. Database search strategy

This investigation focused on freely available data which typically exist from single sources such as the ONS or Hospital Episode Statistics (HES). Where analysis of existing data has already been performed and reported by third parties, these findings have been included in this reporting. For example, The National End of Life Care Intelligence Network has performed an analysis of liver disease deaths based on ONS data (Effiong et al., 2012), and their findings are incorporated into this report.

This exploration and analysis followed a three-stage strategy for exploring available datasets, followed by two stages to analyse data and report findings (represented in Figure 1 below).

Stage 1 consisted of a broad search for all relevant sources of primary data and available reports based on primary or secondary data. The search for electronically stored UK data had three strands:

i) End of life and palliative care treatment delivery;

ii) Prevalence and treatment records for alcohol and illicit drug use;

iii) Prevalence and incidence records of disease/mortality associated with problematic substance use.

Reports where relevant data were analysed and/or amalgamated were also sought. This used the three topic strands as above and included medical and service audits, population, health and social care surveys, and disease-specific enquiries.

Figure 1: Flow diagram: stages of database identification and analysis
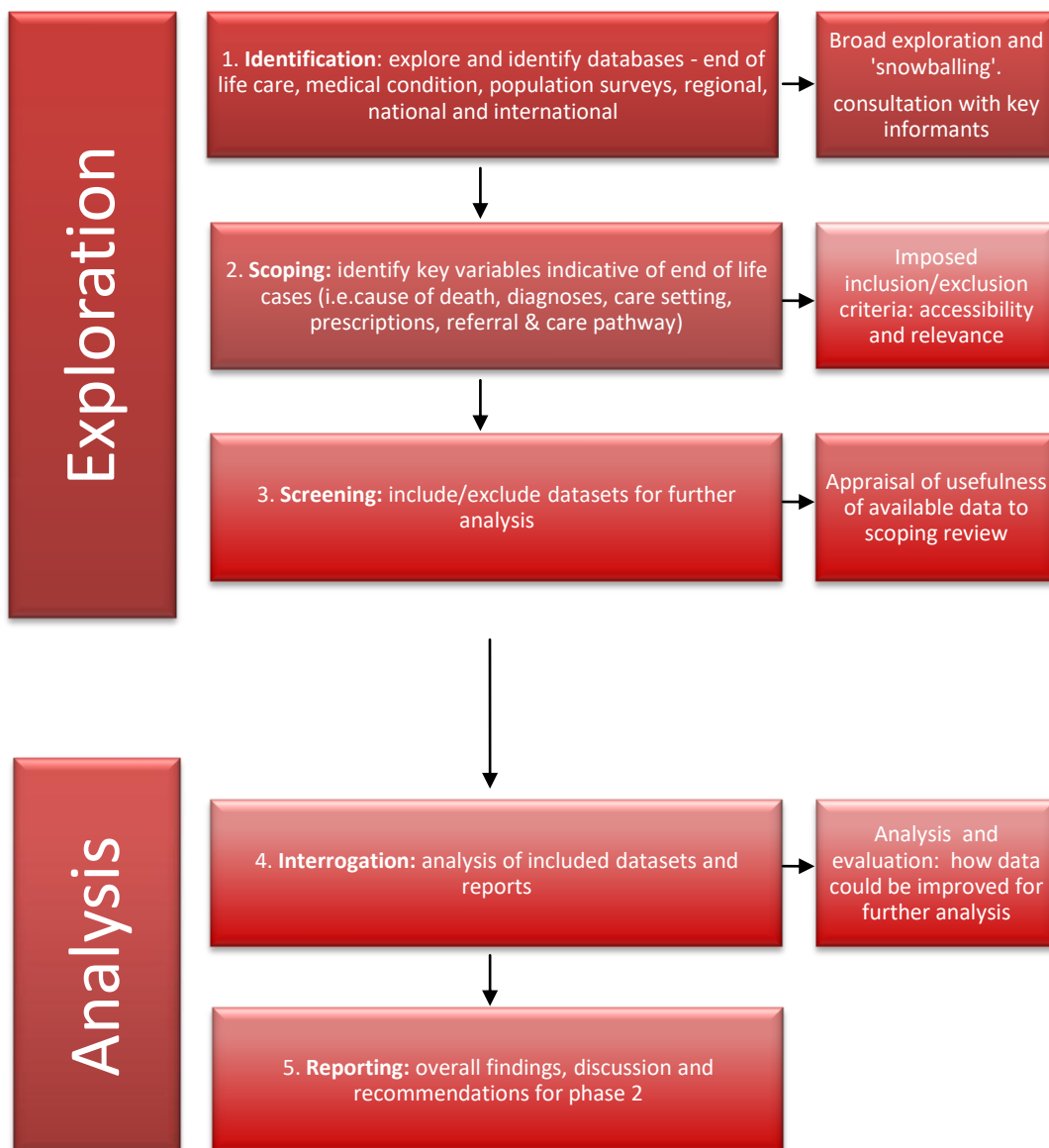
Searches were carried out electronically initially, focusing on known sources such as the Office for National Statistics (ONS), Hospital Episode Statistics (HES), UK Data Service (now NHS Digital), Department of Health, Public Health England, The Royal College of Psychiatrists' Health of the Nation Outcome Scales (HONOS and HONOS 65+), National Council for Palliative Care, Palliative Care Register, Marie Curie and the Liver Trust. These initial searches led to further sources of data (snowballing), identification of relevant data access points, reports and available datasets. Identification of key informants led to face-to-face and email/telephone discussions and further enquiries which resulted in consideration of datasets from the National Drug Treatment Monitoring System (NDTMS), National Alcohol Treatment Monitoring System (NATMS), coroner reports, Clinical Record Interactive Search (CRIS), and the National Programme for Substance Abuse Deaths (np-SAD).

Stage 2 ran concurrently with Stage 1, with all identified potential sources appraised for relevance to the study and evaluated for quality and type of data. At this stage, inclusion criteria were: (1) relevance to substance using population identification; (2) relevance to end of life care population identification and (3) accessibility of data. At **Stage 3**, key sources of data were identified for inclusion. Exclusion criteria were lack of identification of patients with substance use problems for whom end of life care was an identified need (target cases). At this stage, it was clear that no target cases could be directly identified with accuracy, therefore proxy variables of disease type such as liver diseases, head and neck, oesophageal/gastric and bowel cancer had to be used as identifiers of people with problematic substance use, while mortality records were used to identify people in need of end of life care. It was considered that cross-referencing of disease type and mortality data would provide at least an estimation of target cases (people with problematic substance use in need of end of life care).

This resulted in identification of datasets and reports from datasets which were included in **Stages 4** (interrogation) and **Stage 5** (analysis and evaluation of findings). It was felt that records pertaining to cardiovascular diseases would lack the detail required for identifying people with problematic substance use as these diseases are highly prevalent, being the main cause of death in the older UK population. It is recognised however that 'hidden' cases of people with problematic substance use are likely to be embedded in cardiovascular disease data.

3. Findings from the exploration stage

3.1. Identification of data sources (Stage 1)

Key results

- Eight substance use data sources identified

- Fourteen end of life/palliative care data sources identified

- None of the datasets directly linked substance use data with information on end of life care

- Disease-specific clinical audits and ad-hoc population survey data were identified which contribute further information on disease treatment and individual experiences

At Stage 1, eight main organisational providers were identified in relation to national substance misuse datasets (See Table 1 below) and a further fourteen were identified for end of life/mortality data (See Table 2 below).

None of the datasets comprehensively linked data on substance use with information on end of life care (or mortality), and most only covered a partial aspect of the potential population that is relevant to this scoping study. Only the Health and Social Care Information Centre (HSCIC/NHS Digital) and ONS data portals facilitated direct exploration of the collated data. Data from other key sources were accessed through the organisation's own reports or enquiry portals (i.e. Marie Curie Atlas, Public Health England Local Area Health Profiles).

Table 1: Primarily alcohol / drug use data sources

Organisation	Key data	Limitations	Included
Health and Social Care Information Centre (HSCIC) Indicator portal **(Main secondary reports relevant to scoping study)**	Monthly hospital episode statistics, liver disease Hospital episode statistics (admitted patients England 2014 – 15) Liver disease hospital deaths report Hospital admissions related to drug misuse 2014 (Nationally and by region. Also ONS data) Alcohol use and behaviours, drinking-related ill health and mortality Hospital level mortality indicator	Does not identify liver disease that is attributable to alcohol; no data on anticipated deaths. Identifies alcohol use but does not differentiate problematic use. Does not identify drug use. Not all substance use-related; Does not identify anticipated end of life. Does not correlate to ongoing drug misuse. No information on anticipated deaths. Alcohol use categories too broad to identify problem drinking. No information on anticipated deaths. Only reports numbers of deaths. No indication of ability to specify type of death or service received.	Yes
Royal College of Psychiatrists	HONOS HONOS 65+	Only records alcohol or drug use for individuals receiving mental health treatment. No information on mortality or anticipated deaths. Not aggregated nationally – only by CCG or NHS Trust.	No
Public Health England (Incorporating the NTA; part of the DoH)	National Drug Treatment Monitoring System (NDTMS) National Alcohol Treatment Monitoring System (NATMS)	Only records substance misuse for individuals accessing structured treatment (Tiers 3 or 4). Does not record health issues other than having exited treatment due to death.	Yes
National Drug Evidence Centre NDEC	Collation of NDTMS	Only includes attendees of substance use treatment provider services. Does not record data on end of life care needs.	No
Office for National Statistics (ONS)	Alcohol-related deaths	Does not identify specifically alcohol use or dependence. Does not identify those receiving end of life care.	Yes
National Programme for Substance Abuse Deaths (np-SAD)	Coroner reports on cases where illicit drugs are implicated in a death. Includes toxicology and medical certificate causes of death	Inconsistent reporting across the UK. Relies on coroner identification of cases. Excludes alcohol only cases. Includes only acute deaths.	No
General Practitioner Extraction Service	Records alcohol reduction interventions.	No data on substance use beyond alcohol reduction.	No

Table 2: Primarily end of life/mortality data sources

| *Organisation*	Key data sources	Limitations	Included
Hospital Episode Statistics (HES) palliative care coding, Summary Hospital-level Mortality Indicator (SHMI)	Individual Trusts	Variations in definitions of any episode or specialist treatment of palliative care by Trust. Incentive to under-report to reduce hospital mortality rates.	Yes
(Public Health England) National End of Life Care Intelligence Network (NEoLCIN)	ONS and HES data Palliative care register (quality and outcome (QOF) measure for primary care)	Same limitations as ONS and HES (as listed below) Register data underused in NEoLCIN reporting.	Yes
National Audit Office	ONS and HES data	Reworking of HES data *HES and PCMDS RAND conducted 2008. Dated.*	No
National Council for Palliative Care (NCPC)	The Minimum Data Set (MDS) for Specialist Palliative Care Services	Not individualised data. Poor response rates of reporting by service providers.	Yes
Marie Curie	Marie Curie atlas. Regional performance data	Repeated data from the Palliative Care Register	No
Office for National Statistics (ONS)	Deaths and treatment incidence frequencies.	Relies on medical diagnosis for treatment need or cause of death. No patient morbidity status linked to mortality or treatment type beyond immediate disease or cause of death.	Yes
Department of Health	GP patient register dataset	Identifies only alcohol or drug use as self-reported by each patient.	No
	Palliative Care Registers (QOF & Gold Standard)	Not freely available. Access needs to be obtained through the Clinical Practice Research Datalink (CPRD).	No
Association of Public Health Observatories (APHO)	Local Area Health Profiles	Reports prevalence rates rather than individualised data.	No
Electronic Palliative Care Co-ordination Systems (EPCCS)	ONS and HES data and EOL-specific interview data.	Same limitations as ONS and HES data.	Yes
General Practitioner Extraction Service	Palliative Care (QOF) data	Not freely available. Access needs to be obtained through CPRD.	No

Evidence on life-limiting diseases associated with substance use (such as liver disease, cardiovascular diseases, blood-borne viruses and cancers) was also explored for insight specific to this population. Many of these sources did not address end of life care. However, the search resulted in the inclusion of audits from the National Cancer Intelligence Network; Cancer Outcomes and Services

Dataset 2015. Only three recent audits relevant to substance use were included from this dataset. They were The National Bowel Cancer Audit Report (HSCIC, 2015a), The National Oesophago-Gastric Cancer Audit (HQIP, 2015), and The Head and Neck Cancers Audit (HSCIC, 2014).

Although there have been some general population surveys relating to alcohol or drug use, the questions asked in these surveys focused upon quantity and frequency of use, using categories too broad to identify problematic levels of substance use and associated health needs. Therefore, these sources of data were excluded from this review. There are also surveys relating to end of life care for instance, The Palliative and end of life care Priority Setting Partnership (PeolcPCP, 2015), but these did not relate to specifically to the aims of this report.   However, the Health Survey of England – Palliative care services (ONS, 2014a) for 2013 focused on social care and included a household survey on end of life care experiences. This survey report has been included in Stage 4.

Figure 2 presents an organisational map illustrating the sources of data and the datasets and related reports on which this review is based. As it illustrates, primary sources of data come from coroner reports, Hospital Episode Statistics (HES) and General Practitioner Records (GPRD – now CPRD). These primary sources of data inform all subsequent reports including ONS-generated disease and population reports, HSCIC reports, np-SAD and sources of combined data research facilitators such as Clinical Practice Research Datalink (CPRD) and Biobank. Other data sources illustrated in Figure 2 have generated primary data from independent sources including the Minimum Data Set (MDS) from palliative and end of life care providers, clinical audits and surveys carried out on disease-specific incidence and sample surveys.

Figure 2: Organisational map of datasets and related reports informing on end of life care for people with alcohol and drug problems
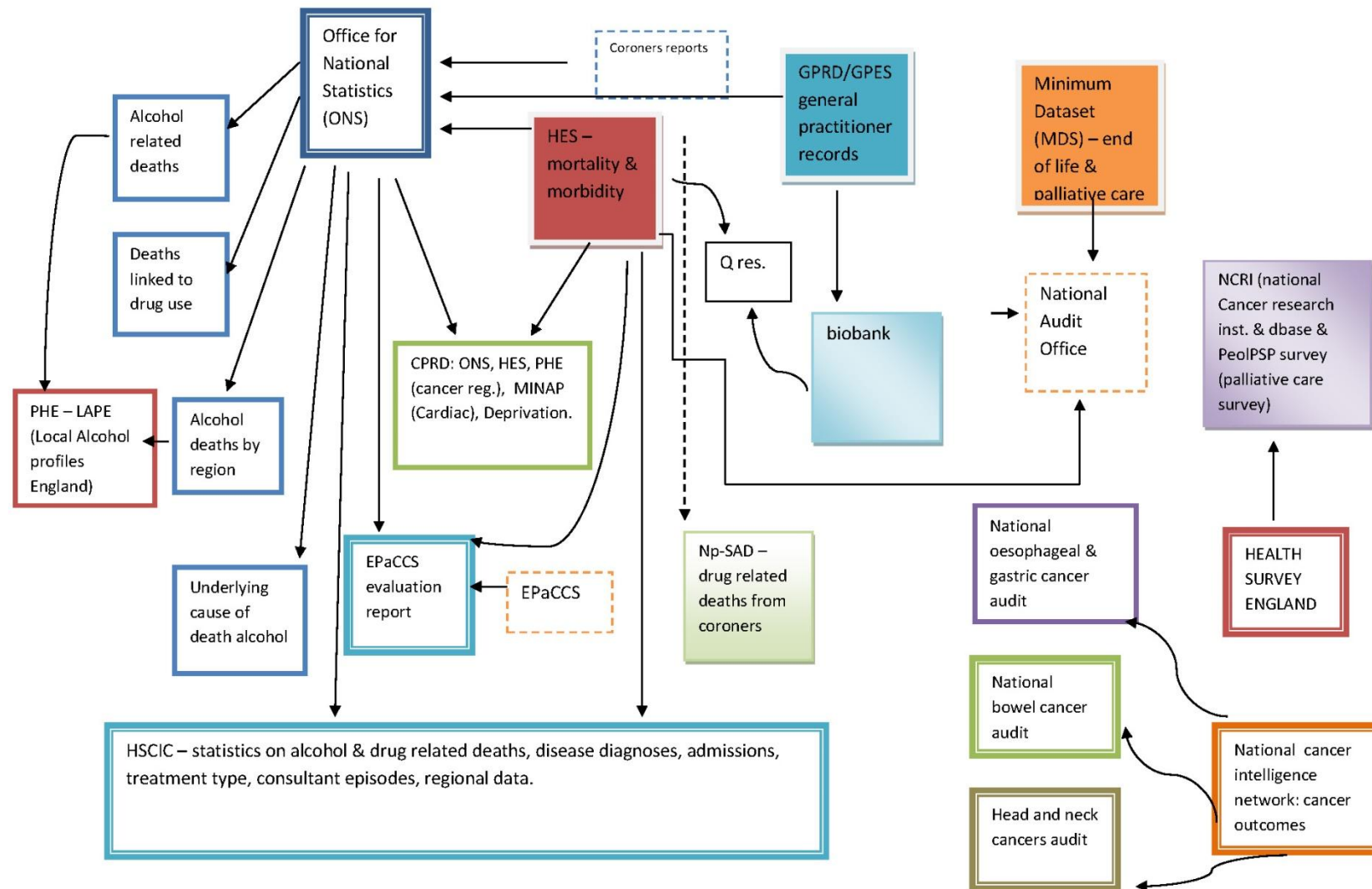
3.2. Scoping for key variables (Stage 2)

Key results: Stage 2

- No whole-population datasets directly identify people with problematic substance use and end of life care needs

- 'Proxy' variables from disease diagnoses were identified that could allow some analysis of likely cases of people with problematic substance use and end of life care needs.

- It would be necessary to link databases in order to obtain more accurate data on this target population.

By the end of Stage 1, it was clear that there is no current whole-population data collection conducted that facilitates direct identification of people with problematic substance use with end of life care needs. Therefore Stage 2 focused on identifying the key variables that would assist in case identification of individuals with substance use problems and end of life care needs via proxy variables. These are factors correlated with problematic substance use such as alcoholic liver disease. Where the direct evidence required is not available - as in this study - proxy variables allow some analysis to take place albeit more limited or narrow in scope. For example, alcoholic liver disease acts as a proxy variable for problematic substance use. Other examples could include medical diagnoses that are consistently recorded in medical certificates of cause of death (MCCDs – usually referred to as death certificates) and clinical audits, and therefore also present a reliable and consistent set of data to use as proxy variables. Examination of the included datasets and reports and supporting evidence, identified possible proxy variables for problematic substance use, namely: liver disease, specific cancers and other conditions with high causal links to substance use.

Due to the nature of the target population being in need of end of life care, and the manner of medical patient recording systems, much of the evidence relating to people with end of life care needs was obtained from mortality and treatment episode records. In order to identify key diseases that can act as proxy variables, additional disease-related data could be obtained from existing patient and referral data, typically from primary and secondary clinical care sources, patient surveys and organisational audits. Therefore, the exploration of data sources included mortality and morbidity data from hospital episode and general practitioner reports, medical audits, patient and population surveys and data collected via end of life service providers and organisations. In addition to these population and clinical sources, public health care surveillance and monitoring sources such as Public Health England were also explored. These sources typically use and report secondary data,

but were useful in aggregating data specifically around the target population, by geographical distribution, demographics and disease type.

Methodological challenges in identifying the target population

As identified in Stage 1, the target population (people who have problem substance use and end of life care needs) cannot be identified in any health or population database or dataset directly. People who have had treatment for drug or alcohol use can however be identified via the National Database for Treatment for Substance Misuse (NDTMS). People who have died from an alcohol-related cause are recorded as such by the ONS, in which this is recorded on the MCCD as a primary or contributory/underlying cause of death. Illicit drug-related cases will include sudden deaths (i.e. accidents) as well as chronic illness such as alcohol-related liver disease. This also applies to drug-related deaths recorded by the ONS. These cases will include acute overdose as well as chronic organ failure due to sepsis or blood-borne viruses, but are only identified by a condition directly attributable to drug use, such as inhalation of gastric contents due to drug-induced stupor. Drug-related deaths are also recorded on the np-SAD (national programme for substance abuse deaths). This database relies on coroner reporting and does not have complete national coverage and therefore would provide a partial picture only. Unlike ONS data, np-SAD includes all mentions of substances found post-mortem, prescription data and coroner's narrative detail where available. However, this dataset is also limited to deaths associated with an acute cause, which would not highlight the more chronic, life limiting conditions associated with end of life care.

Sensitivity and specificity

Proxy variables can be over- and under-inclusive: they can both over-include cases and fail to identify cases. The challenge in identifying people with problematic substance use by disease type is therefore one of sensitivity and specificity: using proxy variables which will identify *likely* cases of problematic substance use without excluding cases (sensitivity), and including *only* those cases of likely problematic substance use and excluding those without problematic substance use (specificity) (Figure 3). This problem exists only for identifying problematic substance use. Identifying anyone who has died and received end of life care does not present the same problem of over- or under-inclusion as records are accurate and comprehensive for mortality and place of death, and have a higher degree of consistency with regard to being in receipt of end of life care. The problems with this data quality are discussed under Palliative Care Registers below.

Figure 3: Sensitivity and specificity case identification errors
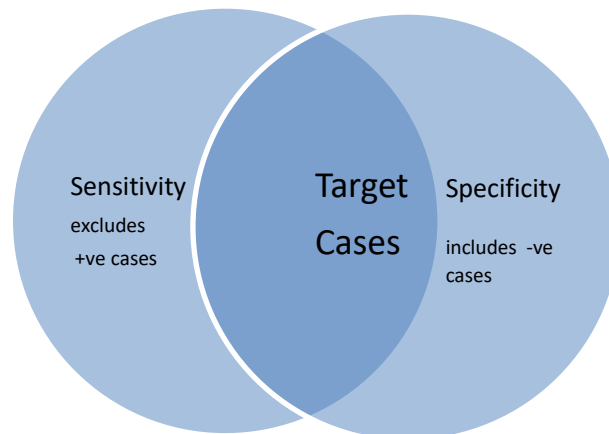
As Figure 3 illustrates, a person diagnosed with, for example, terminal alcohol-related liver disease is clearly a target case, that is: someone who has/has had both problematic substance use and a life limiting condition. A case of unspecified liver disease will lack specific detail to identify whether the person is a target case as it will be unclear whether or not this relates to substance use. Including unspecified cases of liver disease will capture a large proportion of alcohol-related disease cases (such as cirrhosis), but also include those whose liver disease is hereditary or otherwise unrelated to alcohol use (lack of specificity or inclusion of negative cases).   A person with hereditary heart disease may also be a problematic substance user, but the diagnosis is not sensitive enough to identify the person's lifestyle history and therefore such cases may go undetected (lack of sensitivity or exclusion of positive cases). Therefore, there will inevitably be target cases missed from this analysis, and cases included in the analysis that are not target cases. Lack of sensitivity and specificity therefore increases inaccuracy of estimates for prevalence and incidence when using proxy variables.

Variability in disease types as proxy variables
Reliance on diagnostic criteria assumes that target cases can be identified from disease type and cause of death and that people with problematic substance use in need of end of life care will not require care for conditions unrelated to their substance use. Therefore this assumption additionally excludes cases where the primary medical issue is not related to substance use. Likely examples of these may be chronic obstructive pulmonary disease, hereditary or diet-related heart disease, cancers not strongly related to substance use, motor neurone disease, multiple sclerosis, and many others.

As already highlighted, all mentions of cases in this report rely on medically determined criteria for identification as target cases and will by necessity exclude cases that cannot be identified via diagnostic criteria or other means.

In order to improve sensitivity and specificity, further detail relating to cases would be required. Where these are already embedded in the specific data source, these data can improve identification of cases. This will occur where secondary and underlying diagnoses are recorded, where prescription and toxicology evidence is linked to the case and clearly related to problematic substance use (i.e. acamprosate, prescribed for alcohol dependence), or where the person has received substance use treatment. All sources currently do not have all these data on one database. It would therefore be necessary to link databases in order to enhance the accuracy of data on this target population.

- The most useful data source to identify possible cases appears to be cause of death records. These are obtained via coroner records reported comprehensively to the ONS.
- Deaths and treatment episodes are recorded by Hospital Episode Statistics (HES). These are also reported to the ONS.
- Palliative Care treatment episodes recorded by HES give a breakdown of finished consultant episodes by basic patient details (sex, age, length of stay).

There are several organisations currently linking data and can be approached for data interrogation. The most comprehensive appear to be HSCIC and CPRD. Both have access to ONS, HES, national cancer data and levels of deprivation scales, along with other health and social datasets.
The results section (Stage 4) gives a breakdown of sources of data and main findings as reported by the most recent data interrogations for end of life care, alcohol deaths and drug-related deaths.

Additional data

Disease-specific reports and medical audits also provide indicators relevant to this target population. Other direct sources of medical diagnostic data for this target population stem from end of life and palliative care records. As reported below, these are currently poorly reported and do not facilitate accurate surveillance or monitoring.

3.3. Screening for inclusion and quality appraisal of data (Stage 3)

Key results

- Current national data sources also do not facilitate identification of target cases via chronic or terminal disease.
- Public Health England aggregated mortality data are not specific enough to allow identification of cases of patients with problematic substance use directly or indirectly via proxy variables of disease type.
- It is possible to link NDTMS and NATMS (National Alcohol Treatment System) data to ONS data to track cases of people accessing structured treatment.
- Finished consultant episodes from HES could be cross-referenced with underlying cause diagnoses and demographic and treatment data with a bespoke analysis commissioned through NHS Digital.
- Palliative Care Registers offer possibilities to identify patients with specific diseases who are placed on the register by their General Practitioner. This would facilitate identification of cases by the primary reason for palliative care registration and key co-morbidities.
- The cessation of the palliative care database in March 2017 puts an end to any potential for tracking care pathways for this patient group via this route.

Stage 3 comprised an examination of the quality of the data and evidence from the included datasets and reports (Tables 1 & 2), and supporting evidence. This consisted of:

- Identification of definitions of variables within the databases such as the ONS and HES;
- A more detailed examination of disease type and cause of death diagnoses.

The latter was important as these represented the key proxy variables for the identification of possible patients who had problematic substance use. Below is a breakdown of the definitions and appraisal of data quality. Stage 3 results are discussed in the next section by theme of alcohol-related mortality, drug-related mortality, end of life care data and disease-specific data.

3.3.1   Alcohol-related mortality

The Office for National Statistics uses the International Classification of Diseases 10 (ICD-10) to define an alcohol-related death. These are medically-determined diagnoses which are recorded as the underlying cause of death where alcohol is regarded as the direct or underlying cause. These are mostly chronic diseases and conditions (Table 3), reported using 4-character ICD-10 coding.

Table 3: National Statistics definition of alcohol-related deaths (ICD-10)

ICD-10 code	Text
F10	Mental and behavioural disorders due to use of alcohol
G31.2	Degeneration of nervous system due to alcohol
G62.1	Alcoholic polyneuropathy
I42.6	Alcoholic cardiomyopathy
K29.2	Alcoholic gastritis
K70	Alcoholic liver disease
K73	Chronic hepatitis, not elsewhere classified
K74	Fibrosis and cirrhosis of liver (Excluding K74.3-K74.5 - Biliary cirrhosis)
K86.0	Alcohol induced chronic pancreatitis
X45	Accidental poisoning by and exposure to alcohol
X65	Intentional self-poisoning by and exposure to alcohol
Y15	Poisoning by and exposure to alcohol, undetermined intent

Source: Office for National Statistics, 2016

However, the ONS also includes all deaths from chronic liver disease (except biliary cirrhosis – an auto-immune disease) regardless of any mention of alcohol as a contributory factor on the MCCD. The ONS excludes diseases which are only partly attributable to alcohol disease (PAAD) such as head and neck cancers, so only includes wholly attributable alcohol diseases (WAAD). However, it 'assumes' that many cases of cirrhosis and chronic liver disease are alcohol-related and includes these in the ONS data on alcohol-related deaths. Use of WAAD means that identification of cases using ONS definitions is more likely to include cases in which alcohol use is severe, harmful and ongoing and excludes cases in which alcohol use is or has been only risky or hazardous (i.e. heavy non-dependent drinking), leading to a less directly attributable cause of death. Office for National Statistics data may also include cases of cirrhosis and chronic liver disease that are unrelated to alcohol such as viral liver disease. Public Health England (PHE) on the other hand include all disease types in which alcohol is either wholly or partly attributable (WAAD & PAAD), therefore including a range of cancers, strokes and acute deaths. This makes the PHE data more sensitive and better suitable for this enquiry as it captures a wider group of patients with problematic alcohol use. If the

target population is harmful substance users, WAAD appears the more appropriate variable, if hazardous substance users are to be included, then PAAD provides greater sensitivity for case identification. Where alcohol is the substance however, what is deemed 'hazardous' is likely to include a large proportion of the UK population who drink alcohol.

3.3.2   Drug-related mortality

The ONS definition of a drug *misuse*-related death is where drug use or dependence is the underlying cause or where drug poisoning is the underlying cause of death (ONS, 2015). 'Drug' is defined as a substance controlled under the Misuse of Drugs Act 1971. Unlike alcohol-related deaths, this definition does not rely on ICD-10 coding alone. This definition will include direct drug poisoning (overdose) as well as disease conditions directly attributable to drug use such as sepsis. This definition is therefore likely to exclude deaths from chronic organ failure (i.e. liver, kidney, heart) related to blood-borne viruses, or other diseases related to drug use and resultant poor health but not directly related to drug use. Other ONS drug use deaths include over-the-counter medications. However, these are small and specified in the ONS reporting. Coding from ICD-10 for a drug-related death as used by ONS is as Table 4 below:

Table 4: The definition of the ONS headline indicator of a drug related death using ICD-10 codes

ICD-10 Code	Text
X40-X44	Accidental poisoning by drugs, medicaments and biological substances
X60-X64	Intentional self-poisoning by drugs, medicaments and biological substances
Y10-Y14	Poisoning by drugs, medicaments and biological substances, undetermined intent
X85	Assault by drugs, medicaments and biological substances
F18	Mental and behavioural disorders due to use of volatile solvents

Source: Office for National Statistics, 2016

It is important to note that drug overdose deaths are not necessarily acute or sudden deaths. Such deaths often occur due to bronchopneumonia following inhalation of gastric contents during an overdose episode several weeks prior to the death (Webb et al., 2003). Such cases notionally appear to meet the criteria for end of life care, but they could be subsumed into 'respiratory disease' cases in end of life care data and therefore difficult to identify unless the 'overdose' label is retained.

The National Drug Treatment Monitoring System (NDTMS) collects data on structured substance use treatment provided by substance use treatment service providers. The National Drug Evidence Centre collates these data on behalf of Public Health England. Client categorisation consists of opiate users, non-opiate users, non-opiate and alcohol clients and alcohol only clients. Type of non-opiate

substance is recorded along with demographics, referral route, waiting time and treatment type and outcomes. The quality of the data collection is high, with 99.9% accuracy and coverage of reporting from service providers and minimal (less than 1%) of overlap of clients (the same people being recorded by different services for the same treatment episode). This dataset is therefore robust but only covers the population of substance users accessing specialist treatment. This set does not record care received external of the substance service provider or referrals following treatment. For the purposes of identifying end of life care for people with existing drug use problems, this dataset only records acute deaths on service premises or in the community prior to discharge from the service and not deaths that occur in hospital or elsewhere following discharge from the service. Personal information received from the staff at the National Drug Evidence Centre for this scoping study (Miller, 2016) indicates that people with end of life care needs would be unlikely to appear in this database as they would be unsuitable for treatment, and any deaths on service premises would be due to an acute illness. Most clients with an acute terminal illness would be referred to hospital in the first instance. Any deaths recorded in the database are likely to be among clients receiving community care who suffer an acute death while in the community. It is possible to link NDTMS and NATMS (National Alcohol Treatment System) data to ONS data to track these cases (Pierce et al., 2015).

The links between drug use and mortality are harder to establish than those between alcohol use and mortality. Evidence from longitudinal studies indicates that younger drug users are at risk of death from acute events such as overdose, while older drug users are at risk from premature death from a wide range of disease types found commonly in the general population (i.e. Beynon et al., 2010; Stenbacka et al., 2010). Beynon and Lawson (2010) summarise the range of health challenges evidenced among drug users over 40 years of age to include liver diseases, cancers, chronic obstructive pulmonary disease, hepatitis, plus the general debilitation from long-term deprivation (Beynon and Lawson, 2010). This wide range of life-limiting diseases rules out specific identification of drug users requiring end of life care using disease diagnosis as a proxy variable. The only useful diagnosis may be viral hepatitis (A, B or C) which is highly associated with injecting drug use at around 80% of all cases (Health Protection Agency and Department of Health, 2012).

Current national data sources also do not facilitate identification of target cases via chronic or terminal disease. The ONS definition of a drug-related death only includes direct poisoning and mental and behavioural disorders. Therefore, drug-related deaths in England and Wales, as recorded by the ONS or reports using this source, include only overdoses, suicides/self-harm and accidents.

Such deaths are more commonly acute, and only where drug users survive these incidents for any period of time could they potentially receive end of life care. There appear to be no records traceable for such cases without accessing medical records directly.

3.3.3   End of life care data

Hospital Episode Statistics currently include two indicators of palliative care delivery in hospital which are then reported to the Health and Social Care Information Centre (HSCIC):

- The first indicator (percentage of admissions with palliative care coding) records the palliative care provided by each Trust and produces the percentages of completed episodes of palliative care, by either diagnosis or treatment;
- The second indicator (percentage of deaths with palliative care coding) provides the percentage of deaths within the first indicator.

Frequency statistics on palliative care treatment specialty in or commissioned by NHS trusts in England are also published as 'finished consultant episodes' (NHS Digital, 2016a) which refer to any specialist palliative care health professional intervention. This information is broken down into basic demographics (gender, age) and case type (emergency, planned, waiting list/time and bed days). The data are also available as 4-character ICD-10 codes which allow identification of very specific diagnoses, in line with the ONS breakdown for alcohol and drug-related deaths. It appears that the finished consultant episodes could be cross-referenced with up to 20 separate underlying cause diagnoses and demographic and treatment data with a bespoke analysis. This level of analysis would need to be commissioned through NHS Digital.

Data on end of life care are collected by the ONS and HES. Both inform Public Health England and the National End of Life Care Intelligence Network (NEoLCIN). Public Health England aggregate mortality cause into only three categories: cancer, respiratory and circulatory. This does not allow identification of cases of patients with problematic substance use directly or indirectly via proxy variables of disease type.

The Minimum Dataset (MDS) is produced by the National Council for Palliative Care (NCPC) and PHE. The MDS project collates end of life and palliative care data from providers in the statutory, private and voluntary sector. However, the most recent report (NCPC, 2016a) on the MDS states that the current reporting rate at 66% of all services is neither consistent across the country, nor across

service types. Seventy percent of the current available MDS comes from hospice reporting, with only 55% of all hospital teams reporting to the MDS. This means that the MDS provides a good record of hospice provision but misses a large proportion of patients receiving end of life care in hospital settings. According to the NCPC, response rates from the independent and voluntary services to the dataset is improving, but reporting rates from NHS services is declining. This dataset only records numbers of people seen, basic demographics and primary diagnosis. There are no data on other diagnoses or medical needs. Therefore there is no clear indicator of patients who may have problematic substance use.

A useful comparison with ONS recorded deaths is performed in the latest MDS report (NCPC, 2016a) and demonstrates that, while approximately 80% of the reported palliative inpatient care patients were diagnosed with cancer, only 31% of all deaths are recorded by the ONS as being caused by cancer. The implications for the dataset are that this source over-represents the hospice activity and underlines the evidence that hospice services disproportionately treat patients with cancer diagnoses.

The Electronic Palliative Care Co-ordination Systems (EPaCCS) was commissioned in response to the National End of Life Care Strategy (2008). It was designed to initiate an electronic reporting and monitoring system to facilitate co-ordination of care delivery for cases identified as near the last year of life. The EPaCCS report (The Whole System Partnership, 2016) evaluates the EPaCCS system using qualitative and quantitative sources including ONS place of death records, HES and the EPaCCS' own in-depth interviews. EPaCCs may offer a source of evidence for local and regional monitoring of end of life care. However, this does not appear to differ significantly from data which are already available via ONS and HES.

Palliative Care Registers
Primary care services have been encouraged to maintain palliative care registers since the introduction of the End of Life Care Strategy in 2008 (Department of Health, 2008). Register records are incorporated as part of the quality and outcome framework (QOF) measure.

3.4.Recommendations for data recording

Key recommendations

- The Palliative Care Register system and the palliative care coding for hospitals are recorded inconsistently across services, with many categories open to interpretation. Both systems need to be standardised for consistent data collection and accurate analysis across services.
- The TOPS recording tool for the reporting of patient treatment episodes in the NDTMS is not sensitive enough to identify co-morbidities. While there is a focus on mental health and blood borne viruses in the NDTMS system, inclusion of physical co-morbidities would improve health and wellbeing monitoring of patients receiving substance use treatment.

Several sources of end of life care data report a need for improved data recording on site. The National Council for Palliative Care (NCPC) (2012) finds that the lack of secondary cause of death recording limits interpretation of the cause of death and identification of mortality trends. The National Bowel Cancer Audit from 2015 declares an intention to link data to the palliative care database in order to monitor the quality of care delivered by cancer services at end of life (HSCIC, 2015a). This will facilitate care pathway tracking and make end of life care auditable. Cancer services appear to be identifying the need for greater recording within this disease group. It is not clear if other disease audits have identified a similar need. The Palliative Care Registers record primary care patients who are recognised by the general practitioner as requiring end of life care in their last year of life. This resource is demonstrating clinical improvements but is criticised as an audit tool as it relies on medical recognition of cases: the very issue that the Palliative Care Register aims to improve in order to widen access to end of life care. Additionally, hospital recording of palliative care is shown to contain inconsistencies across services due to lack of definition or recognition of palliative care. Hospitals can be penalised under the Summary of Hospital- Level Mortality Indicator (SHMI) with high mortality rates if they have a specialist inpatient palliative care service. This may lead to different interpretations of mortality coding between hospitals and the possibility of 'gaming', leading to inconsistent data recording of mortality and palliative care given (HSCIC, 2013).

A major obstruction to accurate data collection for this patient population currently is the lack of reporting by end of life care and hospice services to the National End of Life Care Intelligence Network (NEoLCIN) Minimum Data Set (MDS). This is a monitoring and surveillance tool which could provide auditing and monitoring of end of life care provision in England if its data were collected consistently and comprehensively. Currently, reporting to the MDS is at 66%, with some areas of

England responding at a rate as low as 33%. In addition, the data being reported is limited, with only place of death being reported with any consistency and poor reporting by hospitals and private care services leading to an over-representation of hospice service activity. Further data required to enable auditing of service use and gaps in service provision would include co-morbid disease types, treatment provided, care pathway, causes of death (at least primary and secondary), and reliable medical history of contributory factors such as alcohol or drug use, previous treatment episodes, and family data. Sustained, accurate and detailed data recording would facilitate clinical audit nationally and, over time, facilitate monitoring of both disease and treatment trends.

Specialist substance use treatment services currently report treatment activity to the NDTMS. Focus on co-morbidities of patients is currently focused on dual diagnosis (mental health and addiction). The Treatment Outcomes Profile (TOPS) as a routine reporting tool is limited. Currently, TOPS is under review with suggestions for the inclusion of parental status, domestic violence and take-home naloxone. There is an opportunity in the review also to consider the recording of co-morbidities to facilitate improved monitoring of life-limiting disease, especially in light of the increasing age of the in-treatment population.

Designed to improve the care of people at the end of their life, the Gold Standard Framework (GSF) Palliative Care Register additionally aims to promote improved identification and prediction of people who are likely to need end of life care. Use of either is shown to improve access to support (McNair, 2015). All primary care general practices should have a register of all patients with supportive or palliative care needs. This identifies both cancer and non-cancer patients who may be in their last year of life. However, the registers are used in different ways within and between general practitioner (GP) services leading to inconsistent data collection and recording (Rushbrooke and Kendrick, 2012). Access to the registers is restricted and requires application to the Independent Scientific Advisory Committee (ISAC) through the Clinical Practice Research Datalink (CPRD), previously the General Practice Research Database (GPRD). The registers offer possibilities to identify patients with specific diseases who are placed on the register by their general practitioner. This would facilitate identification of cases by the primary reason for palliative care registration and key co-morbidities. A limitation of using these data is that the registers rely on medical identification of cases in need of palliative care. It is suggested that clinical recognition is biased by the same inequity that perceives cancer patients as those most in need of end of life care (Gadoud et al., 2014). Therefore an analysis of these data would be subject to the same bias the analysis sought to detect; by examining a dataset over-representative of cancer cases.

3.5. Disease-specific data and evidence

Scoping for information on patient treatment episodes or national clinical audits for diseases most likely to be associated with substance use provided limited results. There were no sources of evidence on hepatitis C or human immunodeficiency virus (HCV and HIV) useful to this scoping study. The National COPD (chronic obstructive pulmonary disease) Audit Programme produces a rolling programme of themed audits. The most recent on secondary care outcomes (Stone et al., 2017), reports high hospital admission and mortality rates with poor recognition of rapid deterioration for certain patients. Their data may be of use in further investigation if substance use patients are identifiable within the COPD cohort. Currently however, this project fails to link treatment audit themes with diagnostic detail to identify substance use patients.

Audit data are collected periodically from HES and the National Cancer Audit Register on specific cancer types, treatment interventions, incidence, prevalence and care pathways. Current audits do not report end of life or palliative care consistently. Only the Head and Neck Cancer Audit reports the treatment and care incidence as a percentage of treatment incidents overall. There is no breakdown of diagnoses, causes of death or co-morbidities which would aid identification of cases. These data could be used for prevalence estimates of cancer disease types using projected prevalence data from other sources mentioned in this report.

3.5.1   Liver disease

Liver disease may be a useful proxy variable of people with problematic alcohol use. Therefore an examination of liver disease prevalence and association with alcohol use may provide evidence of the numbers of target cases embedded within liver disease data. The report by the National End of Life Care Intelligence Network (Effiong et al., 2012) used ONS data from 2009 and reported that liver diseases in general account for 2% of all deaths in England when measured as an underlying cause. This includes liver cancer, alcoholic liver disease, fatty liver, chronic (cirrhosis & fibrosis), and viral liver disease. Later ONS data up to 2012 identify alcoholic liver disease as the leading cause of alcohol-related death, accounting for 63% of such deaths (ONS, 2014b).

The extent of liver disease in the UK is identified in the National Confidential Enquiry into Patient Outcome and Death (NCEPOD, 2013) and the epidemiological study by Williams et al. (2014). This evidence confirms that standardised mortality rates for liver disease have increased 400% since 1970 (using ONS data), with an estimate of three-quarters of liver disease deaths associated with alcohol consumption (Williams et al., 2014). It is important to note that some of this evidence originates

from Scotland which has a higher prevalence of problematic alcohol use than England and Wales. Using this evidence, a useful guideline for using liver disease as proxy variable for UK problematic alcohol use may be to consider that 75% of liver disease mortality is alcohol-related.

There is also evidence of the increase in prevalence of liver disease. Using hospital admission data for England and Wales, it is estimated that, in 2012, there were 600,000 people with some form of liver disease and 60,000 people with cirrhosis, resulting in 57,682 hospital admissions and 10,948 deaths, representing increases of 62% in liver disease and 40% in cirrhosis in 10 years (NHS Right Care, 2013).

It may still be unsafe to assume that liver disease can equate, even as a proportion, to problematic alcohol use, or to make estimates of likelihood of prevalence of target cases from these data as there are other health issues related to liver disease which should be taken into account. The epidemiological survey on the burden of liver disease by Roderick et al. (2004), identifies the rising incidence of alcoholic liver disease in 2003/4, but also highlights the prevalence of hepatitis C (HCV) in the injecting drug user population and the increasing incidence of type 2 diabetes and obesity. They predicted in 2004 that the incubation of HCV and the increasing obesity would result in increases in viral cirrhosis and fatty liver within two decades, increasing the prevalence of non-alcohol-related liver disease. Fortunately, the HCV epidemic has been countered with some success since these predictions, however the escalation in the rate of type 2 diabetes may contribute to proportions of liver disease mortality which is not alcohol-related. There are now approximately 3.8 million people in the UK with type 2 diabetes (PHE, 2016e) and 63% of adults in England are obese or overweight (Baker, House of Commons, 2017). ONS data reporting is not currently identifying such cases as the latest ONS dataset is from 2014. It may be that future reporting may need to differentiate alcohol-related and non-alcohol-related liver disease.

3.5.2   Cancer

As the ONS data indicates, liver cancer is the most likely terminal form of cancer that will be associated with alcohol use. However, alcohol use is currently identified as a risk factor for a range of cancers especially cancers of the mouth (oral cavity) and throat (pharynx), voice box (larynx), gullet (oesophagus), large bowel (colorectum), liver and the female breast. Alcohol consumption also probably has a role in cancer of the pancreas (Committee on Carcinogenicity of Chemicals in Food, Consumer Products and the Environment (COC), 2015). The findings from the COC have prompted

the UK government and the Chief Medical Officer to revise the weekly alcohol units (Department of Health, 2016).

Specific patient data for a range of cancers are collated by NHS Trusts in England and reported to the Cancer Outcomes and Services Dataset (COSD), which is the national standard reporting vehicle for cancer in NHS England. This dataset facilitates audit on clinical outcomes and patient pathways of care, and comparisons by Trust. The National Bowel Cancer Audit Report (HSCIC, 2015a) reports care pathways up to death but does not currently include end of life care. Findings are largely focused on cancer treatment outcomes but there is an intention to link data to the palliative care database in order to monitor quality of care at end of life. This dataset, therefore, is not currently linked but will enable tracking of care pathways for this patient group in the future.

The National Oesophago-Gastric Cancer Audit (NOGC) (HQIP, 2015) is similarly limited in data but includes place of death in the audit. The NOGC report identifies that end of life care pathway is best managed in the community for these patients, and that many patients prefer to die at home (although no evidence is given to support this). In the audit, place of death was recorded as 34% of patients receiving end of life care at home and 'a similar' proportion died in hospital. The remaining proportion died in a care home or hospice. A further analysis demonstrated that 30.6% of patients who were able to die at home were living in areas of least deprivation, in comparison with 39.4% of those living in areas of greatest deprivation. The Head and Neck Cancers Audit (HSCIC, 2014) reports that such cancers have a poor prognosis and significant mortality, especially when diagnosed late in the disease course. While there are data on end of life treatment and care prevalence against other treatments, there is no indication in their report of where this treatment or care was received. These sources of data are currently unable to identify people with problematic substance use directly. However, if further audits include linkage to the palliative care database, this will enable some tracking of cases in the future.

3.5.3   Respiratory diseases

Lung disease is the third largest cause of death in the UK and highly associated with lower socio-economic status, according to the British Lung Foundation (BLF) (2016). The BLF Respiratory Health of the Nation epidemiological research project report, based on data from The Health Improvement Network database and the ONS, also identifies lung cancer and COPD as the main types of lung disease responsible for the highest numbers of respiratory disease deaths. The majority of lung disease deaths are among people over 65 (BLF, 2016), with a predominance of female deaths due to

its prevalence as a disease of old age. Smoking heroin, cannabis and crack cocaine are all associated with chronic obstructive pulmonary disease (COPD) and emphysema, and respiratory diseases are likely to manifest in at a younger age than the general population (Lewis-Burke et al., 2013; Vozoris et al., 2016; Walker et al., 2013). It is not possible however to isolate drug users from smokers or patients with occupational lung disease without further identifiers in this data source.

3.6. Summary

The Stage 3 appraisal process found that no data are available that gives direct information on people with problematic substance use and their use of and access to end of life care. Proxy variables of disease type give some indication of proportions of people who may have alcohol-related diseases such as liver disease. Data relating to cancers generally or cancers with a higher relation to alcohol or drug use than others lack the evidence to make any calculations of estimates currently. People with drug-related terminal illnesses are not traceable via proxy variables as the disease types are too varied to identify cases. Specific data from end of life sources lack the detail to identify cases and is poorly reported, with a bias towards hospice care.

4. Analysis

This chapter reports on the analysis of the included datasets and reports from datasets. It will be broken down into sections: alcohol-related mortality data; drug-related mortality data end of life care data.

4.1. Interrogation of datasets and reports (Stage 4)

Key results

- With the exception of alcoholic liver disease, liver cancer is the most likely cause of death to be linked to alcohol use. However, most people who use alcohol harmfully will die from ischaemic heart disease, in line with the general population.

- People with a history of problematic drug use die at an earlier age than the general population.

- The National End of Life Care Intelligence Network's Minimum Data Set provides no monitoring of substance use or status of patients, and provides only primary diagnosis, so limiting opportunities to identify people with problematic substance use via an underlying disease profile. Patients with associated drug or alcohol health problems could be examined in some detail from the Minimum Data Set if at least a secondary diagnosis were added to the reporting.

- Chronic cause of death for people with problematic alcohol or drug problems is most likely to be cardiovascular or liver disease, therefore statistically, problematic substance users have a disproportionately high rate of hospital deaths compared to non-substance users.

Despite the lack of specific data available, the stage 4 process analysed all included sources of evidence through close reading. The analysis below is divided into the three strands: alcohol-related mortality data, drug-related mortality data and end of life care data for ease of reporting.

4.1.1 Alcohol-related mortality data

Existing data sources

The key source of data on alcohol-related deaths is the ONS as collated in the annual ONS reports on alcohol-related deaths in the UK, from 2014/16. In addition, Public Health England has applied alcohol-attributable fractions (based on general population data) to ONS data to make estimates of

partially alcohol-attributable mortality rates (PHE, 2015). Other sources referred to in this section report diseases associated with alcohol use, all of which obtain their data from the ONS.

ONS 2014/16 prevalence data

The most recent ONS alcohol-related deaths data report (ONS, 2016b) states that up to 2014, alcohol-related deaths decreased from a peak in 2008 (from 15.8/100,000 to 14.3/100,000). This is deaths attributable to alcohol (and including chronic liver disease which includes both directly and partially attributable cases – WAAD & PAAD). Overall, 8697 alcohol-related deaths were registered in the UK in 2014. Males made up 65% of these deaths. Males aged 60- 64 make up the highest proportion of male deaths (47.6/100,000) and females aged 55-59 make up the highest proportion of female deaths (22.1/100,000).

Among deaths wholly attributed to alcohol, alcoholic liver disease is the most common cause of death, followed by cirrhosis and fibrosis of the liver. In 2014, 7281 deaths were recorded as being caused by alcohol across England and Wales. Liver disease was recorded as causing 4624 deaths, with liver fibrosis and cirrhosis causing another 1623 deaths (See Table 5). This means that 86% of the deaths recorded as being caused by alcohol that year were accounted for by alcoholic liver disease, fibrosis and cirrhosis of the liver. Even when deaths where alcohol is recorded as a contributory factor are included (see Table 6), alcoholic liver disease, fibrosis and cirrhosis of the liver still account for 70.1% of alcohol-related deaths.

Table 5: Deaths with an alcohol-related main cause, England and Wales 2014 (ONS, 2016b)

Cause of death[1]	N	Percentage of alcohol-related deaths
Alcoholic liver disease	4624	63.5%
Fibrosis and cirrhosis of liver	1623	22.3%
Mental & behavioural disorders due to alcohol use	517	7.1%
Accidental poisoning by and exposure to alcohol	390	5.4%
Alcoholic cardiomyopathy	87	1.2%
Degeneration of nervous system due to alcohol	14	0.2%
Alcohol induced chronic pancreatitis	13	0.2%
Alcoholic gastritis	6	0.1%
Chronic hepatitis, not elsewhere classified	5	0.1%
Intentional self-poisoning by and exposure to alcohol	2	0.0%
Alcoholic polyneuropathy	0	0.0%
Poisoning by/exposure to alcohol, undetermined intent	0	0.0%
TOTAL	7281	

[1] Numbers of deaths using the final underlying cause of death.

Incidence of diseases associated with problematic alcohol use

It is important not to make assumptions about disease type as a proxy variable without examining the causal links with substance use. There are a range of diseases which are acknowledged to be directly or indirectly caused by substance use. However, the strength of the causal links varies by disease, so using disease type as an indicator of a history of substance use can be problematic. As outlined in the section on sensitivity and specificity, the degree to which certain diseases (wholly or partially attributable to cause of death) are representative of problematic substance use depends on ascertaining proportions of cases within each disease type, and the likelihood of the disease being linked to substance use. Partly attributable measures improve sensitivity (capture more cases) but wholly attributable measures improve specificity (exclude non-cases).

ONS (2016b) data from medical certificates of cause of death (MCCDs) indicate that alcohol was partly attributable to death in 1.2% of all deaths in 2014. Most of these deaths were as a result of ischaemic heart disease (38.5%) or liver cancer (26.9%)[1]. As identified earlier, the likelihood of having an alcohol-related condition is higher among those who die from liver cancer (9.9% of all liver cancer cases) than ischaemic heart disease (1.0%) (Table 6). Yet the total number of deaths from ischaemic heart disease where alcohol is a contributory factor is higher because more people in the general population die from that than die from liver cancer. Among people who die from mouth and throat cancers, alcohol is recorded as a contributory factor in 2.2% of deaths, and other cardiovascular diseases (hypertensive diseases, ischemic stroke, haemorrhagic stroke) are linked to underlying alcohol use at 1.4%, 1.0% and 0.9% respectively.

Table 6: Deaths with alcohol recorded as a contributory factor, England and Wales 2014 (ONS, 2016b)

| Underlying cause of death	No. deaths from underlying cause	No. deaths mentioning an alcohol-related condition	Proportion of deaths mentioning an alcohol-related condition (%)	% of deaths with alcohol as a contributory factor
Ischaemic heart disease	60,509	627	1.0	38.5
Pneumonia	25,386	146	0.6	9.0
Ischaemic stroke	19,094	86	0.5	5.3
Haemorrhagic stroke	8,667	74	0.9	4.5
Cancer of Oesophagus	6,754	26	0.4	1.6
Hypertensive diseases	6,114	87	1.4	5.3
Liver cancer	4,452	439	9.9	26.9
Cancer of the lip, oral cavity, mouth or throat	2,345	51	2.2	3.1
Transport accident	1,792	94	5.2	5.8

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[1] These figures exclude deaths wholly attributable to alcohol.

There are several caveats for all these findings - based on the type of data and the quality of recording. The ONS dataset relies on data recording on medical certificates and the degree to which the cause of death can be traced to substance use. Evidence from other strands of this project shows that alcohol may be omitted as a cause of death from medical certificates to save families from further distress – although the extent to which this occurs is unknown. However, with such a large proportion of alcohol-related deaths being recorded as alcoholic liver disease, cirrhosis and fibrosis of the liver, use of these as proxy variables for people with alcohol use problems is likely to have reasonable sensitivity and specificity. This may provide an adequate estimate for prevalence of this population receiving end of life care, providing these diagnoses are recorded in end of life care records.

Public Health England 2016

These findings use data on reason for admission to hospital as reported by Public Health England (PHE, 2016d). Using a broad measure of alcohol-related disease, where alcohol is a primary *or* secondary cause of disease, PHE identifies cardiovascular disease as the main reason for admission among alcohol-related disease cases in England (49% of all causes) (Figure 4).

Figure 4: Percentage of hospital admissions by disease, injury or condition 2014/15 (broad measure). (PHE, 2016d)
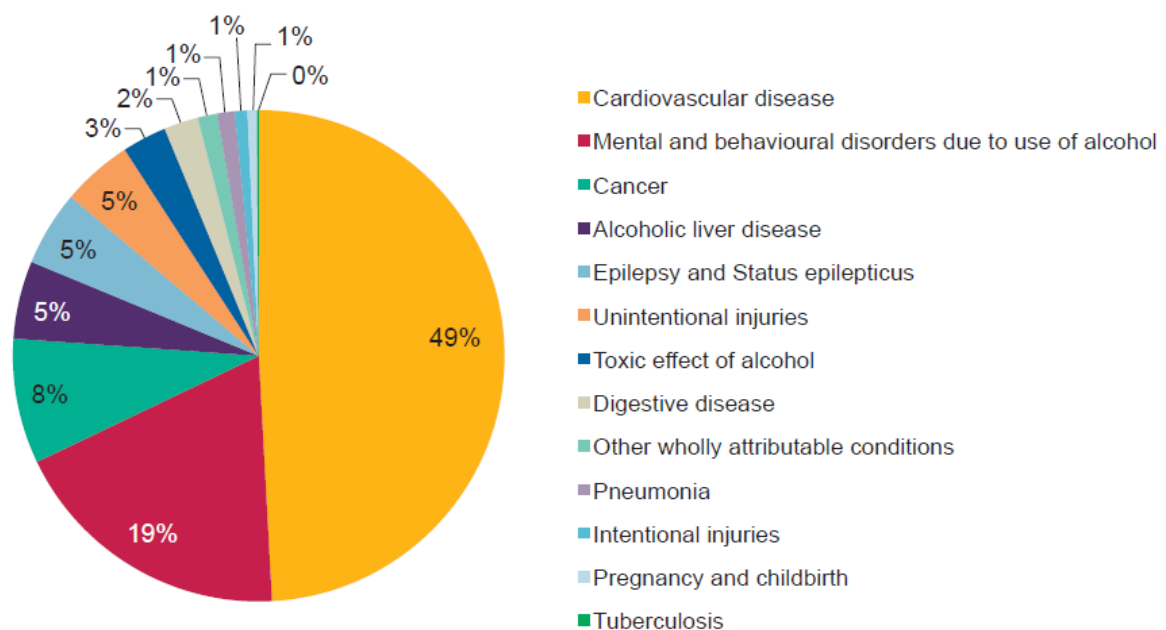

By contrast, the narrow measure, where alcohol-related disease is the primary cause of hospital admission, identifies cancer as the main alcohol-attributable cause for hospital admission (23% of all

causes), with only 12% of admissions wholly attributable to alcohol-related disease and alcoholic liver disease (Figure 5).

These data relate to morbidity rather than mortality, however the difference between the PHE measures of hospital admissions illustrates the unreliability of hospital recording as a source of evidence for the identification of people with problematic substance use who are using health services. It gives an indication of the high rates of possible target cases that are likely to be embedded within patient populations with cardiovascular disease for example, and demonstrates that the proportion of such cases is far less than those with cancer diagnoses.

Figure 5: Percentage of hospital admissions by disease, injury or condition 2014/15 (narrow measure). (PHE, 2016d)
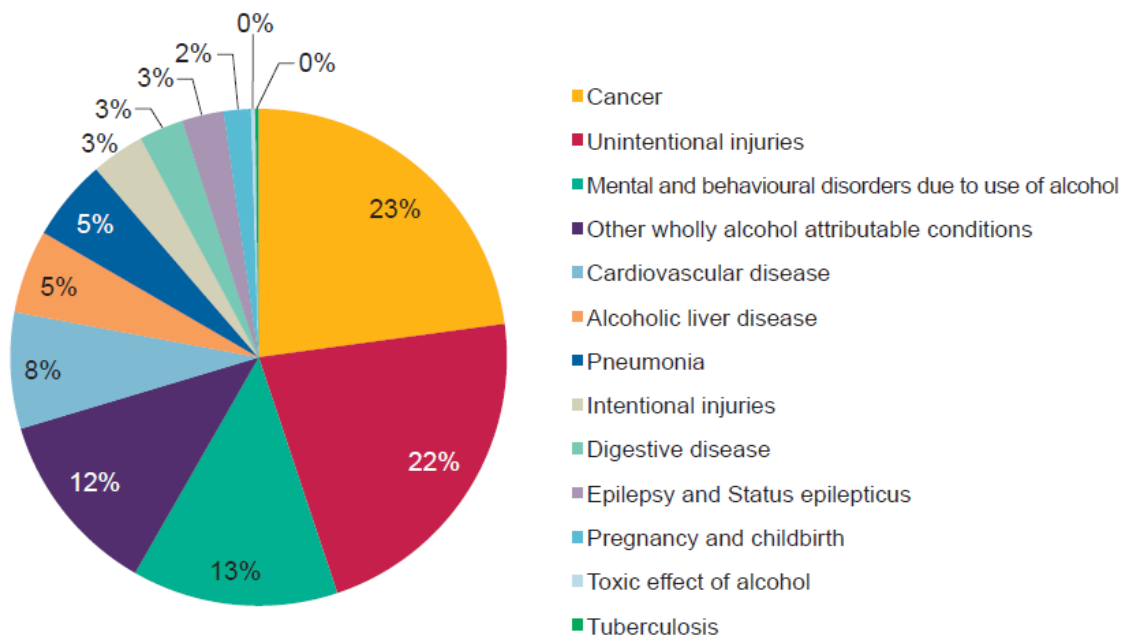
Socio-economic spread

Additionally, PHE explored socio-economic status (SES) and hospital admission for alcohol-related conditions, and found that 41% of all admissions for alcohol-related cancer occur amongst the lowest three socio-economic deciles, with a high proportion of these admitted for cancer of the larynx (48%), and cancer of the liver (41%). Of all alcohol-related liver disease admissions, 53% were from the lower three socio-economic groups (PHE, 2016d). The PHE report also outlines evidence of the alcohol harm paradox in which people of lower socio-economic status, while often drinking at lower levels than people of higher SES, have more susceptibility to alcohol harms and alcohol-related mortality than people of higher SES. This is discussed further in the Alcohol Research UK report

'Understanding the Alcohol Harm Paradox' (Centre for Public Health, 2015). This report suggests five hypotheses for this phenomenon: 1) that the alcohol harms among people in higher SES groups are under-reported; 2) that the different SES groups have different drinking patterns; 3) that higher SES groups have higher social and health resilience to alcohol harms; 4) that groups have unequal access to health support; and 5) that there is a poverty gradient in that harmful drinking leads to poverty. There appears to be no firm explanation for this paradox currently. However, this phenomenon is relevant to this study as any estimates of end of life care prevalence based on proxy variables of disease type may be co-variant with SES; that is, the proxy variables may be measuring SES as much as alcohol-related conditions and therefore excluding heavy drinkers from higher SES groups. This is particularly true if the explanation for the paradox is that alcohol-related conditions for higher SES are under-reported, or that resilience plays a part in the prevention of alcohol-related disease among higher SES groups.

4.1.2 Drug-related mortality data

As outlined at Stage 3, only acute and directly attributable deaths are recorded by ONS as drug-related deaths. As these are largely deaths by overdose, sepsis or accident related to drug-taking, these deaths are unlikely to represent people who would be able to receive planned end of life care. Other sources are required to be able to estimate the prevalence of people with problematic drug use who need end of life care. Prevalence estimates of drug dependence and harmful use among the general population, especially among older drug users, may improve identification of target cases for this scoping study.

The Crime Survey for England and Wales estimated that 3.1% of adults between 16 and 59 years are 'frequent' drug users (Home Office, 2014). The Adult Psychiatric Morbidity in England Survey (APMS) of 2014 estimated prevalence of drug dependence as 3.1% of the general population (McManus et al., 2016), with most symptoms of drug dependence among males under 24 (Roberts et al., 2016). This overall figure includes cannabis use and is based on limited data sources but is reported as likely to be an underestimation of drug dependence in England and Wales.

A more reliable prevalence estimate by the National Treatment Agency (PHE, 2013) was produced using multiple sources, finding that there were approximately 293,879 people aged 15-64 using opiates or crack cocaine in England (8.4/1,000), with 2.5/1,000 injecting drugs between these age ranges. These figures may be a more useful basis for estimating potential chronic disease incidence

among opiate and crack users as they do not include cannabis smoking or non-dependent and occasional use, although they do not include adults over 64 years of age.

According to the NDTMS, 2% of discharged clients died while in contact with drug treatment services during 2015-16 (PHE, 2016b). Most of these were opiate clients (63% of all deaths in treatment) with a median age of 44 years. This accounts for 1.1% of all opiate clients in treatment. A further 817 (30% of all deaths in treatment) alcohol-only clients died while accessing treatment (1% of all alcohol only clients in treatment). This group had the greatest median age among the substance groups (49 years). In comparison, non-opiate and alcohol (5%) and non-opiate only clients (2%) made up only a small percentage of total number of deaths while in contact with treatment services. Non-opiate and alcohol deaths had a median age of (41 years), whereas non-opiate only clients had the lowest median age, with the majority aged under 40 (38 years). This dataset represents only a small proportion of deaths among problematic drug users and it is likely that many of these deaths were due to acute causes, excluding this population from end of life care.

Research evidence that explores deaths among cohorts of drug users gives an indication of causes of death beyond the acute deaths typically used by ONS and PHE to denote a drug-related death. Beynon and McVeigh (2007) traced cause of death of 102 individuals in contact with drug treatment services in the North West of England. Among these, 72 (70.6%) were classified as non-drug related deaths In addition to cellulitis, these non-drug-related deaths included 16 from infection (seven from pneumonia), seven from alcohol-related liver disorders and seven suicides. Those who died from non-drug-related conditions were a significantly older cohort than those who died of a drug-related condition (p = 0.004). This work led the researchers to conclude that a considerable proportion of deaths classified as non-drug-related are likely to result from substance use - particularly through infection. This supports the problem already identified in this report that data recording drug-related deaths are limited to direct cause such as overdose and so exclude more chronic conditions such as pneumonia caused by inhalation of gastric contents, cellulitis and sepsis from injection sites, and conditions brought on by use of other substances such as alcohol.

The longitudinal study by Stenbacka et al. (2010) using Swedish records from 1967-2004 of drug users provides a baseline cohort (n=860) on which to estimate typical cause of death in this population. Key population findings were that the average age of death was 47 years (25-30 years younger than the general population), and 40% also had problematic alcohol use. The biggest cause of death was cardiovascular disease at 15.3% of all these deaths, but the authors report that

cardiovascular disease accounted for a third of the cohort over 55 years. The second largest cause of death was labelled 'accident' at 14.8%. It was not clear if this included overdose but it did include traffic accidents, falls and resisting the police. The authors report that people under 24 accounted for nearly a fifth of accident deaths. Tumour was given as the cause of death for 12.5% of the deaths, and liver cirrhosis and suicides each accounted for 10.5% of deaths. This study indicates that more chronic causes of death among drug users are most likely to be cardiovascular disease (heart disease and strokes), tumours or liver cirrhosis.

Another study to examine the full range of causes of death among opioid users in treatment nationally was undertaken in 2015 (Pierce et al., 2015). Among 198,247 opioid users who had accessed treatment, there were 3974 deaths, revealing that this group were six times more likely to die than the general population. Forty-three per cent of the deaths arose from drug poisoning; with another 21% from external causes. Mortality rates were also elevated for infections, respiratory disease, circulatory disease, liver disease, suicide and homicide. The following table (Table 6) summarises the main causes of death among the group:

Table 7: Summary of main causes of death among opioid users in drug treatment or drug-tested within the criminal justice system (Created by the authors using data from Pierce et al., 2015).

	%	n	SMR[1]	Any additional details / clarifying notes
Drug related poisoning	43.2%	1715	N/A	
Other external causes	21%	835	3.3	Of which, suicide accounted for 5%, and homicide 2%. SMR was 12.2 for Homicide and 2.9 for Suicide (with drug-related poisonings excluded).
Digestive system	11%	437	6.4	8.7% of deaths in total were caused by liver disease (n=345). The majority of these (72%) were due to alcoholic liver disease, fibrosis or cirrhosis of the liver. SMR was 9.6 for cirrhosis.
Circulatory system	11%	437	3.1	
Respiratory system	7%	278	8.9	Half of these deaths were due to chronic lower respiratory disease, a further 39% to influenza or pneumonia
Liver cancer	0.7%	38	9.2	Liver cancer deaths comprised 12.9% of the 296 recorded cancer deaths.

[1] Standardised Mortality Ratio: the extent to which the mortality rate for the group being studied differs from that anticipated for an 'average' population. For example, an SMR 0f 3.3 means that 3.3 times as many deaths occurred in the study group than would be expected in a general population with the same age and gender distribution.

The above evidence and further work by Beynon et al. (2010) indicate that people with a history of problematic drug use die at an earlier age than the general population. Those who survive to older age are less likely to die from an acute death directly associated with drug use (i.e. overdose, acute infection) but, as suggested by Beynon et al. (2010), may be more at risk of morbidities and mortality than the general population, possibly due to their history of drug use. Beynon et al. (2010) found that, among drug users over 40, 15% died of liver disease, 13% from cancers, 8% respiratory disease, 6% viral hepatitis. Among drug users under 40, rates of causes of death not directly linked to drug use were 9% liver diseases, 8% self-harm, 5% cancers, and 5% accidents.

Neither Beynon et al. (2010) nor Pierce et al. (2015) appear to control for alcohol use among the study cohorts, but Stenbacka et al.'s study (2010) demonstrates there is an overlap between problematic drug use and alcohol use, therefore it cannot be ascertained if deaths from cardiovascular or liver diseases are due to a history of harmful drug or alcohol use. Tobacco use is also prevalent among this population and increases likelihood of life-limiting diseases, especially respiratory and cardiovascular disease. Tridimas et al. (2013) report that 71% of surveyed drug treatment clients smoke cigarettes, while only 24% of this study cohort had ever had a spirometry test, despite a large majority (figure unreported) having symptoms of respiratory disease. Respiratory diseases may be an overlooked cause of morbidity and mortality among older drug users.

For the purposes of this scoping review, overlaps between problem drug users and problem alcohol users is not so important, but for the purposes of using disease type to identify target cases, it means that estimating proportions of cases from general causes of death can only be done with accuracy if this overlap is known. All that can be ascertained so far is that approximately 10% of alcohol-related deaths are associated with ischaemic heart disease as an underlying cause as recorded by the ONS, and that approximately 15% of deaths among drug users are likely to be due to cardiovascular disease (unspecified) as reported by Stenbacka et al.'s study. Likewise, calculations would be similarly approximate for the other main causes of death such as respiratory disease among these cohorts.

4.1.3 End of life care data
This section examines the key data sources for end of life care that contain the most specific information for this scoping study, namely: the National End of Life Care Intelligence Network (NEoLCIN) minimum dataset and the Health Survey England 2013 (ONS, 2014).

The National End of Life Care Intelligence Network (NEoLCIN) Minimum Data Set

The most recent dataset publication (NCPC, 2016a) reports that currently 70% of the data is from hospices. Therefore the dataset can only be used to gain snapshots of incidence of end of life care delivered as this is a biased sample. Non-hospice reporting is inconsistent, with missing data and certain locations and types of provider under-represented. However, the response rate for Greater Manchester, Lancashire and Cumbria (GMLC) at 68% was higher than the English national average - and in stark comparison with the North of England region as a whole which has a response rate of 33%. The data collected and aggregated include the number of people seen in each service, bed availability, primary diagnosis, demographics including age, ethnicity and gender, length of care or stay, hours of operation, location of the patient prior to or after care, location of death. There is no monitoring of substance use or status, and, with only the primary diagnosis recorded, limited opportunity to identify people with problematic substance use via an underlying disease profile.

According to the MDS report (NCPC, 2016a), most end of life care activity occurs as community care, with 38.1% of reported people seen in the community by services, followed by 29.8% of people given hospital support. Inpatient numbers were recorded as only 11.2% of people seen.

Almost 80% of people accessing inpatient care had a cancer diagnosis, while between 60% and 70% were seen as day care, community care, hospital support or outpatients. The greatest number of non-cancer diagnoses patients are reportedly seen for hospital support (the report does not state the percentage).

Cancer cases are broken down in to cancer types as listed in Table 8. There is no breakdown of digestive cancers that would allow identification of liver cancer cases.

Table 8: Cancer categories as reported by the End of Life Care Minimum Data Set (MDS)

Lip/oral/pharynx	Female genital	CNS
Digestive	Male genital	Lymphoid
Respiratory	Urinary	Other specified
Breast	Eye/brain/other	Multiple

An examination of the distribution of non-cancer patients reported to the MDS, by type of care received, shows that the most often seen patients have chronic respiratory disease, heart conditions, motor neurone disease (MND) and neurological disorders (Table 9). Liver disease is not

identified specifically, however, as the larger percentages are recorded as 'other non-cancer' diagnoses, there appears to be an inadequate identification of non-cancer diagnoses generally in the MDS. A further breakdown of cases by type of service within the report finds that rates of hospital support given has increased since 2008/9 from 14% to 27%, but this proportion is increased particularly by cases of dementia. The number of people seen with non-cancer diagnoses as outpatients has also increased from 14.3% to 28.5% and diagnosis type is not reported for this population.

Table 9: Distribution of diagnoses other than cancer seen in each setting and in death registrations. (Sourced from T*he National Minimum Data Set:* NCPC, 2016a).

	Inpatients %	Day Care %	Community Care %	In-Hospital Support %	Outpatients %	ONS 2014* %
Other non-cancer	32	15	28	41	56	27
Chronic renal failure	4	2	4	4	2	1
Chronic respiratory disease	21	33	20	12	11	10
Dementia	5	1	15	12	2	16
Neurological disorders	10	22	9	6	7	4
Motor Neurone disease	10	11	7	1	5	1
HIV/AIDS	0	1	0	0	0	0
Heart conditions	17	16	17	21	17	42

*Comparison data: all deaths (acute deaths excluded)

In the previous MDS report, the National Council for Palliative Care (NCPC, 2012) expresses concern that there is currently no collection of secondary cause of death. This concern continues to apply to the current MDS. If these data were collected, combined with the reporting of other diagnoses, it would aid in the identification of target patient populations.

Collation of the MDS dataset ceased in March 2017, reportedly due to both financial reasons and recognition of the need for an extensive review of the collection system (NCPC, 2017). Prior to that, all data had been cross-tabulated with region, place of death, cause of death, ethnicity, age, gender type of organisation, response rates, length of stay, bed usage, intervention types and rates. Cases could therefore have been examined in some detail but it would have required the addition of at least a secondary diagnosis to aid in the identification of possible patients associated with drug or alcohol problem use.

This MDS dataset is due to be replaced by the Palliative Care Clinical Dataset (PHE, 2017). While it adds social and care information to the data collected, it does not appear to improve on the MDS in terms of collecting patient health history. Collection of patient NHS numbers will however allow use of this dataset for data linkage with GP and hospital records.

Health Survey of England – Palliative care services 2013

The Health Survey of England is an annual survey focusing on different topics each year. The 2013 survey focused on social care and included a specific survey on end of life care experiences of approximately 2000 adults living in private residences in England who had experienced a death of someone close to them in the last 5 years (ONS, 2014a). The main report for this survey is poorly described, lacks focus on diseases and does not include any data related directly to substance use. However some of the findings may add to an overall picture of experiences from the carer perspective so it has been included in the analysis.

The survey found that participants who reported that the person close to them had died of cancer were twice as likely to mention use of end of life care compared with those reporting other illnesses (68% of men and women for cancer, 31% and 34% respectively for other illnesses). This finding is in keeping with earlier reports from end of life care evidence indicating that cancer patients are more likely to receive specialist end of life care services than people with other terminal illnesses.

The survey also reports that reasons for not receiving end of life care services were either that the person died in hospital (36.5% of all respondents) or that the death was sudden (27% of all respondents). Approximately 12.5% said the patient did not want end of life care; that end of life care was not available (12.5%); or that they did not know about the service (4%). This is a self-report survey where not only does the quality of the data rely on the accuracy of reporting, but also, as a

household sample that obtains data from relatives retrospectively, it will exclude people with terminal illness who have no close family.

This survey's findings further illustrate however that specialist end of life care availability is heavily weighted towards cancer cases and suggests that people with other illnesses are less likely to access specialist end of life care. The percentage of deaths by cancer among the general population is 28% (ONS 2016a) compared with the 68% of cancer cases identified in this survey accessing end of life care. While this difference in use of end of life services may be due to clinical reasons, it underlines the fact that people with cardiovascular and non-cancer liver diseases are less likely to receive end of life care. Evidence above (i.e. ONS and PHE data on causes of death) already identifies that chronic cause of death for people with problematic alcohol or drug problems is most likely to be cardiovascular or liver disease, therefore statistically, people with problematic substance use tend to have less access to specialist end of life care than people with a cancer diagnosis

5. Discussion and recommendations

This section will summarise and discuss the findings from the analysis of datasets and reports. From this analysis and discussion, recommendations can be made both for improved investigation and for improved recording and monitoring of end of life care for people with problem substance use.

5.1. Interrogation of datasets and reports (Stage 4)

The interrogation of existing datasets and reports at Stage 4 identify a range of factors that make precise estimates of prevalence and incidence of people with problematic substance use and end of life care needs unreliable.

Estimates can be made using disease type as a proxy variable to identify substance use among end of life data. The ONS assumption of 63% of liver disease deaths being alcohol-related (ONS 2014b) indicates that a large proportion of people with alcohol use problems do not enter specialist end of life care services as liver disease is under-represented among patients receiving specialist end of life care. Estimates that 80% of specialist care service referrals are for people with cancer indicates that non-cancer patients are largely excluded from these services. This does not preclude people with alcohol-related disease receiving end of life care in hospital however, as the NCPC reports that most non-cancer patients are seen by end of life care specialists in a hospital setting. Whether the ONS' 63% figure includes the 10% of liver cancer cases associated with alcohol (ONS, 2014b) is not known. Nevertheless, as reported by Effiong et al. (2012) end of life specialist services are not delivering in-patient care to a large proportion of people with cirrhotic, viral or alcoholic liver disease. The same can be said for people with cardiovascular disease of which an estimated 1% will be associated with alcohol-related conditions. The picture appears more uncertain for people with drug-related chronic illnesses as the cases cannot be easily identified or estimated using disease diagnoses and there appears to be an overlap between drug users and alcohol users among patient cohorts. However, some evidence is emerging that older drug-using populations carry a burden of liver cirrhosis, cancers and respiratory disease, often with an earlier age of onset.

In the absence of systematic screening and recording of alcohol and drug use among all patients with end of life conditions, and the omission of end of life care or physical co-morbidity surveillance by substance use treatment services, it is not possible to determine accurately the scale of the end of life care need for people with alcohol or drug problems without more detailed data analysis.

A more accurate estimation of end of life care delivery to people with substance use problems can only be obtained if patients with problematic substance use can be identified with a high degree of accuracy. This requires routine collection and recording of patient histories that extends beyond the disease diagnosis related to their end of life care. These data are most likely to stem from services delivering end of life care at any stage of the process, therefore including primary care, hospitals and specialist palliative care services. In the meantime, a more accurate monitoring of end of life care delivery to these patient groups requires improved identification of cases using existing data. These data are currently collected in different monitoring systems which use different definitions of drug- or alcohol-related disease, direct causal links or indirect causes, and include cases either only by first disease type or where drugs or alcohol may be mentioned on MCCDs. This means that data linkage requires compatibility in the first instance to permit merging of databases, or a degree of detail in order to improve sensitivity and specificity, such as history of alcohol or drug use, or treatment for an alcohol or drug addiction. Currently, patient substance use history is not routinely recorded in either treatment monitoring or audit surveys and therefore these cohorts are best identified through the NDTMS datasets and primary care patient records.

5.2. Future research recommendations

1. **Use of existing data:** Access HES palliative care (finished consultant episodes) data and link with ONS mortality data to obtain a measure of incidence of disease type and hospital provision of end of life care.

2. **Data linkage:** Develop/use proxy variables to support the analysis of existing data. Conduct a review of links between diseases and substance use to obtain estimates on which to calculate sensitivity and specificity of proxy variables, and produce estimates of incidence and prevalence.

3. **Direct access to patient records:** Invest in data linkage and analysis between HES and ONS mortality data using the HESID index. Access to case identifiers (via patient records) removes the necessity of using proxy variables.

Identification and calculation of prevalence and incidence estimates for people with substance use problems requiring or receiving end of life care using existing data would require bespoke commissioned analysis of data currently recorded by HES, ONS, PHE, NHS Digital and the palliative care registers. An examination of HES palliative care data using the all diagnoses 4-character data from the *Hospital Admitted Patient Care Activity: Diagnoses* and cross referenced with the HES palliative care episodes from the *Hospital Admitted Patient Care Activity: Main specialty* would give a reasonable estimate of frequencies of people with alcohol- and drug-related underlying diagnoses who receive end of life care in hospital. While this would have missing cases, estimates of sensitivity and specificity could be calculated to give a measure of accuracy of the frequencies of included cases.

The above approach relies on using diagnoses as a proxy variable to identify people with problematic substance use. It would also be less reliable for drug use cases as this proxy variable is far less representative of drug use patients than alcohol use patients. However, it would establish a good overall indicator of proportions of patients receiving palliative care in hospital settings who are likely to present with problematic alcohol use.

Data linkage

It is possible to use the HES patient identifier (HESID) which links the ONS mortality dataset to HES person identifiable data (the HESID index) (HSCIC, 2015b). This dataset is compatible with ONS and results in assigning a unique HES patient identifier (HESID) to the ONS death record for that person, allowing for anonymous patient tracking across all HES datasets (Accident & Emergency, Admitted Patient Care and Outpatients). This would facilitate the analysis of deaths and treatments both within hospitals and in the community for all patients on the HES and ONS databases. It also provides information on admission and discharge type and consultant finished episodes from HES datasets, and place of death, primary and underlying cause of death and disease mentions from the ONS database. This service requires application to the NHS Digital Data Access Request Service (DARS) with costs charged according to the degree of work required.

Data linkage between databases such as ONS, HES and patient records is also facilitated by trusted third parties; Q-Research, the Administrative Data Research Network (ADRN) and the well-established Clinical Practice Research Datalink (CPRD). The latter is a government-level service supported by the NHS, the National Institute for Health Research (NIHR) and the Department of

Health, facilitating linkage with HES, ONS, cancer registrations and measures of deprivation. Data linkage via CPRD would enable more detailed identification of patients at end of life with problematic substance use via their primary disease type and recorded co-morbidities. As discussed earlier however, using disease type as a proxy variable weakens prevalence and incidence estimates. Therefore, none of these facilities will improve sensitivity and specificity of case identification nor enable care tracking without the inclusion of patient histories via medical records.

Direct access to patient records

A more accurate approach would be to access patient records directly in order to identify patients from their medical records who have problematic alcohol and/or drug use issues. These data would need to be cross-referenced with end of life care and mortality data. This could be performed with whole population data via GP records, CPRD, ONS and HES (HESID), or using samples from patient databases such as Biobank. Biobank maintains ongoing medical records of over 500,000 people over 40 years of age (in 2006-10) and facilitates further research of participants for medical research (Biobank, 2017). These data would include both GP and hospital medical data. Access to individual patient histories would enable more accurate identification of patients with a history of drug or alcohol use without relying on disease type as a proxy variable.

The recommended study design to gain reliable and more accurate estimates on prevalence and incidence of this population group would be to use both approaches; sampling patient record data and using the HESID data linkage to cross-reference HES data on diagnoses and end of life care episodes with ONS mortality data. Comparison with non-substance-related diagnoses patients would be facilitated through both approaches, and would also produce a higher quality study design (comparison study) and increase the quality of findings.

5.3. Recommendations for data recording

- The Palliative Care Clinical Dataset commencing in 2017 may provide more detailed data on patients accessing specialist palliative services and enable some analysis of complexity of care or data linkage via NHS patient identifiers.
- The Palliative Care Register system and the palliative care coding for hospitals are recorded inconsistently across services, with many categories open to interpretation. Both systems need to be standardised for consistent data collection and accurate analysis across services.

- The TOPS recording tool for the reporting of patient treatment episodes in the NDTMS is not sensitive enough to identify co-morbidities. While there is a focus on mental health and blood borne viruses in the NDTMS, the inclusion of physical co-morbidities would enable improved health and wellbeing monitoring of patients receiving substance use treatment.

The planned replacement of the MDS with the Palliative Care Clinical Dataset (PCCD) may facilitate data linkage between the PCCD and ONS, HES and CPRD data through use of patient NHS identifiers. Other data proposed for collection on the PCCD does not appear to improve identification of co-morbidities or otherwise give the patient's health history.

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