

# RESEARCH REPORT

## **Rapid Evidence Assessment:**

### End of Life Care for People with Alcohol and Drug Problems

*“There is a dearth of evidence overall and no body of evidence that identifies effective interventions, responses, or models of practice.”*

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## Table of Contents

Acknowledgements.....	2
Executive Summary.....	4
Section 1 - Background .....	5
Section 2 - Methodology.....	7
2.1 Formulating the REA questions .....	8
2.2 Conceptual framework.....	9
2.3 Protocol .....	10
2.4 Data extraction and synthesis .....	11
2.5 Assessing quality and relevance .....	12
2.6 Limitations of methodology .....	13
Section 3 - Findings .....	15
3.1 Gaps in the evidence .....	17
3.2 Thematic groups.....	18
3.2.1 Pain Management (n=25) .....	18
3.2.2 Homeless and Marginalised Populations (n=24) .....	21
3.2.4 Alcohol-related (n= 6) .....	23
3.2.5 Miscellaneous .....	24
Section 4 - Discussion.....	26
4.1 Good practice recommendations.....	27
4.1.1 Managing pain .....	27
4.1.2 Homelessness and marginalised groups .....	29
4.1.3 Alcohol literature .....	31
4.2 Challenges for care responses.....	32
4.3 Directions for future research .....	34
Section 5 - Conclusion.....	35
References .....	36
Appendix A.....	39

## Executive Summary

1. This Rapid Evidence Assessment (REA) set out to determine the nature and extent of the international research evidence on current responses to end of life care for people with substance problems.
2. There is a dearth of evidence on this issue and no body of evidence that specifically identifies effective interventions, responses, or models of practice.
3. The REA, therefore, refocussed on a broader scoping of the evidence and producing a systematic map of the evidence available, the themes and implications for practice, and future research.
4. A final sample of 60 papers was included in the review, 32 of which reported empirical research. Of the 32 empirical papers, quality assessment indicated that only nine were of high quality, 18 were of moderate quality and five were of low quality.
5. Most of the papers identified came from North American countries and to a lesser extent, Europe and Australia. Only eight were UK based.
6. More than two thirds of the papers were quantitative in approach. Only 11 papers (34.3%) were qualitative.
7. The majority of papers focussed on some aspect of pain management and prescribing practice where there are, or have been, substance problems. Most of these focussed on people with cancer diagnoses.
8. A small body of work focussed on particular groups of people, primarily homeless people.
9. Six papers focussed on alcohol use among people with cancer diagnoses.
10. There were some common recommendations relating to safe and effective pain management strategies, harm reduction strategies and the acknowledgement of complex comorbidities among this group of people.
11. For pain management, screening tools and active monitoring (urine testing, written agreements) of people using substances were most commonly recommended responses. Clinicians talking to people about their substance use and being aware of harm reduction approaches were also recommended.
12. Recommendations for supporting homeless substance users at the end of lives included the provision of alcohol and care in shelter environments, patient contracts, safety plans, supervised drug consumption and advance directives.
13. The alcohol-related papers highlighted the need for an awareness of alcohol withdrawal at end of life and the need for routine alcohol assessment among patients in palliative care settings.
14. Common challenges for care providers working with alcohol again highlighted concerns about safe and effective pain management. They also highlighted the “lifestyle factors” that are associated with substance use and which raise professionals’ anxieties about difficult behaviour to manage.
15. The literature also highlighted the under-utilisation of preventative or primary care services by this group of people, the need for empathic communication by professionals, and a flexible service response.

# Rapid Evidence Assessment: End of life care and substance use

This report presents the findings of a Rapid Evidence Assessment (REA) on the subject of end of life care for people with alcohol and other drug problems. It forms one part of a wider, six strand programme of research exploring this topic. The other strands are:

- examining how many people with substance-related chronic or terminal illness are receiving, or in need of, end of life care in the UK.
- exploring how people with substance use problems, past and present, experience end of life care.
- exploring the experiences of family members, friends and carers supporting a relative with both problems.
- determining the challenges and opportunities professionals face supporting people with substance problems and chronic or terminal illness.
- key informant interviews to explore the context of substance use and end of life care in the UK.

## Section 1 - Background

In the last two decades there have been a number of changes evident among the population whose use of substances, be they alcohol or other drugs, is problematic. The most notable changes are:

- an increase in the numbers of older drugs users and a resultant rise in rates of death from non-drug related conditions (Beynon, 2010),
- the increase in alcohol-related morbidity and mortality among older users (Kaplan et al. 2012), and
- the emergence and increasing use of New Psychoactive Substances (NPS - previously known as Legal Highs).

The first of these changes, the increase in older drugs users may be due, in part, to the transformation in approaches to treatment for illicit opiate users in the 1990's (McKeganey 2006) and, specifically, the widening of access to methadone prescription (Clausen 2008, Clausen et al. 2009). This expansion in access has meant that growing numbers of current and previous substance users now survive long enough to die of the sorts of conditions more commonly found in deprived cohorts of the wider population (Corkery 2008; Beynon et al. 2010). Alternative explanations are that individuals are continuing to use for longer or starting drug use later in life. Regardless of causation, there is evidence of an expansion in the numbers of older drugs users known to treatment agencies in the UK (Beynon et al. 2010; Beynon 2010). Further, changes in life expectancy in the general population leading to a pattern of population ageing is likely to be mirrored in the smaller population of substance users.

Prior to these changes, substance users had disproportionately died from overdoses (accidental or deliberate), violence, accidents and disease directly associated with either substance or route of administration such as HIV, liver disease and bacterial infections (Gibson et al. 2008). The shifts in harm reduction and treatment policies means that older substance users (over the age of 40) are now more likely to die of a non-drug related cause than users under the age of 40 (Stenbacka et al. 2008, Benyon et al. 2010). Substance users, however, are more likely to die at an earlier age than the general population and have patterns of disease and morbidity that reflect the impact of substance use or the traumatic life experiences more frequently encountered in this group (Beynon et al. 2009, Beynon et al. 2010).

The second of these changes is the increasing rate of alcohol-related morbidity and mortality connected to chronic and acute alcohol difficulties (Shield et al. 2014, Chang et al. 2008, Taylor et al. 2010). This is a more complex picture with highest consumption among more affluent cohorts of the population (Office for National Statistics, 2017) but the highest rates of alcohol-related problems amongst the least affluent (Erskine et al. 2010). Substance problems have been associated with increased cancer risk, for example, an increase of 7-19% for the development of oral cancer associated with alcohol consumption (Petti 2009). There is strong evidence that alcohol causes cancers of the oropharynx, larynx, oesophagus, liver, colon, rectum and breast (Connor 2016). Excessive alcohol consumption is linked to a number of other chronic and potentially end of life conditions, including cardiovascular disease and liver cirrhosis (Rehm et al 2009). Ratib et al. (2014) suggest there has been a 50.6% increase in cirrhosis in England between 1998-2009 and that it is more common in younger men and women (this includes both alcohol-related and non-alcohol-related liver disease).

The final set of changes is the increase in the use of New Psychoactive Substances (NPS). Some of the more immediate consequences of NPS use are apparent in the prisons system and in admissions to hospital accident and emergency departments for acute intoxication (Ralphs et al. 2017, Liakoni et al. 2016) but what the longer-term impacts on mortality and morbidity might be are not yet understood.

For the general population, while life expectancy has been increasing, so too has the number of years spent at the end of life living with disability and ill-health (Bell and Marmot 2017). This has led to a growth in the numbers of deaths which can be anticipated and which are likely to require palliative and end of life care (Etkind et al. 2017). However, little is known about the nature and extent of need for such care by substance using populations or how well services are equipped to work with the people with problematic substance use. The wider programme of research, of which this REA is part, sets out to fill this gap in knowledge. Specifically, this REA focussed on determining what is already known and identifying gaps in the evidence base.

## Section 2 - Methodology

This strand of the research programme exploring end of life care for people with substance problems set out to answer the following research question:

What does the existing international research and wider literature tell us about current responses to end of life care for people with substance problems?

The question focussed initially on care *responses* and was broken down further into the following aims:

1. to explore and document the evidence base that already exists on responses to end of life care for people with substance problems,
2. to identify gaps in the evidence relating to focus and methodology,
3. to identify examples of good practice, and
4. to highlight future directions for research.

A Rapid Evidence Assessment (REA) methodology was identified as the most appropriate research tool to use. The UK Government defines REAs as providing "... a more structured and rigorous search and quality assessment of the evidence than a literature review" but one that has narrower parameters and is not "as exhaustive as a systematic review" (Department for International Development (DFID), 2017: online). Thus, REAs stem from Systematic Review methodology which traditionally focus on interventions and whether or not they work using experimental or quasi-experimental research design. By contrast, REAs are used to:

- gain an overview of the density and quality of evidence on a particular issue.
- support programming decisions by providing evidence on key topics.
- support the commissioning of further research by identifying evidence gaps.

(DFID, 2017: online)

These uses of REA outputs clearly spoke to the research aims while its methodology enabled a more rapid evidence review to inform other project strands as appropriate. Further, given that a REA is conducted within a shorter time-frame than a Systematic Review, a methodology was needed that, while timely, retained the key systematic review characteristics of transparency, replicability and comprehensiveness (Government Social Research and EPPI Centre, 2009; Galvani & Forrester, 2011; GSR, 2013).

The Government Social Research Framework (GSR) set out a 10-step framework for conducting REAs (GSR, 2013):

1. Formulating the REA questions.
2. Conceptual framework.
3. Writing a protocol.
4. Defining inclusion/exclusion criteria.
5. Search strategy.

6. Data collection.
7. Screening and selecting studies.
8. Assessing quality and relevance of studies – non-impact questions.
9. Synthesis of findings.
10. Communicating findings.

## 2.1 Formulating the REA questions

The questions for this REA were what the GSR refers to as ‘non-impact’ questions (GSR, 2013). Given the breadth of our main research question and the perceived lack of research in this area, impact questions which focussed on whether a particular type of care response was effective were not appropriate. Thus, non-impact questions included a range of questions which underpinned the six strands of the research. Table 1, below, sets out the key research questions the category or categories of non-impact question addressed:

*Table 1: Key research questions and type of non-impact question*

REA Question	Type of non-impact question (GSR, 2013)
What is the prevalence and incidence of palliative/end of life care and co-existing substance use	Correlation question
What are the experiences of people receiving interventions where there is concurrent alcohol or other drug use and co-existing palliative or end of life care conditions	‘Needs’/Process/Attitude/Implementation questions
What are the clinical/practice challenges for professionals supporting people using alcohol or other drugs with co-existing palliative or end of life care conditions	Implementation/Attitude questions
What are the experiences of family members, friends and carers of people receiving interventions where there is concurrent alcohol or other drug use and co-existing palliative or end of life care conditions	‘Needs’/Process/Attitude/Implementation questions
What good practice models and care pathways exist for people with co-existing substance use and end of life conditions, and their families, friends, carers	Implementation question

Our REA questions were broader in scope than some REA questions would be traditionally due to a) needing to explore what evidence existed and b) not being focussed on specific interventions as systematic reviews usually are. Our starting point was determining if there were any interventions for this group. In a new area of research and practice, such narrow focus would have resulted in few, if any, findings.

As the review progressed, the lack of a cohesive body of work to answer the research questions indicated that a combination of an REA and systematic mapping methodology (Clapton et al. 2009) would be most beneficial. This review still considered these 5 key research questions but a dearth of evidence prevented a more nuanced approach in exploring the sub categories articulated in the original key research questions.



Systematic maps aim to describe the existing literature, and gaps in the literature, in a broad topic area, and the literature quality and content can be analysed in depth or more superficially as appropriate to individual projects. (Clapton et al. 2009: 11)

Thus, the review was conducted with the rigour of planning and approach of an REA. However, as a result of our experience conducting the REA, and the diversity of the literature found, it also encompassed systematic mapping of the review's findings (see page 16).

## 2.2 Conceptual framework

Within the literature, the definitions of palliative care and end of life care are vague and ill-defined with authors often interchanging between the two terms without delineation. For this REA, we examined the existing theoretical debates and sought advice from experts in the field. We based the definition of *palliative care* on a combination of World Health Organisation (WHO) guidelines and a final sentence from European Association of Palliative Care (EAPC) definition. However, we also strengthened the definition with the inclusion of family members, carers and friends. Our definition for palliative care is as follows:

Palliative care is an approach that improves the quality of life of patients and service users facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It also provides care to family members, friends and carers of patients and service users to recognise their need for support in their own right and as well as to support them to care for their relative or loved one. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

*End of life care* is difficult to define since recognising dying is hard to assess or acknowledge with many chronic diseases. For this REA our end of life definition remains similar to the palliative care definition but a time scale of the last 12 months of life is added. This is in keeping with the General Medical Council's definition of the end of life (2010) which refers to patients 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with, (a) advanced, progressive, incurable conditions, (b) general frailty and co-existing conditions that mean they are expected to die within 12 months, (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition and (d) life-threatening acute conditions caused by sudden catastrophic events.

*Substance use* was defined as problematic alcohol or other drug use, current or previous, prescribed or illicit, while receiving palliative or end of life care.

## 2.3 Protocol

This REA was an iterative review and the protocols for the initial five searches that were conducted are detailed in Appendix 1 of the REA supplementary appendices document. They set out the original protocols for the review. However, the search strategies were adapted as the REA proceeded due to the very limited relevant data generated by the initial protocols. This approach allowed us to refine the questions and focus once the review was underway which is one of the features of an iterative, as opposed to an a priori, review.

Three broad groups of evidence were relevant:

1. existing research on palliative and end of life care
2. existing research on substance use
3. the wider health and social care literature, policy and practice documents.

The search protocol needed to ensure these bodies of evidence were included. Common to all five searches, (detailed in Appendix 1 of the supplementary appendices document) were the databases, additional sources and fields used (see Table 2 below).

*Table 2 – Search fields, databases and other sources*

Search within fields	keywords/ subject terms abstract
Databases	Amed, Psycharticles, Ovid, Ageinfo, MedLine, Ebscohost, ASSIA, Social Care Online, Web of Knowledge (including Social Science Citations Index), Web of Science, SSCI, Samsha, NIAAA,

The search terms obviously differed across the searches according to their particular focus, for example, families of people with substance problems or prevalence and incidence. Common to all five searches were terms relating to end of life, palliative care and substance use (see Table 3 below):

*Table 3 – Search terms common to all strands*

<b>Key search terms:</b>	<ol style="list-style-type: none"> <li>1. alcohol* or drink* or drug* or substance or addict* AND</li> <li>2. palliative care or end of life care or dying</li> </ol>
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Studies reviewed were published in peer-reviewed journals between 1<sup>st</sup> January 2004-1<sup>st</sup> August 2016. The rationale for the starting date parameter of 2004 was the publication of key reports concerning end of life and palliative care that year (NICE 2004, Gysels and Higginson 2004). An additional limiter was that the papers were written in English.

After conducting the five separate searches there were limited data generated from the search terms. Specific, well-defined areas that were initially identified could not be found within the literature. Subsequently, the search terms were broadened to capture all the literature within this field (see Table 4 below).

*Table 4 - Final search terms*

<b>Key search terms:</b>	<ol style="list-style-type: none"> <li>1. end of life, palliative, dying, death, life limiting, life threatening</li> <li>2. drug misuse/abuse/use, substance use/misuse/abuse, medication use or abuse, alcohol</li> </ol>
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Inclusion and exclusion criteria were drawn up for each search and applied throughout the screening process; title, abstract, and full text. We also excluded tobacco-related studies. Excluded papers were coded A-E (see coding table below in Table 5).

*Table 5 – Coding table*

<b>A</b>	Is not related to palliative or end of life care
<b>B</b>	Is not related to substance use
<b>C</b>	Is not related to palliative or end of life care nor substance use
<b>D</b>	Not about pathways; not about professional practice concerns; not about family and social networks; not about impact or considerations.
<b>E</b>	Does not meet the above, but is of interest so placed in separate folder.

For ‘borderline’ papers, further discussion took place between two reviewers as to whether the paper should be included in the review. If any disagreement remained, the papers were reviewed by a third member of the research team who had the casting vote. There was no hand searching of references within this REA. Two researchers subsequently read all the included papers to identify initial themes or topic areas.

## 2.4 Data extraction and synthesis

As outlined previously, given the dearth of intervention studies and the limited literature found through the initial searching, a systematic mapping approach was adopted. This facilitated the development of a visual map of the existing literature on the broad topic of substance use and end of life care. It also allowed categorisation of the existing evidence in a number of ways, including its methodology, focus and country of origin (see Appendix 2 of the supplementary appendices document).

Textual narrative synthesis (Barnett-Page & Thomas 2009) was used to explore any similarities, differences and relationships between papers. This was facilitated by a three-step process (Lucas et al. 2007) including:

- 1) Study grouping; in which studies belonging to each of the sub-groups were identified with two researchers independently categorising and theming the papers. If there was any disagreement, a third researcher reviewed the paper.
- 2) Study commentaries were produced in an excel file to summarise key aspects of the papers in relation to the subgroup within which they were included. This included both key findings and/or recommendations that address the aims of this REA. In terms of quality control each commentary was reviewed by a second researcher independently to assess the summary in relation to the original paper.
- 3) Sub-group synthesis was then produced, for example examining aspects of good practice in palliative care within the context of cancer and substance misuse.

## 2.5 Assessing quality and relevance

The quality of the individual studies was assessed based on six principles derived from DFID (2014) guidance (Table 6).

*Table 6 - Criteria used to assess individual empirical studies*

Principles of quality	Associated questions
Conceptual framing	Does the study acknowledge existing research?
	Does the study construct a conceptual framework?
	Does the study pose a research question or outline a hypothesis?
Transparency	Does the study present or link to the raw data it analyses?
	What is the geography/context in which the study was conducted?
	Does the study declare sources of support/funding?
Appropriateness	Does the study identify a research design?
	Does the study identify a research method?
	Does the study demonstrate why the chosen design and method are well suited to the research question?
Cultural sensitivity	Does the study explicitly consider any context-specific cultural factors that may bias the analysis/findings?
Validity	To what extent does the study demonstrate measurement validity?
	To what extent is the study internally valid?
	To what extent is the study externally valid?
	To what extent is the study ecologically valid?
	To what extent are the measures used in the study internally reliable?
	To what extent are the findings likely to be sensitive/changeable depending on the analytical technique used?
Cogency	Does the author 'signpost' the reader throughout?
	To what extent does the author consider the study's limitations and/or alternative interpretations of the analysis?
	Are the conclusions clearly based on the study's results?
	Is the study dealing with an on-going or completed intervention?
	Is it part of a wider initiative or is it self-contained?

A seventh criteria that is commonly used is reliability. It describes how robust results are in the sense of being able to replicate stable results. This was not used as it was found not to be assessable for most of the studies. A further criterion, relevance, was taken into account in the literature search process that produced the evidence base, but was not included as a factor in the quality assessment. The empirical studies in the evidence base were scored on all six criteria (listed in Table 6 above) on a three-point scale reflecting the extent to which the studies followed good research practice:

- 3 = no concerns;
- 2 = some minor concerns;

- 1 = major concerns.

This results in a score ranging from 6 to 18 for each study. Studies were then assigned a quality category of high, moderate or low, based on their score (Table 7).

*Table 7: Quality abbreviations*

Quality score	Symbol	Definition
High (14–18)	↑	Comprehensively addresses the majority of the principles of quality.
Moderate (10-13)	→	Some deficiencies in attention to the principles of quality.
Low (6-9)	↓	Major deficiencies in attention to the principles of quality.

All empirical studies (n=32) referred to in this REA were scored according to these criteria. Table 8 summarises the evidence base found for this REA in terms of types of study and quality. The quality indicator for each individual empirical study is highlighted in Appendix 2 of the supplementary appendices document.

*Table 8: Quality ratings of empirical literature*

Study quality	Symbol	Type of study	Number	% of all studies
High (14-18)	↑	Primary Secondary	9	28.1%
Moderate (10-13)	→	Primary Secondary	18	56.2%
Low (6-9)	↓	Primary Secondary	5	15.6%
Total			32	100%

It is important to note that a low or moderate ‘quality’ rating does not imply that a study was poorly designed or executed, and does not suggest that its conclusions are incorrect or unreliable. It can simply mean that the report of the study did not fully explain its design or methods.

## 2.6 Limitations of methodology

The decision to set the cut-off date at 2004 meant that some studies prior to this date were not reviewed and it is not possible to know how many would have met our inclusion criteria. Nevertheless, agreeing and adhering to a date limiter is an accepted feature of REA’s as is the need to set limits on the retrieval of full texts (Government Social Research and EPPI Centres 2009). Within substance use and palliative/end of life care there are very large associated literatures such as multiple morbidities, problems with chronically ill substance users and issues around cause of death and patterns of particular conditions (for example, head and neck cancers). Capturing the nuances of end of life and substance use within these competing contexts is challenging. For instance, within this REA there appears to be limited published literature relating to alcohol and palliative and end of life issues. There is likely to

have been more literature relating to alcohol had search terms such as liver disease been included. We are aware that other passing references to substance use and end of life care are buried in wider literature. This is not a limitation in the searches undertaken as much as a limitation in systematic review methodologies, particularly where the literature is not well developed. Alternately, complex associations and interactions mean relevant issues (such as substance use and end of life) are not explicitly identified in a piece of research.

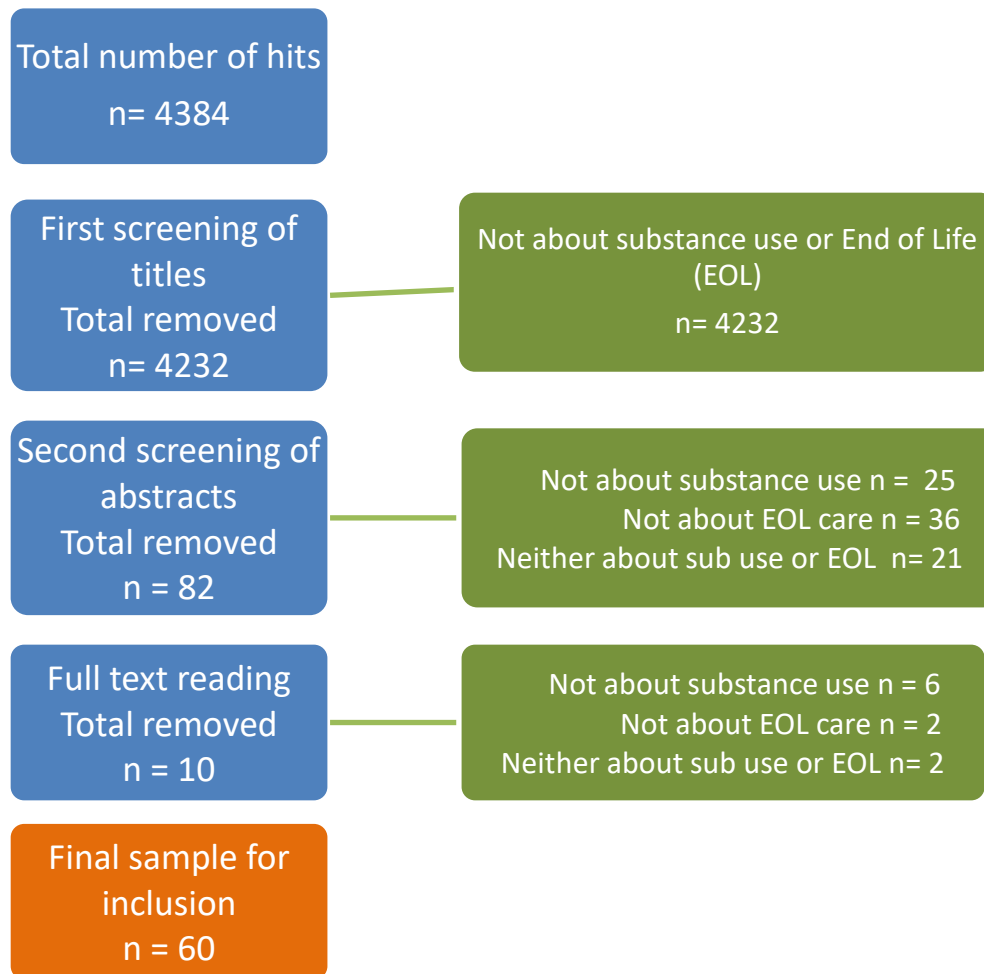
A further limitation related to the challenges of comprehensively identifying relevant material from the grey literature. This is primarily attributable to the very large volume of hits associated with each of our search terms separately and the lack of time within an REA to mine many thousands of hits for relevant data. As a result, the grey literature was excluded from this review and this should be an area of focus for future research.

A final significant limitation is that the papers were predominately from the USA, Canada and to a lesser extent, UK, Europe and Australia. Clearly, there is likely to be significant diversity of both substance use and end of life practices across the globe. Papers from outside this domain are present but are few in number. This is an important finding in its own right, however, it creates difficulties in interpreting the applicability of results since factors such as service provision and broader social systems for delivering help in the context of end of life/palliative care and substance use may differ in a global context.

## Section 3 - Findings

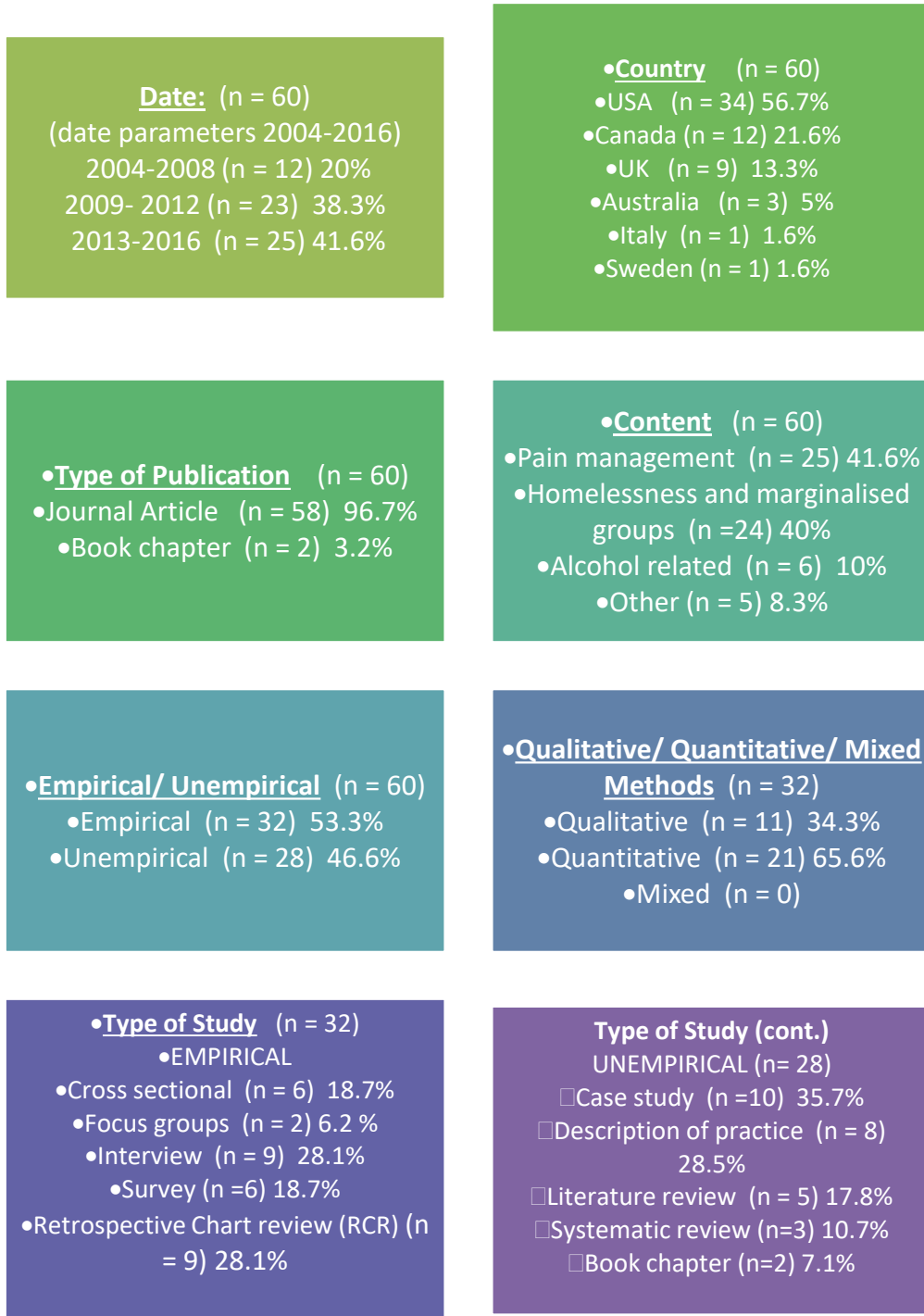
The final search of peer reviewed articles resulted in 4384 hits. After the first screening of titles, the inclusion and exclusion criteria were applied at abstract and full text reading stages (see Figure 3.1 below) resulting in a final sample of 60 papers (Appendix A in this report provides a reference list of all 60 papers).

Figure 3.1 – Review process from initial search to final sample of papers



There were 60 papers generated from the search after applying the inclusion and exclusion criteria. They were, however, extremely diverse in methodology, focus and audience. The systematic map below (Figure 3.2) illustrates the range of evidence found among the 60 papers.

Figure 3.2 - Systematic Map: Substance Use and End of Life Care



1.



The majority of papers found were published in the last decade and were North American (USA or Canadian) in origin. Just over half were based on empirical research of some kind with more quantitative data than qualitative data presented. The greater number of journal articles compared to other sources was a result of our search strategy which focussed on published research. As with other new areas of research, for example sight loss and substance use (Galvani et al. 2016), there were a number of clinical case studies presented in the literature.

As the systematic map shows, the topic focus of the evidence could be grouped around three main themes: pain management (n=25), homeless and marginalised populations (n=24) and alcohol-related papers (n=6). In addition, there were five remaining papers which were diverse in focus and methodology. In terms of these three main categories, there were some overlap within the papers, for example, pain management with alcohol use or within homeless populations, however, the focus of the papers remained predominately within the categories assigned.

### **3.1 Gaps in the evidence**

In addition to what is there, systematic maps helpfully highlight significant gaps in the evidence base. Very little research has been done in the UK on co-existing substance use and end of life care with only eight pieces of UK literature identified. Most published research in this area has been generated in North America. This review was limited to English language literature so it is possible that some additional literature is available in other languages. The dearth of literature on this topic, however, suggests that, if there was additional literature, this would not be a large body of work.

The systematic map also shows that less than two thirds of the literature identified was empirical work with the remainder descriptive papers, book chapters, single case studies, or reviews of literature. It also needs to be noted that several articles by two authors appeared to be drawn from the same research project (McNeil and Guirguis-Younger 2011, McNeil et al. 2012a, McNeil et al. 2012b, Song et al. 2006a and Song et al. 2006b) thus the number of research studies documented in the evidence found does not represent the number of studies undertaken.

The existing evidence is also dominated by quantitative research with approximately one third of it using qualitative methods. This means there is limited research evidence of the lived experiences of those who live and work with co-existing substance use and end of life or palliative care needs. There were no identified papers related specifically to family or carers/supporters of people with substance problems at the end of life. Within all the empirical papers (either quantitative or qualitative) there were only eight papers that documented professionals' perspectives, three that mentioned service user perspectives of family members and carers' involvement, and seven that documented service users' perspective or those with experience of receiving services previously.

Finally, the map shows a narrow and limited topic focus of the evidence to date<sup>1</sup>. The themes identified are drawn from a very diverse literature in both focus and methodology (see Appendix A below). However, the majority focus on some aspects of pain management and prescribing practice where there are, or have been, substance problems and predominantly among people with cancer diagnoses; a small body of work focusses on particular groups of people, primarily homeless people; several papers have an alcohol-specific focus often in relation to cancer care.

There were no intervention or evaluation studies and no practice models that were underpinned by a robust evidence base relating to substance use and end of life care. There was no consensus about what constitutes good practice although there were common underlining recommendations particularly relating to a) pain management strategies involving screening and monitoring and b) harm reduction strategies for homeless/marginalised populations in addressing (and acknowledging) the complex comorbidities in patients with substance problems. There were no studies relating to New Psychoactive Substance use (NPS) and its impact on end of life care. There were only four papers examining older drug users (Beynon et al. 2010a, 2010b, Roe et al. 2010 and Williams et al. 2014). Two papers examined changing mortality of drug users in treatment (Beynon et al. 2010a, 2010b), the third explored the experiences of drug use and ageing (Roe et al. 2010) and the fourth focused on older jail inmates (Williams et al 2014).

In spite of the dearth of research in this area, and the lack of quality of much of the existing evidence, the following section offers greater detail on the results of this REA taking each thematic group in turn.

## 3.2 Thematic groups

To recap, the evidence fell into three thematic groups with seven papers categorised in a Miscellaneous category. The three themes were: Pain Management, Homelessness and Marginalised Populations, and Alcohol-Related evidence. (Details of the all these papers can be found in Appendix 2 of the supplementary appendices document. The reference list for these papers are listed in Appendix A to this report).

### 3.2.1 Pain Management (n=25)

Pain management was marginally the largest category to emerge from the peer-reviewed literature. The majority (n=23) were from the USA with the other single papers from Canada and the UK. The studies ranged from clinical chart/note reviews (Barclays et al. 2014, Childers et al. 2015, Kwon et al. 2013, 2015, Rowley et al. 2011), to small scale case study reviews (Arthur et al. 2016, Burton-MacLeod et al. 2008, Farnham 2012, Kirsh and Passik 2006, Koyyalagunta et al. 2011, Kutzen 2004, Walsh and Broglio 2010). There was also one integrated literature review (Carmichael et al. 2016) examining assessment and risk in relation to opioid misuse within cancer care and two systematic reviews (Chou et al. 2009, Taveros and Chuang 2016). Chou et al. (2009) examined opioid misuse in the context on non-cancer chronic pain, and Taveros and Chuang (2016) examined pain management

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<sup>1</sup> We offer a note of caution, however, in that the thematic groupings are our own and others may group them differently.

strategies for people on methadone maintenance therapy. Five studies used structured questionnaires as part of their approach (Williams et al. 2014, Tan et al. 2014, Childers and Arnold 2012, Knowlton et al. 2015, Blackhall et al 2013).

The remaining five studies were discussion papers:

- Krashin et al. (2012) presented a discussion examining pain where there was co-morbid substance use and presented guidelines in which he suggested all pain patients should be routinely assessed via screening tools, urine drug tests and treatment agreements in the provision of safe, effective pain care.
- A second paper by the same author, also based on expert opinion, offered a further exploration of issues related to risk assessment; including comprehensive history taking to include history of substance misuse, family history of substance misuse, history of childhood abuse and psychiatric co-morbidities. This is within a palliative care context and the authors again suggest the importance of using a validated assessment tool, such as CAGE, (which is a screening tool for problem alcohol use) (Krashin et al. 2015).
- Passik et al. (2009) explored and discussed opioid misuse in cancer care. Screening for, an assessment of, aberrant drug taking behaviour was important as was screening for psychiatric conditions and routine urine testing.
- Pancari and Baird (2014) presented a discussion paper regarding drug diversion for prescription medications within an American context. This relates to people that could potentially divert medications including family/carers and health professionals. One of the contexts was end of life care and systematic monitoring of patients at risk through "home" agreements was encouraged.
- Riesfield et al. (2009) reviewed guidance from existing published literature and suggests recovery programs, treatment, and written opioid agreements are important. He stated clinicians need to treat pain aggressively and address anxiety and depression. Clinicians also need to monitor these patients closely.

In terms of the populations of interest, the majority of papers (n=13) were within a context of pain in cancer care (Arthur et al. 2016, Barclay et al. 2014, Burton-MacLeod et al. 2008, Carmichael et al. 2016, Childers et al. 2015, Kirsh and Passik 2006, Koyyalagunta et al. 2011, Kwon et al. 2013, 2015, Passik et al. 2009, Rowley et al. 2011, Taveros and Chuang 2016 and Walsh and Broglio 2010). One study examined pain in prison populations (Williams et al. 2014) whilst Kutzen (2004) and Knowlton et al. (2015) focused on pain in the context of HIV disease with Koyyalagunta et al. (2011) also exploring a subset of HIV patients.

The other studies examined substance misuse from a general palliative care context (Childers and Arnold 2012, Farnham 2012, Krashin et al. 2015, Tan et al. 2014, Pancari and Baird 2014, Riesfield et al. 2009) with two covering chronic non-cancer pain (Chou et al. 2009, Krashin et al. 2012). A number of papers acknowledged both the complexity of pain management and persistent issues of under-treatment of patients with substance misuse issues (Farnham 2012, Koyyalagunta et al. 2011, Krashin et al. 2015, Kwon et al. 2015, Lum 2003, Passik et al. 2009, Rowley et al. 2011, Walsh and Broglio 2010, Williams et al. 2014). This led most papers to emphasise the need for comprehensive assessment as an essential step in managing pain in people using substances, requiring active engagement from the clinician.

### 3.2.1i Screening tools and processes

In terms of recommendations, screening for substance misuse was a central theme, particularly within the papers examining cancer care (Barclay et al. 2014, Burton-MacLeod et al. 2008, Carmichael et al. 2016, Childers et al. 2015, Kirsh and Passik 2006, Koyyalagunta et al. 2011, Kwon et al. 2013, Passik et al. 2009, Walsh and Broglio 2010). This theme extended to papers examining non-cancer pain (Chou et al. 2009, Krashin et al. 2012, Pancari and Baird 2014, Riesfield et al. 2009) and with general palliative care populations (Farnham 2012, Krashin et al. 2015, Tan et al. 2015). Tan et al. (2015) surveyed Palliative Medicine Fellowship program directors in the USA and most were aware of the importance of screening for substance misuse although 67.6% did not have a written policy. Kutzen (2004) focused on pain within HIV disease and this paper focused on using pain assessment tools, so screening for pain rather than substance misuse.

There was an emphasis on the need to use validated tools (Arthur et al. 2016, Barclay et al. 2014, Carmichael et al. 2016, Childers et al. 2015, Farnham 2012, Kirsh and Passik 2006, Koyyalagunta et al. 2011, Krashin et al. 2012, 2015, Passik et al. 2009, Walsh and Broglio 2010) with some papers recommending or using a particular measure to assess substance use, for example, SOAPP-R, which assesses potential opioid misuse (Krashin et al. 2015, Passik et al. 2009) or CAGE, to screen for alcohol problems (Arthur et al. 2016, Kwon et al. 2013, 2015). From their systematic review, Chou et al. (2009) recommended the need for better screening measures since there was no strong evidence to identify predictors for drug-related behaviours. Urine screening was recommended by some papers to identify patients with substance use problems (Arthur et al. 2016, Barclay et al. 2014, Childers et al. 2015, Kirsh and Passik 2006, Krashin et al. 2015, Passik et al. 2009). Some papers recognised that psychiatric co-morbidities could lead to “chemical coping” strategies and that screening/referral for psychiatric morbidities was an important element of assessment (Burton-MacLeod et al. 2008, Kirsh and Passik 2006, Koyyalagunta et al. 2011, Krashin et al. 2015, Kwon et al. 2015, Passik et al. 2009).

“Chemical coping” was defined in this literature as the potential for patients with a history of problematic substance use to use substances in an attempt to control unmanaged pain. In relation to cancer, Kwon et al. (2015) commented that substances were used “to cope with the various stressful events associated with the diagnosis and management of cancer” (pp 693). Kirsh and Passik (2006) also mentioned “pseudo-addiction”; behaviours that are misunderstood by health and social care staff as drug seeking (when patients “act out” when distressed) rather than originating from poor or inadequate pain control. Kutzen (2004) suggested there was a need to distinguish between tolerance, physical dependence, and addiction, although did not specify how this can be achieved.

### 3.2.1ii Monitoring pain and prescribing

Active monitoring of patients with identified substance use problems was explored in a number of papers. Monitoring activities included pill counting (Arthur et al. 2016, Barclay et al. 2014, Carmichael et al. 2016, Farnham 2012, Taveros and Chuang 2016) and enabling only a limited supply of medication or prescription monitoring programs (Arthur et al. 2016, Barclay et al. 2014, Carmichael et al. 2016, Farnham 2012, Kurtzen 2004, Taveros and Chuang 2016). This population may require more frequent outpatient visits (Koyyalagunta et al. 2011) with Kirsh and Passik (2006) further suggesting that ongoing prescriptions should

be dependent on patient attendance on a 12-step program. Urine testing (including random testing) was also recommended for monitoring patients on opioid therapy with a history of substance misuse (Arthur et al. 2016, Carmichael et al. 2016, Farnham 2012, Koyyalagunta et al. 2011, Krashin et al. 2012, Passik et al. 2009). Some papers suggested written opioid agreements with expectations and rules (Burton-MacLeod et al. 2008, Farnham 2012, Kirsh and Passik 2006, Koyyalagunta et al. 2011, Krashin et al. 2015, Kutzen 2004, Passik et al. 2009, Taveros and Chuang 2016). Some authors also mentioned drug diversion as a potential issue for clinical concern (Krashin et al. 2015, Kirsh and Passik 2006, Pancari and Baird 2014, Tan et al. 2015). This relates to either the patient selling, or their family/friend using or selling, prescribed opiates. They suggest assessing family substance use in order to identify risk and monitor accordingly. This requires health professionals to actively monitor potential drug diversion within this population.

### **3.2.2 Homeless and Marginalised Populations (n=24)**

This group of papers focussed on people who are homeless or precariously housed, those with mental health difficulties (including a paper, Antoni et al. 2012, looking at the experiences of US army veterans), and those with HIV in the context of multiple social problems. Three papers addressed marginalised populations more generally (Doukas 2014; Dzul-Church et al. 2010; Sulistio and Jackson 2013).

#### 3.2.2i Homelessness

The majority of papers in this thematic group focussed on homeless and precariously housed people (Hudson 2016, Collier 2011, Dzul-Church et al. 2010, Kusel and Miaskowski 2006, MacWilliams et al. 2014, McNeil and Guirguis-Younger 2012a, 2012b, McNeil et al. 2012a, McNeil et al. 2012b, Page et al. 2012, Podymow et al. 2006, Song et al. 2007a, 2007b, Webb 2005). Most were qualitative studies conducted in Canada (n=7), with four from the USA, one from Australia and two from the UK. Four papers by McNeil and colleagues in Canada drew on a single primary piece of qualitative work to examine the needs of homeless people, including staff experiences of their needs. They also highlighted some areas of good practice based on their data. These included the provision of alcohol in shelters and proposals for supervised drug consumption in order to increase engagement with palliative care services. The research looked at gaps in services and proposed that some of these could be met by shelter-based palliative care. The work of Song et al. (2007a, 2007b) and Podymow et al. (2006) identified similar issues. Both these authors found that end of life advanced directives were very positively perceived by homeless people including 'do not attempt cardio-pulmonary resuscitation' orders.

MacWilliams et al.'s (2014) case study approach identified similar issues but focused on the consequent difficulties with compliance in treatment. In particular, they discussed what this then meant for pain control and reducing the risks of sudden crisis and deterioration where someone is homeless. Kushel and Miaskowski (2006) identified the usefulness of "patient contracts" as a means of addressing such difficulties using a case-based approach. The remaining papers examining homelessness included one review paper, Hudson (2016) from the UK, Webb (2005) who examined seven UK hostel workers' experiences in relation to supporting homeless people at the end of life and a paper by Page et al. (2012) which looked at causes of death amongst homeless people in Alberta, Canada. The findings of this study showed that most deaths were due to "natural causes"; that is, not the types of death

often associated with drug use such as overdoses and suicides. Page et al. (2012) also proposed that this meant that the circumstances of death could have been improved by more effective delivery of end of life care to homeless persons.

### 3.2.2ii Mental health

Mental ill health arose as a sub-theme in a number of the papers identified in this review. However, mental health was identified as a primary issue in a review paper by Miovic and Block (2007) looking at psychiatric disorders in advanced cancer, and as a co-existing issue in Antoni et al (2012) where it was located amongst the difficulties experienced by US army veterans. Depression is known to be associated with chronic and terminal illness and with pain, both as a factor in causation and as a consequence of illness. This links with the pain literature, where a number of authors suggested screening and referral to secondary mental health services (Barclay et al. 2014, Burton-MacLeod et al. 2008, Kirsh and Passik 2006, Koyyalagunta et al. 2011, Krashin et al. 2015).

### 3.2.2iii HIV

Halman et al. (2014) undertook a retrospective chart review (single institution) from 83 late-stage HIV patients highlighting substance use co-morbidities of a subset of people dying with HIV-related conditions. Two papers from the USA, Karus et al. (2004) and Morgan and Kochan (2008) explored HIV in relation to substance use and end of life and found issues of underlying poverty and a lack of sufficient health insurance. HIV disease *per se* was not seen as an issue for end of life care but rather HIV in a cluster of mental health problems alongside substance use, the combination of which raises the sorts of issues previously highlighted around compliance and pain control.

### 3.2.2iv Marginalised populations

There were four papers addressing what we have termed marginalised populations.

- Doukas (2014), in a discussion paper, explored whether methadone counsellors in Canada were equipped to deal with the multiple morbidities increasingly associated with ageing drug users, proposing that training was needed to increase counsellors' palliative and end of life care skills.
- Dzul-Church et al. (2010) interviewed 20 patients at one hospital in the USA who were terminally ill. The issues associated with dying in poverty and with minimal or no health insurance were highlighted.
- Australian authors Sulistio and Jackson (2013), presented a single case study to illustrate the complex issues that arose in providing end of life care for a person who had used multiple substances and who experienced emotional and social difficulties. They propose that this combination of factors is likely to be increasingly evident among people presenting to services and will raise powerful challenges for staff. Their case study shows how their team addressed these challenges.
- Mundt-Leach (2016) in a literature review recommended that a discussion is needed about what recovery means in the case of addiction at end of life calling for closer working relationships between palliative care and addictions services.

### 3.2.4 Alcohol-related (n= 6)

There were six papers identified that had alcohol as a primary focus (Dev et al. 2011; Irwin et al. 2005; Kwon et al. 2013b; Mercadante et al. 2015; Poonja et al. 2014 and Webber and Davies 2012).

- Dev et al. (2011) undertook a chart review from which 598 patients from the USA completed a screening survey to establish the frequency of undiagnosed “alcoholism” in patients with advanced cancer who were referred for palliative care, and to explore its correlation with alcoholism, tobacco use and use of illegal drugs. These data suggest that alcoholism is highly prevalent and frequently under diagnosed in patients with advanced cancer.
- Irwin et al. (2005) reviewed terminal restlessness<sup>2</sup> through four illustrative case studies, from an Australian perspective, suggesting that alcohol withdrawal may be a contributing factor. They recommend universal screening for alcohol misuse in all patients with advanced cancer.
- Mercadante et al. (2015) conducted a prospective prevalence study of rates of alcoholism (using the CAGE questionnaire) amongst 443 advanced cancer patients admitted to two palliative care settings in Italy. The rates of CAGE-positivity were low in this population. Of those CAGE-positive patients, they were more likely to be male and younger, independent of diagnosis and performance status. The authors highlight the brief alcohol assessment tool CAGE as a useful tool for detecting alcohol problems and suggest routine assessment should be introduced within palliative care settings.
- Poonja et al. (2014) conducted a retrospective study in Canada of 102 consecutive adult patients with liver cirrhosis removed from the transplant list or denied treatment. Records were assessed to determine access to palliative care. Patients who were removed from the waiting list were not often referred for palliative care although many had pain and nausea. ‘Do not attempt resuscitation’ (DNAR) orders and goals of care were seldom discussed with patients.
- Webber and Davies (2012) conducted an observational and cross-sectional study (n=120) on the prevalence of alcohol disorders in UK patients with advanced cancer and found alcohol disorders in this cohort of patients were not associated with the higher symptom burden found in other studies. Prevalence of alcohol use disorders was lower than in the general UK population.
- In a retrospective study, Kwon et al. (2013b) examined patients’ notes to explore patient characteristics of US cancer patients referred early to palliative care. Early referrals were often younger, showed more CAGE positivity, were referred post radiotherapy, diagnosed with head and neck cancer, and presented with a greater number of symptoms.

Five of the papers examined alcohol use in relation to cancer and one related to liver cirrhosis. The prevalence of alcohol use disorders in the advanced cancer population in the US has been estimated at 14-38% (Parson et al. 2008, Jenkins 2000). Webber and Davies (2012), however, found a rate of 18%; a lower proportion than that in the general

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<sup>2</sup> Terminal restlessness is a common end of life symptom (Kehl 2004).

population. To what extent that reflects different rates in the respective US and UK populations is not clear.

Men form the overwhelming majority of problem alcohol users identified in most studies; usually by a factor of more than 2:1 and this continues into the palliative/advanced cancer population. Problematic alcohol use appears to be more common in younger palliative populations (Kwon et al. 2013b). The most frequently used alcohol screening instrument documented in the evidence to date appears to be the CAGE questionnaire although others are used in addition to, or instead of, CAGE. The papers focussed on screening and concerns about "undocumented" alcohol difficulties. This focus on screening for alcohol problems among the end of life care population mirrors the concerns identified in the pain literature around "chemical coping" (Kwon et al. 2015).

Most studies in this section and in pain management (above) find higher symptom burden to be associated with alcohol and other substance use. This may be due to the well-documented link between problematic alcohol consumption and head and neck cancers (Boffetta and Hashibe 2006) and higher rates of smoking amongst alcohol users (Dev et al. 2011). Webber & Davies (2011) found that half of the head and neck cancers cases in their study screened as positive for high-risk alcohol use using the AUDIT tool. Miovic and Block (2007) estimated that 33.6% of those with head and neck cancers in their study met criteria for alcohol dependence.

### **3.2.5 Miscellaneous**

Of the five remaining papers, three focussed on drug-related deaths:

- Beynon et al. (2010a) examined the changing patterns of causes of death amongst substance users in the North West of England. They found the median age of death rose from 36.46 in 2003-04 to 41.38 in 2007-08 and that causes of death were increasingly related to chronic conditions more associated with older age.
- Stenbacka et al. (2010) reviewed changes in substance-related mortality patterns in Sweden. The average age of death was 47 years - 25-30 years less than the general population. Women had lower mortality rates and accidents and suicides were the most common causes of death in younger substance users, with cardiovascular disease and tumours most common amongst older substance users.
- Corkery (2008) reviewed classification issues in drug-related deaths (DRD) in the UK and found DRDs fall into two broad categories; those directly attributable to drug use (overdoses and poisoning) and indirectly attributable, that is, related to drug use such as infections and accidents. The author suggests that more attention is given to direct DRDs rather than the long-term consequences of drug use.

Two papers looked at older drug users in particular:

- Roe et al. (2010) undertook qualitative interviews (n=11) with older drugs users who used a voluntary drug treatment service and found drug use impacts negatively on health and family relationships and support. Many older users lived alone and had multiple experiences of loss.
- Beynon et al. (2010b) reviewed UK patterns of drug use with a focus on older users. They found older drug users presented with particular challenges such as interactions



between legal and illegal drugs, lack of social support, cognitive impairment and issues around managing pain, particularly at end of life.

### **3.2.6 Summary**

In sum, the findings of this REA demonstrated a largely heterogeneous literature, with limited empirical work in any specific area of end of life care for people with substance problems. In the thematic analysis of these studies, pain management was, marginally, the largest category (n=25), followed by homeless and marginalised groups (n=24) and finally, alcohol-related papers (n=6). The majority of studies focused exclusively or predominantly on cancer populations, including 14 studies within the thematic category of pain management and all six of the papers related to the alcohol literature. Within the pain literature, six studies were from more general palliative care populations with three related to HIV and two to non-cancer chronic pain. There were a small number of miscellaneous papers (n=5). In terms of geographical distribution of the published literature, the majority of the studies were from North America, (n=46; 76.7%) with the second largest sample from Europe (n=11; 18.2%). Only eight papers were from the UK. Therefore, the majority of the published literature from this REA is from a narrow geographical area. Within the thematic category of homeless and marginalised populations, the studies focused on mental health needs, HIV and homelessness and often related to service provider response. This category was often represented by studies using qualitative approaches (n=9) and therefore exploratory in nature, examining both service user and service provider perspectives.

## Section 4 - Discussion

This review of the evidence set out to answer the following research question:

What does the existing international research and wider literature tell us about current responses to end of life care for people with substance problems?

Our aims were to:

1. explore and document the evidence base that already exists on responses to end of life care for people with substance problems,
2. identify gaps in the evidence relating to focus and methodology,
3. identify examples of good practice, and
4. highlight future directions for research.

The evidence base has been presented above (aim 1). What is evident is the lack of research on responses and interventions for people with problematic substance use and end of life care needs. There is only a small and diverse literature that lacks depth and quality. The gaps in the existing evidence are many (aim 2), however, this is not surprising in a newly recognised area of practice. Research has yet to respond to the emerging practice needs in a significant way.

The third aim was to identify examples of good practice and highlight the challenges, obstacles or barriers that services encountered in working with co-existing substance problems and end of life care needs (aim 3). In developing the search strategy, search terms were included to identify papers that specifically addressed practice. However, despite trying a variety of terms, no papers were found. The search strategy field was abstracts and but when the final group of papers were read it became clear that there were examples of practice and indicators of barriers or challenges embedded in several papers whose main focus was in other areas, for example, pain management or homelessness.

Identifying "good" practice clearly involves a measure of judgement as to whether the practice described is "good" or "bad". In more well-developed fields, there may be existing quality standards which can be used to measure or review practice. However, this is a relatively new literature and, as detailed above, a diverse and heterogeneous one. Thus, there is no clearly identified consensus on good practice nor are there agreed quality measures. There is also the question of applicability across services; what may be good practice in opiate prescribing in a palliative oncology service is not likely to have broad relevance to controlling alcohol consumption in a shelter with the aim of engaging and retaining people in services. So, in appraising whether practice can be argued to be "good", we have drawn on indicators from other, relevant fields. For example, substance use services have long used harm reduction strategies and low threshold strategies to retain and engage people in the service. As this is accepted good practice, we have identified those papers who share such aims in considering palliative and end of life issues. In the case of the pain literature, there is some similarity in aiming to reduce harm but less consensus as to

how best to achieve this. Here there is also the question of good for whom? There appears to be an emphasis on strategies such as pill counting, short prescriptions and drug urine testing. This may be good practice within a framework of concern about drug diversion and “chemical coping” but not in terms of engagement of ‘hard to reach’ persons or as an effective means of managing pain. In the discussion below we draw out these themes to illustrate both practice examples and where the relevant debates lie.

## 4.1 Good practice recommendations

A number of recommendations<sup>3</sup> for practice emerged from the literature. These have been presented below. However, consideration needs to be given the range of contexts within which they were developed.

### 4.1.1 Managing pain

In terms of good practice in relation to pain management, most of the papers were based on anecdotal evidence rather than strong empirical data. There were, however, some common recommendations from the diverse papers focusing on risk management and risk assessment:

#### Not under prescribing for pain

There was an acknowledgement in a number of papers that the most significant prescribing problem in relation to substance misuse is the persistent under treatment of pain in this population, driven by the inappropriate fear that opioids will be misused (Passik et al. 2009, Carmichael et al. 2016, Farnham 2012, Kirsh and Passik 2006, Knowlton et al. 2015, Kutzen 2004, Lum 2003, Walsh and Broglio 2010, Williams et al. 2014). Indeed Farnham (2012) suggests uncertain prescribers may withhold medication and appropriate doses and this could lead to “aberrant, pseudo-addictive” behaviour in patients. Carmichael et al. (2016), for example, comment that opioid-use disorder in cancer is especially difficult to identify, in part because the problem may be formed in terms of “overtreatment” rather than abuse” (p77).

#### Screening for substance use

Identifying substance use was important for most authors with Arthur et al. (2016) suggesting that drug screening (within palliative care clinics) can be used to initiate an effective conversation about the potential dangers of drug behaviours. Most papers suggested universal screening using validated screening tools. Since distinguishing patients with potential or actual substance misuse issues was challenging, universal screening of patients was suggested by most papers as the best way to accurately capture this population. Urine drug testing was also recommended but generated debate about whether clinicians would have the expertise to manage a positive result (Carmichael et al. 2016). Urine drug testing appeared to be recommended as a secondary screening tool to monitor ongoing compliance to opioid therapy. A number of papers recommended screening family members too and assessing for potential drug diversion (Barclay et al. 2014, Krashin et al. 2015, Tan et al. 2015).

#### Screening for risk factors for substance use

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<sup>3</sup> These are recommendations from the evidence and not those from the research team.

Krashin et al. (2015) also suggested assessing for validated risk factors for developing problems with opioid use, for example, assessing for a history of substance use, including smoking, family history of substance misuse, history of childhood abuse including post-traumatic stress disorder, and psychiatric comorbidities (anxiety, depression, personality disorder).

#### Talking about substance use

Underpinning most papers was the prerequisite requirement of effective and often direct communication (Arthur et al. 2016, Burton-MacLeod et al. 2008, Carmichael et al. 2016, Farnham 2012, Passik et al. 2012, Tan et al. 2015). Whether this happened, how to achieve it, and what sort of strategies would be helpful in managing direct conversations about substance misuse, was not a feature of the current literature. This literature also suggests that clinicians need to distinguish between pseudo-addictive behaviour(s), such as chemical coping and misuse of prescribed medication (Burton-MacLeod et al. 2008, Farnham 2012, Kwon et al. 2015). They may also need to distinguish between active users, individuals in methadone replacement therapy, and those in recovery (Kutzen 2004) and these require comprehensive, expert negotiations that many general clinicians may feel unequipped to undertake.

#### Awareness of harm reduction approaches to substance use

Underlying approaches to substance misuse were articulated by some authors, with harm reduction rather than abstinence seen as a more helpful approach (Burton-MacLeod et al. 2008, Knowlton et al. 2015, Passik et al. 2012). Burton-MacLeod et al. (2008) suggests that the goal should be harm reduction because the person could be too emotionally/psychologically and physically compromised to engage in abstinence programs. There should also be liaison with local substance misuse teams to reach realistic goals (Farnham 2012).

Table 9 below summarises either the good practice identified to date in the evidence or recommendations for practice.

Table 9: Practice guidelines for pain management drawn from evidence

Category	Practice guidelines
Universal screening for substance misuse	Universal screening using a validated tool, for example, CAGE, AUDIT (screening tools for alcohol misuse), ORT, SOAP-SF (Screening tools for opioid and substance misuse).
Ongoing screening and monitoring for substance use	Consider random urine drug testing (UDT). Screen family members to avoid drug diversion. Observe for behaviours associated with addiction (requests for dose escalation, A&E visits, unscheduled clinic visits related to pain complaints, seeking early prescriptions, lost opioid prescriptions, approaching different prescribers, forged prescriptions). During follow- up visits use tools such as Pain Assessment and Documentation Tool (PADT) to assess levels of analgesia, the effect on capacity to self-care, adverse reactions
Safety plans for identified patients with substance problems or high risk patients	Involve and refer to specialist Multi-disciplinary Team (MDT) support that may include psychiatric/ psychological, or drug rehabilitation services. Written opioid agreements with expectations rules and consequences. Consider supervised medicines administration. Use one prescriber. Frequent outpatient appointments. Use slow release pain medication with limited supply of breakthrough painkillers that can be monitored. Pill count. Use non-opioid adjuvant medications <sup>4</sup> whenever possible. Try non-pharmacological interventions (for example, relaxation & counselling).

#### 4.1.2 Homelessness and marginalised groups

The literature identified in this REA did not contain any papers which specifically focussed on recommendations but several of the empirical papers proposed models which may have wider applicability.

The Canadian literature (McNeil and Guriguis-Younger 2012a, 2012b, McNeil et al. 2014, McNeil et al. 2012a, 2012b, Podymov et al. 2006) examined models of innovative and responsive policies and practices emerging from work concerning homeless populations and end of life and palliative care. McNeil & Guirguis-Younger (2012b) looked at barriers to accessing end of life services and at the challenges that these populations present to service provision. Legal substances such as alcohol and over the counter medication did not appear

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<sup>4</sup> Adjuvant medications are used in conjunction with opioids to deal with specific symptoms, an example would be non-steroidal, anti-inflammatory drugs (NSAIDS).

to present barriers to accessing care. This appears to be due to a facility unique to Canada, the Managed Alcohol Programmes (MAPS). These are facilities which dispense alcohol hourly to prevent withdrawal. As the authors make clear, while an in depth discussion of these facilities in relation to end of life care was outside the scope of their work, the presence of such services were clearly perceived as providing stability and opening up access to services which made a significant difference.

The place of supervised drug consumption (McNeil and Guriguis- Younger 2012a, 2012b) was discussed further in McNeil et al. (2014). This study discussed the need to develop such services to break down a significant barrier to access for some people including a "low-threshold service", which explicitly aims to minimise barriers to access. Their proposal was that this approach could be piloted including facilities for supervised drug consumption.

Although this strategy may be difficult to implement for a variety of reasons including legal constraints, the authors proposed that there were indications of the efficacy and cost effectiveness when barriers to access were addressed. They also found that drug use often declined or stabilised and the risk of over-prescribing reduced when greater trust was built leading to more accurate disclosure of consumption.

Delivering services in settings that are familiar to substance using and homeless populations has been trialled in the UK as well as Canada (Hudson 2016). Despite a desire to support harm-reduction and a willingness to facilitate dying in a location of their choosing, some of the studies reviewed by Hudson showed that it was sometimes difficult, due to environmental and resource constraints, to fully achieve these goals (MacWilliams et al. 2014, McNeil et al. 2012a, Webb 2015).

*Table 10: Practice guidelines*

<b>Category</b>	<b>Practice guidelines</b>
Environment(s) of care	Deliver services in settings familiar to service users (e.g. "shelter based care", services in needle exchanges).
Philosophy of care	Use of a harm reduction rather than abstinence only model. Services should aim for low threshold strategies; those with minimum restrictions on service users' normal patterns of behaviour.
Service delivery	Need for services to be flexible and responsive. Need for coordinated care with a case manager/case worker to prevent service users slipping through the gaps. Partnering of agencies to promote joint working.
Safety plans for identified substance misuse or high risk patients	Piloting of supervised consumption (of both alcohol and illicit drugs).

The literature suggests that the implementation of good practice within this population group is challenging for formalised care providers (Karus et al 2004; Dzul-Church et al 2010, Page et al 2012; McNeil et al 2012; McNeil and Guriguis-Younger 2012a, 2012b, McNeil et al 2014, Hudson et al 2016). There is the underuse of primary and preventive services leading to greater use of emergency health provision, particularly for people living with homelessness or substance use or both (Hudson et al 2016). This makes advanced care-planning challenging. There appears to be a lack of flexibility within service provision such as hospitals and hospices, leading patients with substance problems to self-discharge from hospital/healthcare settings due to restrictions on consumption of drugs or alcohol (McNeil and Guriguis-Younger 2012a). Engaging with self care and follow up after treatment is not a priority for this population. The challenges of maintaining treatment regimens and difficulties in attending planned appointments led to interruptions in care and again this makes formalised support challenging. From a patient perspective, previous experiences of mistrust, discrimination or limits on behaviour (for example not being able to drink alcohol or seek and consume illicit drugs) generated a reluctance and wariness to engage with health care (McNeil and Guriguis-Younger 2012a, McNeil et al 2012b). This was also often within the context of underlying mental health difficulties (Antoni et al 2012, Miovic and Block 2007). From a staff perspective there was distress and emotional burden from supporting patients/clients in spite of limited training in both end of life and substance use issues (McNeil et al 2012a, 2012b, McNeil and Guirguis-Younger 2012b).

#### **4.1.3 Alcohol literature**

The alcohol literature was sparse with only six papers included in this REA. The recommendations were similar to the pain management literature in terms of proposing universal screening for alcohol misuse (Dev et al. 2011, Kwon et al 2013b, Mercadante et al 2015). Identifying alcohol misuse was important because it was associated with more distressing symptoms than those patients who did not misuse alcohol (Mercadante et al. 2015), particularly in head and neck cancers (Kwon et al 2013b). Identifying alcohol misuse was also important because it could indicate “chemical coping” as well as a potential underlying mental disorder (Dev et al. 2011). Referring to specialist palliative care services was important since this was often overlooked by health professionals (Poonja et al 2014) as were issues related to alcohol withdrawal at the end of life (Irwin et al 2005).

Table 11: Practice guidelines related to the alcohol evidence

Category	Practice guidelines
Universal screening for alcohol misuse	Universally screening for alcohol misuse using a validated tool (For example, CAGE).
Ongoing screening and monitoring for alcohol use	Routine CAGE screening (younger patients are particularly at high risk of being CAGE positive). Frequent pain assessment. Assessment and treatment of alcohol withdrawal.
Safety plans for identified patients with alcohol problems or high risk patients	Assess for mental disorders. Involve and refer to specialist Multi-disciplinary team support that may include psychiatric/ psychological, or drug rehabilitation services. Frequent review of symptom distress.

## 4.2 Challenges for care responses

There were two broad sets of challenges identified in the literature which may affect the implementation of the practice guidelines above:

1. Achieving safe and effective pain management within the context of an individual's ongoing substance use.
2. Managing the "lifestyle factors" that may be associated with substance use. This latter category encompasses behaviours and a range of anxieties and experiences that the person brings to service contact. The latter challenges may also involve families, friends and acquaintances who present behaviour that is difficult to manage and impacts on others.

In terms of services used, what the literature shows is that substance users are likely to *under-utilise preventive or primary care services* (Hudson 2016, MacWilliams et al. 2014, McNeil et al. 2014), whilst over-utilising emergency services such as A & E. Some of the literature documented how substance users present to emergency services when acutely or seriously ill (French et al. 2000, Thakarar 2015, Wise-Harris 2017). It was reported that they have short admissions with premature self-discharge, and receive terminal diagnoses very late into the illness trajectory. This serves to mitigate against planning for death and high quality care (Song 2007a, McNeil 2012a, 2012b).

The importance of *effective and empathetic communication* by clinicians/professionals was highlighted in the literature (Miovic and Block 2007; Hudson ; Mc Neil 2012a, 2012b, 2014, Burton-Macleod et al. 2008, Barclay et al. 2014, Arthur et al. 2016). In Miovic and Block's paper (2007: p 1672), the authors comment on the need for clinicians to listen; "A chance to be heard and understood, explore fears and concerns, mourn losses, articulate hopes and final wishes, and share the unique meaning that illness has for each individual".



Morgan and Kochan (2008) propose that a *flexible service response* is central to meeting the complex challenges and needs that services are faced with. Similarly, MacWilliams et al. (2014) presented a case study and also interviewed six workers from a variety of settings including a primary care hospital-based team, a hospital-based palliative care team, a long-term residential programme for homeless men, a community-based homelessness nursing team, and a community-based team working with homeless people or those at risk of homelessness. The interviews explored issues of service provision and homelessness in relation to end of life care and showed the need for both flexibility and the importance of coordination by formalised care providers. They proposed that a case manager or case worker approach was the most useful approach.

A paper by Mc Neil et al. (2014) report the findings of a small (n=13) qualitative study of residents in a specialist palliative HIV care facility which enabled supervised drug consumption. They found that residents were more willing to engage with palliative care services if they did not have to hide their drug use. McNeil and Guirguis-Younger (2012b) further discussed harm reduction in a policy oriented paper looking at the place of supervised drug consumption for illicit drug users in palliative care services. The authors comment that whilst much of the existing literature in this field stresses the need to understand the social context for substance use, this is seldom explored: "little attention has been paid to the ways in which the challenges posed by substance use may be compounded by homelessness" (2012b, pp 351). The barriers for people accessing services were competing priorities, for example, accessing illicit drugs, and a sense of exclusion from services. Participants described how continuing illicit substance use and the associated "income generating strategies" (2011, pp 353) led service users to "de-prioritise" health, decreasing routine or preventative contact with healthcare providers. This, combined with a lack of trust and fear of judgement, and feelings of shame led to an avoidance of contact unless acutely ill. The policies and zero tolerance of end of life care providers presented significant barriers to access and many participants felt that the nature of end of life settings, "*quiet, calm, serene*" (p 354), meant that services would exclude people with substance problems based on anticipated behavioural issues.

The two USA papers (Song et al., 2007a, 2007b) which explored the attitudes of homeless persons themselves to death, dying and end of life care, report on aspects of the findings of a qualitative study using in-depth interviews with 53 homeless people. The lack of the presence of a family or close friends assumed in most palliative care models was a space often filled by homelessness workers; a pattern also found in Webb's (2015) study. In the latter case, hostel staff described being with dying residents in their own time "that weekend I spent 17 hours at the hospital in my own time" (p 242) to avoid people dying alone and without a familiar face. They were also involved in vital practical matters such as arranging funerals. Song's work highlighted how important advance directives were to the homeless people they studied and how often it was hostel staff who were named as their surrogate decision makers rather than families or friends. Homeless, marginalised and, what Dzul-Church et al. (2010) termed "underserved patients", include very large numbers of those with substance use problems or histories and lives characterised by trauma and deprivation. They present challenges to services but also frequently have the greatest range of unmet needs, which are compounded when seriously or terminally ill.

### 4.3 Directions for future research

The following research implications have been drawn from this REA:

1. There is a dearth of research evidence on this topic. More empirical research needs to be conducted exploring all aspects of problematic substance use and end of life care. Particularly in non-cancer contexts, prevalence studies, service provision and evaluative research.
2. There is a lack of data from countries outside of North America. Comparative studies would be particularly beneficial to our understanding of the issues and health and social care responses within different cultural contexts.
3. There were few prevalence studies. This is an area requiring more epidemiological research to provide a wider context for policy and practice development
4. In terms of methodological inquiry, more quantitative approaches are needed to provide larger scale data on the experiences and needs of particular populations involved in service provision, e.g. palliative care social workers, community nurse provision.
5. Further research is needed on conditions other than cancer that co-exist with substance use, both in terms of their prevalence and incidence, and also the health and social care responses available to people with experience of both substance use and life limiting illness.
6. Research that identifies models of good practice in working with co-existing substance use and end of life conditions. Such models of good practice need developing, piloting and evaluating for their effectiveness.
7. Qualitative inquiry is required to establish the needs of family and friends of people with substance use problems at the end of life.
8. Such qualitative inquiry should extend to patients' voices which are under-researched.
9. Research must also include the experiences, views and attitudes of social and health care professionals in responding to the overlapping issues of substance use and end of life conditions.
10. There was limited evidence found in relation to alcohol (for example, problematic alcohol consumption at the end of life and/or liver cirrhosis) and end of life care. Further work needs to be done in this area given it is the most commonly used substance after tobacco.

## Section 5 - Conclusion

This Rapid Evidence Assessment set out to explore current responses to, and models of practice for, people living with problematic substance use and end of life care conditions. It was quickly established that there is a dearth of research available on this topic and thus the focus of this review was broadened to identify what evidence was available, its focus, quality, and the gaps in the research evidence base.

The resulting body of work comprised 60 papers, primarily from peer reviewed journals. It was quite disparate in focus, with a wide range of research populations, research questions and methodological choices. The available evidence resulted in three clear, but limited, groups of papers, those focussing on pain management and prescribing, those focussing on alcohol and end of life care and the third group including a body of work on homeless people with a small number of other papers including co-existing mental health or HIV-related conditions.

This is clearly an area of work where far more research is needed. The gaps identified are considerable and need to be filled in order to provide an evidence base on which to build future good policy and practice, both in the UK and internationally.

This report not only sets out the findings of the REA but provides a systematic map of the existing evidence and its characteristics. It also provides a narrative on some of the recommendations and practice challenges which were embedded in the papers reviewed. These can help expand the debate on how best to ensure that the health inequalities faced by people with substance problems needing end of life care can be overcome.

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## Appendix A

FINAL PAPERS (n=60)	Country of Origin
Antoni, C., Silverman, M. A., Nasr, S. Z., Mandi, D. and Golden, A. G. (2012) 'Providing Support Through Life's Final Chapter for Those Who Made It Home.' <i>Military Medicine</i> , 177(12), Dec, pp. 1498-1501.	USA
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Blackhall, L. J. Alfson, E. D. Barclay, J. S. (2013) Screening for Substance Abuse and Diversion in Virginia Hospices, <i>Journal of Palliative Medicine</i> , 16 (3) 237-242	USA
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Carmichael, A. N., Morgan, L. and Del Fabbro, E. (2016) 'Identifying and assessing the risk of opioid abuse in patients with cancer: an integrative review.' <i>Substance Abuse And Rehabilitation</i> , 7 pp. 71-79.	USA
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