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[Galvani, Sarah](#) (2018) *End of Life Care for People with Alcohol and other Drug Problems and their Families: Final Project Report.* UNSPECIFIED. Manchester Metropolitan University.

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November 2018



FINAL PROJECT REPORT

End of Life Care for People with Alcohol and other Drug Problems and their Families

**What we know
and what we
need to know**

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on behalf of the research team



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Introduction

This research began as a conversation about practice. It emerged from an opportunistic conversation with Ms Annette Fleming, the Chief Executive of Aquarius, a Midlands-based alcohol, drug and gambling charity. She reflected on the number of people reaching the Aquarius service when they were very unwell and wondered about the extent to which they were supporting them appropriately. Further discussions with practice agencies supporting people with problematic substance use (alcohol and other drugs) and/or people nearing the end of their lives ensued. The support for the exploration of this topic was overwhelming. We heard how, increasingly, people with problematic substance use were presenting to hospice or end of life care and we heard some of the clinical and practice challenges this posed. Similarly, we heard how substance use professionals were supporting an increasingly older population with complex health and social care needs, and how it was difficult to determine whether such needs indicated someone's end of life.

A preliminary exploration of the literature found few research studies and a large gap in the evidence relating to the combined issues of problematic substance use and end of life (or palliative) care.

This research, therefore, began by laying the foundations; by exploring, systematically, the existing evidence base and whether current quantitative datasets enabled us to draw any conclusions about prevalence and incidence of combined problematic substance use and end of life conditions. It also sought the expertise of key informants; individuals who were leading their area of practice in responding to people with end of life conditions who were, or had been, using substances. As a result, this programme of research set out to explore end of life care for people with problematic substance use from a range of perspectives. It sought the experiences of those who received, or were in need of, substance use and end of life care including people in and out of services. It sought the views and experiences of families, friends and carers, and the views of the professionals who supported both groups.

This research programme, although unique, was exploratory. It has resulted in evidence that advances the policy and practice debates in relation to people with problematic substance use at, or nearing, the end of their lives, but it has also raised further questions and highlighted gaps in research, policy and practice that are yet to be filled.

This report summarises the findings of this programme of research. Each strand of the research programme – six in total – has produced its own full report and summative Briefing report. These are available here: <https://endoflifecaresubstanceuse.com>. This report begins by providing a brief policy context for the research and an overview of the research questions, aims and objectives. The core of this report will be i) the headline findings from across the six strands of the research programme and ii) the common messages from across the project. It will conclude with consideration of the next steps for the development of this research, and its application to policy and practice.

Policy Context

In 2017, the UK recorded 3,756 deaths from drug poisoning (ONS, 2018a). Two thirds of those deaths were a result of problematic drug use (n=2,503). The highest rates were found in the North East and North West of England. For alcohol, the number of deaths was higher. In England alone, the latest figures (2016) showed 5,507 “alcohol-specific deaths” an increase of 4% on the previous year (ONS, 2018b). Most of these were a result of “alcoholic liver disease”. Further, alcohol-specific hospital admissions stood at 337,000 with 39% of people admitted in the 45-64 age group, closely followed by those aged 65-74. On a broader measure, where the secondary diagnosis was alcohol-related, there were 1.1 million estimated hospital admissions in the same time period (ONS, 2018b) with almost half (46%) found in the 55-74 age groups and with more than 200,00 in the 75 years and over age group. The majority of these were for heart problems, followed by mental and behaviour problems, cancer, and alcoholic liver disease. Clearly these figures are only the tip of the iceberg as most people with problematic substance use are likely to sit outside of services and engage only at crisis point.

Policy responses for people with problematic substance use who are at, or near, the end of their lives are addressed by two separate policy contexts: end of life (and palliative) care and substance use (alcohol and other drugs). There is no recognition of the co-existence of these overlapping needs reflected in these policy frameworks.

Substance use policy

Substance use policy at a national level has always responded more readily to illicit drug use compared to its legal partner, alcohol, despite consistent evidence of the higher costs of alcohol-related harm. The British Government’s national drug policy, *2017 Drug Strategy* (H.M. Government, 2017), identifies four priorities; i) demand reduction, ii) restricting supply, iii) promoting “global action” and iv) a ‘recovery’ approach to treatment. It is the latter that is of most relevance to this research given that it focusses on the needs of the people using substances to “live a life free from drugs” (p7). The ‘recovery’ discourse replaces previous harm reduction frameworks and puts greater emphasis on the rights and responsibilities of the individual. For people with problematic substance use reaching the end of their lives, and those working with them, this is not a helpful framework. This policy language and emphasis risks marginalising this group of people further and reinforcing their sense of shame and guilt.

In 2012, *The Government’s Alcohol Strategy*¹ (H.M. Government, 2012), highlighted the increase in alcohol-related liver disease, its cost to the NHS and pointed to the forthcoming Liver Disease Strategy as a response to the increase. The Liver Disease Strategy was subsequently dropped by the Government and never published. Much of the 2012 alcohol strategy directed responses for alcohol-related harm to a local level and regional administrative structures. Most regional budgets have been severely cut as a result of austerity measures, with the result of service losses (Advisory Council on the Misuse of Drugs, 2017) and reduction of people entering treatment (Public Health England, 2018).

¹ At the time of writing, a new national alcohol strategy for England is expected in 2019.

In sum, the national policy context for substance use does little to support this group of people, nor to support the practitioners who work with them. Working towards recovery targets and ‘successful completions’ does not allow for the recognition of substance use staff delivering excellent and dignified care for people at the end of their lives. Thus, while future policy can be improved, it falls to local and organisational levels to build local policy and good practice for this group of people and practitioners.

End of life policy

The consistency in messages from end of life policies in the last decade has been their strength and their weakness. In 2007, the Gold Standards Framework was introduced to support the delivery of end of life and palliative care. It set out three key processes: identify end of life, assess needs and preferences, and plan care. It embellished these processes with the seven key tasks, or the seven ‘C’s’: communication, coordination [of care], control of symptoms, continuity [of care], continued learning, carer support, care in the dying phase (Hansford and Meehan, 2007). A year later, the national *End of Life Care Strategy 2008* (Department of Health (DH), 2008: 10/11) acknowledged the need for everyone to have a “good death” and highlighted the importance of care pathways for commissioning and integrated service delivery where identification of people at end of life was followed by care planning, care coordination, high quality service provision, “management of the last days of life”, care after death and support for carers.

Seven years later, the publication of *Ambitions for Palliative and End of Life Care: A national framework for local action, 2015-2020* (National Palliative and End of Life Care Partnership (NPELCP), undated) set out a similar vision and six related ambition statements. It highlighted the need for “fair access to care”, “joined up care”, “empathetic and competent” staff and a “better response from the health and care system” and from wider society to “sudden, unpredictable or very gradual dying” (p.10/11). The framework also acknowledged the failings in the system including inconsistent end of life care, unequal access to end of life care, fragmented services, staff needing adequate support and preparation for practice, and “poor coordination of services” resulting in “distress” to carers (NPELCP, undated: 11). In the same year, the NHS produced an independent review of National Institute of Health Research (NIHR) on end of life services, *Better Endings: Right care, right place, right time* (NIHR, 2015). Its summary of research highlighted the need to improve care across all settings given the inequalities in accessing specialist palliative care teams, the lack of coordination of services for conditions other than cancer, and the “persistent inequalities in who is likely to die where” with hospices for cancer patients and hospitals for the “deprived” or “very old” (NIHR, 2015: 7). It recognised how both professionals and patients can find it hard to discuss end of life and put advance plans in place. It identified the need for the wider workforce to be adequately prepared to care for people at the end of life, as well as the need for joined up care and “getting care in time”.

Thus, while the vision and ambition delivered in these documents is consistent and the failings are recognised in developing a forward-facing policy, it suggests that not much has changed if the ambitions of 2007/2008 are so similar to the ambitions of 2015. Of particular concern for people with problematic substance use, is whether this apparent lack of progress, together with a lack of recognition of them as a marginalised group, mitigates against any positive moves towards greater access to end of life care.

Research questions, aims and objectives

From the outset this project was designed to be exploratory. No programme of research had previously explored this topic nor drawn simultaneously on the variety of sources as part of its research design. Our preliminary literature searches found very limited evidence of other work with this focus and therefore our research questions were designed to remain broad. In particular, they focussed on identifying current practice responses to people at the end of their lives where there is problematic substance use and to identifying models of care for this group of people, their families, friends, carers and professionals. The project was effectively seeking to establish the groundwork on which to build future research, practice and policy, starting with the 'what do we know' and 'how many people are affected' and moving on to hear people's experiences, challenges and solutions.

We identified six research questions as follows:

1. What does the existing international research and wider literature tell us about current responses to end of life care for people with substance problems?
2. What practice or care pathways already exist to support adults with substance problems needing end of life care, and the families/carers of these people? What facilitators and barriers to end of life care are experienced by individuals and their families?
3. How many people with substance related chronic or terminal illness are receiving, or in need of, end of life care in the UK?
4. How do people with substance problems, past or present, experience end of life care?
5. How do family members, friends and carers (FMFCs), experience the care and support provided to their loved one? To what extent have services been responsive to FMFCs own support needs?
6. What are the challenges and opportunities professionals face supporting people with substance problems and chronic or terminal illness?

These six research questions were addressed in different strands of the research programme. Each strand developed more detailed aims and objectives prior to the commencement of the research. They can be found in the relevant Briefings and full reports for each strand at: <https://endoflifecaresubstanceuse.com>. An overview of methodology for this research programme can be found in Appendix 2.

Headline findings

The following section brings together the headlines from the overall programme of research in a bid to answer the questions we set out at the start.

What do we already know?

The quick answer is very little. The Rapid Evidence Assessment (REA) (Witham et al. 2018) was our primary source of data to address this question. Our focus, initially, was on *current responses* to end of life care for people with problematic substance use. Our hope was to find models or methods of practice with this group of people. However, our early suspicions about a possible lack of research were confirmed by the REA's systematic search of the literature. As a result, the search was broadened beyond 'current responses' to any literature focussing on any aspect of co-existing end of life care and substance use.

Even with this broadened focus, the REA found a dearth of research evidence. Within our date parameters of 2004-2016, only 60 peer reviewed articles were found in the international, English language, literature: of which just 32 were reporting empirical data and only nine of these were categorised as 'high quality' studies. The articles were diverse in focus, methodology and quality and were difficult to group together. However, through identifying the key focus of the papers two main groups emerged: one group centred on pain management and prescribing practice at end of life for people with problematic substance use, either current or historical. These related primarily to people with cancer diagnoses and were North American (USA) in origin. The second group focussed on homelessness and marginalised populations and end of life care where substance use was one of the needs identified. There were a small number of papers relating to alcohol, again focussing exclusively on cancer diagnoses, and a further small group of papers including older people's substance use and end of life care, and patterns of substance-related mortality.

REA – Content headlines

1. There was considerable concern and debate from clinicians about prescribing medication with addictive potential, to people who were or had used substances problematically.
2. The need for skilled assessment of risk factors for, and of, substance use was a common theme, underpinned by the ability to talk effectively about substance use and end of life with people.
3. The need for clinicians to consider how best to support homeless populations including the use of advanced directives, pain control, and reducing the sudden risk of deterioration and crisis, was highlighted.
4. The alcohol papers identified the need for: routine screening for alcohol use, recognition of higher symptom burden associated with alcohol use, and alcohol withdrawal at the end of life, and improved referral to palliative care support.

Gaps in the evidence include:

- little UK-based research
- a lack of empirical work,
- no research focussing on family involvement in care or their needs,
- lack of qualitative research,
- no intervention or evaluation studies,
- no practice models,
- no consensus about good practice.

Certain drugs did not appear at all in the literature, for example, New Psychoactive Substances, and will likely play a role in future dual presentation.

How big a problem is this?

Again, the quick answer is we don't know. The secondary analysis of existing datasets (Webb et al. 2018) found no health or population datasets that contained data to enable an estimation of prevalence or incidence of co-existing substance use and life-limiting or terminal illness. What practitioners tell us is that this is increasingly an issue for them in practice, but no data currently exist that would allow us to quantify this within the freely available datasets. This leaves a tension between practice reports and what policy makers might consider 'evidence'.

Webb et al. (2018) could have used proxy variables, for example, disease type or cause of death, to estimate prevalence but they would be unreliable given the data often record only acute deaths, such as overdoses, and not those indirectly associated with substance use. Further, while alcohol-related conditions, such as liver disease, are possible proxy variables, there is no equivalent for drug-related terminal illness given the range of possible disease types within this group.

In their report, Webb et al. provide summative details of the range of datasets available and what they do and do not report. It appears there is a significant gap in the data recording of co-morbidities or co-existing conditions and behaviours in all the datasets accessed. The authors found that the Office for National Statistics data and Hospital Episode Statistics were the most reliable sources of the single issues, so combining data across the two datasets would give some indication of scale if this were possible in the future.

Webb et al. (2018) also found that deaths attributable or partly attributable to substance use are not always recorded as such, however, the available data suggest that heart disease is the biggest killer among people with problematic substance use. This is no different from the general population except this group of people are more likely to die from it at a younger age. This concurs with our research where people with experience of problematic substance use and end of life care recruited to the study ranged in age from their 30s to their 70s (Ashby et al. 2018).

The data show that end of life care services are weighted towards cancer cases and, while the risk of various cancers increase for people with problematic substance use, there is a far wider range of life-limiting conditions that can affect this group of people. It is heart conditions and non-cancer liver disease which are likely to be the cause of death for many people in this group.

What are the experiences of people with substance problems at or near the end of their lives?

The people with experience of substance use and end of life needs, who took part in this research, were overwhelmingly positive about the care they had received or were receiving from substance use and specialist end of life services. However, this was not the case with their experiences of wider health and social care services – acute care, primary care and social care were criticised.

There was limited information from people with experience on the ways in which specialist substance use services responded when someone was nearing the end of their lives. This may be explained by people leaving or being discharged from treatment as their health conditions worsen but it could also be a result of a substance use service environment that focusses on recovery and has yet to consider the needs of this group of people.

A key message from this group of participants was how people carried with them a substance use identity and how this coloured their experiences with services. Their experiences of, and thus the anticipation of, discrimination and stigma from service providers prevented people from accessing services until they were in crisis. This resulted in late presentation to services and, ultimately, to limited opportunity for end of life care planning.

Barbara, aged 55.

"Having been a social drinker, Barbara developed an alcohol problem as her marriage began to break down in 2004. With the help of the alcohol service, Barbara stopped drinking in 2008 but relapsed in 2012, which resulted in her being hospitalised again. Following a home detox, she relapsed after a stressful event in 2015 and has been receiving support from the alcohol service since then. She has now stopped drinking. Barbara was diagnosed with liver cirrhosis in 2008. It was only on her second hospital admittance, when she refused to leave until someone explained what was happening to her body, that the hospital brought in the local alcohol support service. Following recent internet research on the British Liver Trust website, Barbara asked her GP for a liver function test and referral to specialist liver unit. She now has a diagnosis of end stage liver disease and hepatic encephalopathy. She also has peripheral neuropathy, sleeping difficulties and osteopenia²." (Ashby et al., 2018: 25)

Communication about the end of life, or lack thereof, was a strong theme from the interviews with moving recollections from people about their experiences. Examples include people who had been 'accidentally' told they were nearing the end of their lives by a professional who assumed, perhaps not unreasonably, that the person already knew. Barbara (above) had to issue an ultimatum about not leaving the health care facility until someone explained to her about her health status. Several people mentioned being afraid of what to expect and feeling a lack of control over the end of their life due to a lack of communication. Given evidence suggesting a general lack of communication about end of

² Osteopenia refers to decreased bone density but not to the extent of osteoporosis. This decreased bone density leads to bone fragility and an increased chance of breaking a bone (fracture).

life by practitioners, the failure here may be unrelated to their substance use histories. However, in the context of peoples' negative service experiences, it is reasonable for them to assume their needs are being overlooked because of their substance use.

Where people reported having received holistic approaches to care, these were experienced as far more compassionate and caring than single focussed or short-term care approaches. Examples of good care included staff being available to answer questions and reassure people, and a lack of judgemental attitudes. Such an approach allowed for relationships to build and enabled people to begin to overcome the marginalisation and stigmatisation they experienced as someone with problematic substance use.

How are families' needs recognised and addressed?

Our research found that support for families, friends and carers (hereafter 'families') of people with problematic substance use at the end of life was limited (Wright et al., 2018; Yarwood et al., 2018). While services worked with families, the focus of such work was often on their relative's needs at the end of life and there was little recognition of the families' own needs. For some families their relative's ill health or death was anticipated and, in this context, some took on considerable, demanding caring responsibilities which had a negative impact on their health and wellbeing. Their own needs as carers were often not recognised by professionals before, at the time of, and after, their relative's death. They reported receiving little support from health or social care professionals to prepare them to deal with the stigma they felt having a relative die from substance-related condition, or to help them with the longer-term effects of substance-related bereavement.

Families were often unaware of what was happening to their relative until late or too late as a result of the person avoiding services, presenting to services late, or denying that they had a substance-related health problem.

Kate, early 40s, daughter

Kate told us her father had an alcohol problem all her life. Her father's health deteriorated through his 50s & 60s; he continued drinking, had multiple health problems and no interest in treatment other than support from his GP. Kate talked a lot about his denial about his problematic alcohol use and dying and his 'near miss' (from death) in 2011. Her father was admitted to hospital towards end of 2013 and died after about three weeks. Kate was present during this time and when her father died. However, his denial affected Kate's ability to have conversations with him about end of life wishes. Kate also raised queries about a DNR (do not resuscitate) order and aspects of her father's medication in the final weeks and felt able to challenge decisions through her own professional knowledge. (Wright et al., 2017, unpublished)

For some family members, their relative's end of life condition was a shock and they needed good communication from the professionals working with their relative to understand how unwell their relative was. Furthermore, families described a number of 'missed opportunities' for health and social care professionals to identify end of life needs in the months and years leading to their death as well as poor care – usually from primary and

acute care providers. While good practice was outweighed by poor practice in family reports, their narratives spoke of the importance of feeling genuine care, compassion and reassurance from the professionals around them.

If health and social care professionals can be confident in talking to family members (with permission from the person with experience), and can offer empathy and encouragement to help family members recognise their own needs, their experiences could be improved significantly. This may require training for practitioners or new delivery approaches.

What challenges are professionals facing and how do they overcome them?

It was evident from the substance use and hospice professionals we spoke to in our partner agencies that the commitment to supporting people in a non-judgemental manner was excellent. In many cases professionals went above and beyond their remit to find creative ways to support or advocate for people with experience and their families. However, through both the data collection with this group of professionals, and the data collected from our range of key informants, some very clear challenges emerged.

The challenges fell into three key groups: i) challenges at individual level, ii) at organisational level, and iii) at a wider systems level.

At an individual level, neither group of staff found identifying the ‘other’ issue easy. For hospice professionals this was complicated by signs and symptoms of deteriorating health having two potential causes; their life-limiting condition and their substance use. For substance use staff, the fluctuating nature and impact of a person’s substance use mixed with the impact of poor health and social conditions made identification of end of life more difficult. However, how and when to raise the subject with someone was considered difficult to determine. The key informants concurred and cited this lack of confidence as a barrier to engaging people in discussion about the end of their lives. Further training in how to talk about death, dying, and substance use was seen as part of the solution and may serve to address the lack of routine assessment and lack of confidence or willingness for some professionals to talk about it.

A key challenge for the professionals and the people they supported was the stigmatising health and social care environment people encountered. Many examples were given of services and individual professionals (often from primary or secondary care) discriminating against people with substance problems and failing to give them appropriate care, respect or dignity.

Professionals identified their own frustration, sadness, emotional stress and concerns about personal safety when supporting people with problematic substance use at the end of their lives.

At an individual and organisational level, symptom and pain management was a major challenge with concerns about over- and under-prescribing with calls for guidance on safe prescribing. Another concern was the diversion of prescribed medications by family and friends. This latter group of people could also be challenging, particularly where they also had substance problems or where family responses to their relative’s treatment were not supportive.

At a systems level, having a substance use commissioning and service delivery environment embedded in a 'recovery' discourse when this group of people are not going to recover was, in general, considered inappropriate. The lack of reference to end of life or palliative care in substance use policy, and vice versa, was seen as not helping drive recognition of this growing group of people. A lack of clear care pathways was identified as unhelpful to this cohort whose multiple and complex needs resulted in them needing to navigate a number of services when often they struggled to attend one. The gaps in services, the fragmentation of those services that remained, inflexible service provision, and slow responses from agencies, were all reported as having a negative impact on care provision.

What good practice exists?

Daniel, aged 41.

"Daniel has been a heroin user since he was 15. He has been in drug treatment several times, but never managed to abstain from drugs. Daniel found out that he had hepatitis B and C almost a decade ago and is under the care of his local hospital's liver unit. Over the past ten years he started drinking alcohol as well, but his mother's terminal illness has motivated him to become abstinent before she dies. Daniel has now been engaged with the substance use service for two years: receiving methadone treatment, key worker support and attending an art group. He has stopped drinking. At home he is assisted by a carer for 10 hours a week who makes sure he attends all his appointments and supports him with some social activities. Daniel understands that he is not going to recover and fortunately his carer has had end of life training and so they have both recently attended a Death Café (where people can gather to drink tea, eat cake and talk about death) as a first step in beginning to plan for a good death."

(Ashby et al., 2018: 25/26)

This research sought to identify examples of good practice from the perspective of all our participants. The full reports from each strand of the research provide examples that demonstrate the innovation, advocacy and commitment shown by individual professionals. These ranged from a substance use professional who had considered how to phrase some questions about end of life care planning, to the hospice professional who recognised that her agitated patient was withdrawing from alcohol in the last days of his life and quickly gave comfort by giving him a glass of his favourite drink. There were also a few examples of good practice in partnerships, for example, between a substance use service and a palliative care consultant, where the mutual support provided an improved service. People with experience of services spoke of the care and warmth with which they had been treated – unusual in their experience of other services. A family spoke in glowing terms about substance use staff and one volunteer who had supported them following the death of their relative in very distressing circumstances.

These examples of good practice have been brought together in a dedicated document on good practice (Galvani and Wright, 2019, forthcoming). It draws together these types of positive experiences, others identified in the literature reviewed, examples provided to us by key personnel around the UK, and links to existing resources.

Common themes

A number of common themes emerged from across the different strands of this programme of research:

1. Recognising the importance of communication
2. Understanding the complexity and multiplicity of needs
3. Countering stigma and stereotyping
4. Addressing symptom and pain management
5. Delivering compassionate and non-judgemental care

1. Recognising the importance of communication

Underpinning many of our findings was the vital importance of communication. Figure 1 below illustrates the ways in which communication emerged from this research.

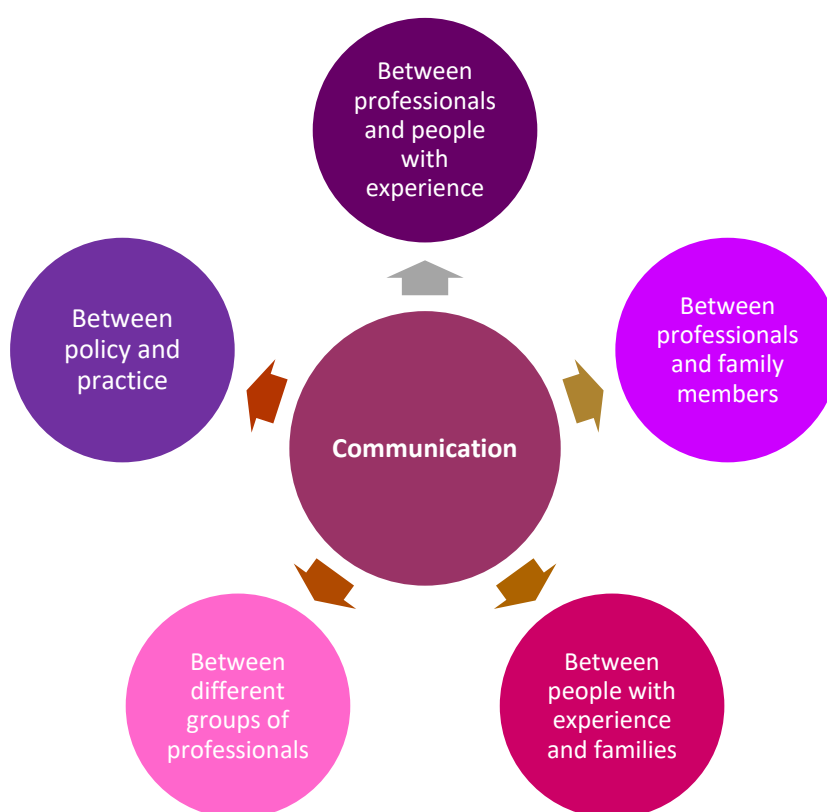


Figure 1. Communication channels

Communication, or lack thereof, sits at the heart of the findings of this project. Whether it was professionals finding it difficult to ask questions about substance use or end of life care, or family members unable to communicate their grief and loss to others for fear of stigma and shame, or professionals across disciplines not having communication channels in place, effective communication was highlighted as an important component of good care. Often it was missing for the participants in this programme of research. In particular, a frequent message was the need for better communication between substance use and end of life professionals to encourage mutual support and training and to help each other with people with the co-existing issues.

Communication failings, through a lack of competence or confidence on the part of professionals, appear to be addressed easily in theory. Solutions include further training and education, greater efforts at partnership working, a commitment to listening to another person’s perspectives, and supporting individuals and families to have conversations about end of life. Both substance use and end of life are sensitive issues to talk about with someone if the person is not prepared and that is equally true for family members, individuals themselves or professional staff. People may fear offending or upsetting the person, showing their ignorance, not wanting to ‘open a can of worms’, not knowing how to begin the conversation and which words to use. In addition, in work and home environments, where time is limited due to hectic daily schedules or lack of staff and resources, communication can suffer.

Improving communication for, and with, this group of individuals, their families and the professionals who look after them, is vital. It is key to helping people needing care to be identified sooner and thus access support and end of life care sooner. People with alcohol and other drug problems can be reluctant to engage with services for fear of a negative response so skilled communication is required. It is imperative that communication reaches out to people and is followed by an offer of something that is helpful and supportive rather than ignorant or condemnatory.

2. Understanding the complexity and multiplicity of needs

A second common theme was the reported complexity and multiplicity of needs presented by this group of people (see figure 2 below). In all strands, there was evidence to suggest that identifying, responding to, monitoring, and providing services to people with problematic substance use at the end of life, was limited due to these overlapping and multiple needs.

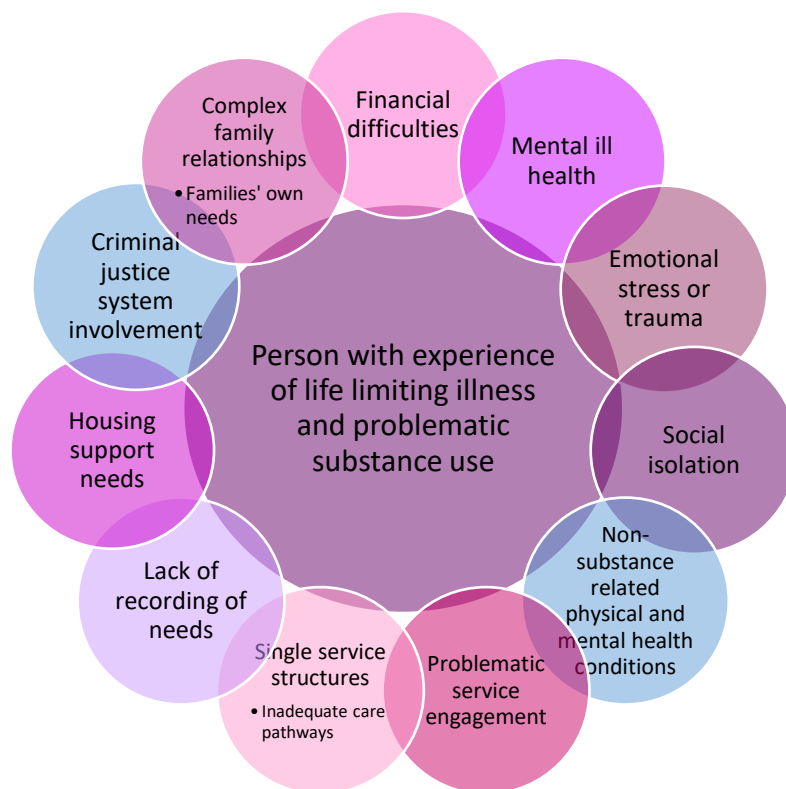


Figure 2. Multiplicity of needs

The REA highlighted how the existing evidence is predominantly cancer focussed and focussed on specific issues, such as pain management, or specific groups of people, for example, homeless people. The dearth of other research evidence from a range of perspectives and on conditions other than cancer shows the lack of attention to this group of people whose needs go far beyond cancer, homelessness and prescribing challenges. However, it may reflect the challenges of researching people with overlapping health and social care conditions.

The research exploring people's experience of substance use and end of life needs showed how they often had to navigate through multiple systems to get their needs met by a range of separate services. This would be at a time when they were least able to do so due to ill health. The need to attend a plethora of services for appointments was off putting and resulted in a lack of engagement. What people found most helpful and supportive was when services met a range of their needs through a holistic service response.

The multiplicity and complexity of needs extends to family, friends and carers who navigate the needs of their relative in addition to their own health and social care needs. Family members may also use substances problematically, presenting challenges to their involvement with their relative's care. The family data revealed the extreme strain families faced in providing care and the range of emotions they faced with little support and no access to resources. Relationships with their relative can be fractured or non-existent or, alternately, engaged and despairing. The data also highlighted how family members could feel ambivalent about providing that care, with the stress and strain of caring impacting negatively on their own health. Families reported little professional attention given to their own support or care needs.

For hospice professionals, the complexity and multiplicity of needs people presented with challenged them to determine which symptoms related to substance use and which related to their terminal illness or other health conditions. This could be particularly challenging because the person's health condition and their substance use could change and fluctuate in short spaces of time. Professionals were not sure when and how to make referrals to other services. They also had to balance care of the relative in the last days of their lives with the expectations of family members which were not always aligned. For substance use professionals, identifying end of life given the range of health and social care needs people receiving formal treatment services presented with was difficult. Their multiple health problems were a barrier to service engagement. Deaths in service were seen as 'unsuccessful [treatment] completions' and no credit was given to the professionals who had supported or worked with people to that point.

Ultimately single focussed services, assessments or models of care are likely to fail this group of people, their families, and those who attempt to support them. A multiple agency team with clear pathways, partnership practice in place which is needs-focussed, is more likely to provide support to all involved.

3. Countering stigma and stereotyping

Hospice Professional

"We got a referral from a hospital team and it was a lady, she was described as an 'ex IV [intravenous] user'. What was really sad about this lady, because she had that label, and that's 20 years since she's been an IV user.... She's not using, but she's still got the label. The sad thing was that she presented at the doctor's several times, and it was assumed she just wanted pain killers, and nothing was done, it was ignored. ... They just kept assuming she was coming back for pain killers. Actually, it turns out this lady, she's riddled with cancer and it was only diagnosed when there was brain involvement. Somebody at last actually listened to her. She's only [in her 40s]. So, when I did the second visit and her sister was there, they were really, really, angry and hurt. They were saying if she hadn't had that [label] on her record, she would have been treated better." (Galvani et al., 2018: 33)

The stigma attached to substance use, and the negative stereotypes relating to the people who have problems with substances, are entrenched. The impact of this stigma and stereotyping can negatively impact the experiences and perceptions of families and carers also. The qualitative data strands of this programme of research heard how such stereotypes resulted in poor experiences of care, summarised as follows:

1. People with experience are reluctant to engage with health and social care services because of previous experiences of negative attitudes towards them.
2. Health problems are attributed to substance use by some clinicians with no further investigations until they have 'stopped drinking' or using substances.
3. Poor or absent care, or lack of timely health care, can lead to increased suffering for the person with experience and their family members.
4. Practitioners make assumptions that people know about their health condition, leading to a lack of communication with the person about it and/or a lack of referrals to substance use or end of life care.
5. Assumptions are made by prescribers about people wanting prescription medication to misuse it, when in fact they are unwell.
6. People do not discuss and/or hide their substance use within end of life/hospice settings due to anticipation of negative attitudes and reduced care.
7. Families, friends and carers feel unable to discuss their relative's ill health because of the shame and stigma about their substance use.

There were also reports of the perception of the hospice environment as serving a middle class, older clientele which, for example, prevented people from accepting a bed when it was offered due to concerns about not fitting in.

Overcoming the entrenched social stigma and negative stereotypes surrounding substance use requires a paradigm shift. While they are not addressed on a national scale, people will continue to experience discriminatory attitudes and behaviour which further excludes them from accessing, or engaging with, the care they need.

4. Addressing symptom and pain management

Prescribing medication to alleviate pain and symptomatology is a concern for end of life clinicians with prescribing responsibility. Research evidence and other literature on this topic quickly emerged as part of this study's Rapid Evidence Assessment (Witham et al., 2018). Among the concerns were people with terminal illness who were 'chemically coping', that is, using substances to top up the inadequate pain relief they had been given. Through both the REA and the qualitative research, it was apparent that end of life clinicians were concerned about under-prescribing pain medication and leaving people in pain. This would be more likely where people had built a physical tolerance to opioid-based drugs through their own substance use. This was counter-balanced with concerns about over-prescribing and risking overdose, particularly if people were not open about their current level and patterns of substance use. Other concerns from nurse prescribers included fears for their own safety when visiting people in homes and communities where other drug users were present, particularly if people knew they had 'prescribing pads' with them.

Clinicians were concerned about under- and over-prescribing pain medication for people using substances or with substance use histories.

Further concerns related to 'drug diversion', that is when medication prescribed for an individual is used by people other than the person it is prescribed for. People at end of life can be prescribed 'Just in case' medication to take home for additional pain relief. This was a concern when family members and friends of the person were known to have substance problems. The use of safes for medication in people's homes and lockable boxes were some of the solutions found.

However, there were also reports of individuals with histories of substance use refusing opioid-based medication, even in their final days and weeks of life because of concerns about triggering their previous problematic substance use, fear of future withdrawal symptoms, or of not being in as much control as possible at the end of their life. This presents a different set of challenges for clinicians prescribing pain relief.

Research participants expressed the need for guidance on prescribing for this group of people at end of life; some to support their own practice and others to share with wider agencies. While evidence from the REA advised a comprehensive screening tool for substance use should be used by palliative and end of life clinicians, the professional participants reported the need for guidance that balanced adequate pain relief with respecting someone's choice to continue to use in the final period of their lives.

5. Delivering compassionate and non-judgemental care

Nephew, in his 20's

"There was only one nurse on that ward in the whole time [he] was there, that was decent, that did her job...she was absolutely lovely...she was the one that made sure that [he] got everything he needed and nothing was too big for her, no job was too big or small, she would help if she could and everything you asked, she made an effort for."
(Family) (Templeton et al. 2018)

Literature within the REA and the qualitative data collection of this research promoted the need for compassionate and non-judgemental care. People with experience, and their family members, talked about a key professional or group of professionals who had been caring and supportive and had treated them well.

What is chastening is that this type of care was not a routine occurrence for this group of people; compassionate and non-judgemental care was a new experience for many of them. There were examples of professionals from our partner agencies advocating for people, being innovative and creative in their practice, going above and beyond what might be expected of them.

Where both professionals and people with experience had worked in, or received, a holistic model of care, this worked well for them. Meeting people's needs at their starting point and recognising their priorities was a key component of that care.

Unfortunately, not all health and social care providers offered such care, the result of which ranged from disrespectful treatment to people avoiding service engagement. For some the result reported was an undignified and uncomfortable death. The reported reason for this appears to be the person's current or historic use of substances. It speaks further to the need for better training at qualifying and post qualifying levels for health and social care professionals, but also stronger public health messages that remove the stigma and negative attitudes towards people with problematic substance use.

Substance use professional

"The thing that strikes me most about people is the loneliness and the isolation. And I've worked with a couple of people, probably about three or four people in the last six months that have died at home on their own. They've been in hospital, they've been diagnosed with predominantly liver complaints, physical health complaints and have deteriorated and deteriorated until they've passed away - usually on their own. So I think ... the thing that strikes me is, I suppose, it's the feeling of hopelessness that clients have."

(Galvani et al., 2018: 32)

Next steps: what needs to change in policy and practice?

Each strand of this research programme has identified the implications for policy, practice and further research. Full details are available in the respective reports (<https://endoflifecaresubstanceuse.com>). The research team was keen to propose recommendations and changes that could be delivered in the current climate of austerity but there are gaps in policy and services that will need time and/or money invested if the needs of people with substance problems at end of life are to be fully met. The following section offers an abridged and summarised version of policy and practice recommendations.

Policy

National

1. There is a need for greater reciprocity in national and local policy, where palliative and end of life care policy considers the needs of people with substance use concerns, and substance use policy considers the needs of those with palliative and end of life care needs. A focus on health inequalities and access to services would be appropriate.
2. Data needs to be collected routinely and systematically to begin to establish trends and the scale of the co-existing problems.

Local/regional

3. Development of local and regional level policy is needed that brings together substance use and end of life care agencies and relevant front-line partners. Such a group can work towards a policy framework which is responsive to local needs, local ambitions, diverse cultural contexts and considers current funding and service pressures in seeking ways forward.
4. The potential role that communities could play warrants particular attention – not least in reaching out to individuals who are reluctant to engage with formal healthcare services.

Organisational

5. Development of policy on working with people with overlapping end of life care needs and substance use is required. This should include policy decisions on access to appropriate services for this group of people, routine questioning, recording and monitoring of substance use and/or end of life care needs, appropriate responses, joint working and referral practice, to name a few. It should be accompanied by practice guidance and training as appropriate.

Cross cutting policy

6. Public health messaging must begin to address the stigma and stereotypes about people with substance problems and their families. For many people, it interferes with providing a quality of life and dignity in dying and death. It also would support family bereavement after their relative's death.
7. For this group of people, the dominant policy discourse of 'recovery' from substance use is not appropriate. Practice models built around it could further marginalise this group of people and inhibit service engagement.

8. There needs to be explicit inclusion of harm reduction models in substance use policy at all levels for this group of people and for the professionals who support them.
9. A more holistic approach to support for people with multiple complex health and social care needs is also required to overcome the current problematic and ineffective single-issue treatment pathways. This needs to be evidenced in both end of life and substance use policy at a national and local level.
10. Greater consideration at all levels of policy needs to be given to support for families, both in their role as carer or family member, and to meet their needs *in their own right*.
11. Improved monitoring and surveillance of service accessibility for disadvantaged patient groups will require more detailed and specific data collection at service delivery level but may need to be driven by national policy asks.

Practice

1. The development of effective local partnership working protocols between substance use and end of life care agencies is needed to support both sets of staff in responding to challenges as they arise. Such partnerships should extend to wider health and social care agencies where possible including mental health and social care.
2. Training and practice guidance at an individual and organisational level about working with these overlapping issues is required for both substance use and end of life care professionals. Integrating training with other specialists would be ideal. This training should include understanding the implications of having a 'substance user' identity, how to talk to people about the 'other' issue (including communicating end of life diagnoses clearly), addressing feelings of guilt and shame, caring with compassion, and advanced care and safety planning.
3. Substance use services need to pay greater attention to identifying people with multiple complex health needs who may die prematurely. This will enable them to explore, and potentially access, appropriate palliative or health care services in a timely way.
4. Family service provision within existing end of life and substance use services needs reviewing or introducing. Active recruitment of families may comprise community outreach and hospital inreach to encourage engagement with services.

Practice recommendations

1. Develop local partnerships.
2. Introduce training and practice guidance.
3. Earlier identification of multiple and complex needs.
4. Review and introduce family service provision.
5. Provide emotional support to staff.
6. Increase specialist end of life care capacity, to respond to a more diverse population.
7. Consider delivering end of life care in a range of accommodation types.
8. Ensure education on end of life and substance use on all professional courses.

5. Ensure that professionals within substance use services are supported to cope with end of life care, loss and bereavement and that professionals in end of life services are supported to cope with the emotional and clinical challenges of supporting someone with problematic substance use.
6. Greater capacity is required in specialist end of life care services for people with complex and less predictable end of life conditions. Consideration also needs to be given to the increasingly diverse characteristics of people at the end of their lives with problematic substance use, for example, a younger age group. This may require separate service provision when budgets allow, particularly for those whose behaviour excludes them from hospice provision but who still require support and care at the end of their lives.
7. As suggested by the literature in the Rapid Evidence Assessment, consideration should be given to delivering end of life care within the shelter and hostel system to meet the needs of homeless people with substance problems at the end of their lives.
8. Introducing education on substance use, end of life and palliative care in professional qualifying programmes will also lead to a more informed workforce. This would include medical and nursing training, counselling and substance use professionals, and wider health and social care professionals.

Next steps: research and resources

This section highlights further research questions and resources that could helpfully be developed to support practice with people at the end of their lives with problematic substance use.

Research

1. What would be the best model or approach to supporting people with experience of problematic substance use and life-limiting conditions in developing an effective model of care. This needs to combine qualitative and quantitative measures to ensure people's experience of service provision is captured.
2. What are the best models of practice for supporting families?
 - a. Establish a programme of research and evaluation which is designed to understand how best to support families and the positive outcomes that services, interventions or practice models may have.
3. Will linking of Hospital Episode Statistics palliative data and Office for National Statistics mortality data allow us to obtain a measure of disease type and hospital provision? Access to case identifiers (via patient records) removes the necessity of using proxy variables.
4. What would be the cost savings of intervening effectively at earlier stages, thereby minimising repeated use of emergency or non-elective health and social care services?
5. What impact will newer drug groups, such as New Psychoactive Substances, or over the counter drugs, have on morbidity, mortality and end of life care.
6. What are some of the main barriers to effective end of life communication?
7. How does care need to differ to meet the needs of sub-groups of people with substance use and EOL concerns – for example, by gender, age, ethnicity, nature of substance use?

Resource development

1. Examples of good practice were scattered throughout the qualitative research and in some of the evidence reviewed. Collation of this good practice, supplemented with additional interviews with some key informants, would be a first step to supporting practice. Further guidance could target specific professional groups.
2. Policy briefings need to be developed that propose a set of standards for working with this group of people. A previous example of this is *Dying Well in Custody Charter: A national framework for local action* with an accompanying *Self-Assessment Tool* (Ambitions for Palliative and End of Life Care Partnership, 2018a, 2018b).
3. There is a need for guidance on prescribing for people with current or historical substance use, and how they can be addressed while not compromising the care of those who wish to continue drinking or taking drugs.

Conclusion

This research programme was designed to explore end of life care and substance use, drawing on a range of sources and from a range of perspectives. Specifically, it sought to identify current responses to people with problematic substance use needing end of life care, and their families. While no practice models were found, a broader exploration of the existing evidence, combined with the collection of new empirical data, has shed important light on existing practice and care.

This research was conducted in collaboration with our practice and community partners, as well as our people with experience advisory group and our national advisory group. These research partnerships have led to a body of new research knowledge, as well as the development of new and innovative methodologies. Without this partnership practice this research would not have been possible.

There are some examples of dedicated and innovative practice in our research findings. However, we found more examples where health and social care practice fell short. We need to learn lessons from both and plan for future care in partnership across specialist areas of practice. Importantly, the need for better and more skilled communication at all levels was highlighted and we need to explore further why such communication has presented the difficulties for, and barriers to, care provision identified in this research.

This is a unique and timely project borne of a practice concern about improving services for people with problematic substance use who were at, or near, the end of their lives. The complexity of their multiple needs was repeatedly highlighted through the course of this research. It is evident that no current single service will address such needs. Given the UK has a rapidly ageing population, with evidence of problematic substance use increasing among older age cohorts, there is a need for urgent attention from policy and practice alike.

End of life care for people with problematic substance use is a new area of research and practice. Much of the work to date has focussed on specific populations and specific health conditions, primarily cancer, but there is a lot more to learn about this group of people. It includes a population dying at a younger age, in full or in part, as a result of their problematic substance use. There is also much work to be done in terms of supporting the primary care givers: family, friends and carers. This project is only the tip of the iceberg.

Perhaps the key challenge in taking this research forward is the need to balance the moral argument, for better care and dignity in dying for this group of people, with an economic argument which is more likely to persuade commissioners about the need for change. However, to begin to do so, there needs to be recognition of the issues, and a willingness to identify and record need. This research suggests we still have a long way to go.

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Appendix 1. Terminology

Substance use

Throughout this report we use ‘substance use’ to refer to the use of alcohol and other drugs, including prescribed medication. Problematic substance use is the terminology used when someone’s use of substances has become problematic in some aspect of their lives, for example, health, relationships, criminal justice involvement, finances, housing.

End of life

Our definition of ‘end of life’ accords with the General Medical Council definition (2009):

“People are ‘approaching the end of life’ when they are **likely to die within the next**

12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.”

(Gold Standards Framework, 2017: online).

Appendix 2. Methodological summary

Table 1 (below) provides an overview of each research question and the corresponding data collection and analysis methods adopted. The range of methods we adopted included traditional methods of data collection, for example, Rapid Evidence Assessment or Focus Groups, to those less known, for example, SAQD (secondary analysis of qualitative data).

For the research with people with experience of substance use and end of life needs, members of the team developed a new data collection methodology, Person-Centred Evolving Method (PEM) (Ashby, Clayson and Wright, 2018). Essentially, a toolkit of data collection choices, the PEM resulted from debate about how to best collect such data from a group of people whose health and social circumstances may not allow data to be collected in more traditional ways and who may be considered vulnerable and easily exploited. Full details of the PEM can be found in the Full Report entitled, *Interviews with people at the end of life: End of Life Care for People with Alcohol and Drug Problems* (Ashby, Wright and Galvani, 2018).

People with experience advisory group

In addition to more traditional methods of data collection and analysis, the PWEAG (People with Experience Advisory Group) played an important role in supporting the research process. Through the project's community voice partner, VoiceBox Inc³, people with experience (PWE) were involved in the research process. Some people in the PWEAG sat outside of services, others were receiving or had previously experienced, relevant services either for themselves or a family member. These were people who may normally be considered 'hard to reach' when in fact they were quite easy to reach when approached in the right way. The involvement of an intermediary from VoiceBox, Amanda Clayson, who already had relationships in relevant community spaces, facilitated this process. She was able to advise the team on the right approach to involving people meaningfully in this research and led to the team learning more about how, where and when to involve people.

Further details of the work of the PWEAG and the importance of their involvement are available in a separate report (Clayson, 2018) at: <https://endoflifecaresubstanceuse.com/reports-and-resources-2/>

³ Voicebox Inc. is a community-based enterprise driving change through community-led activities from research to practice development to social action. It works co-productively and creatively through real and raw capture and communication of people's lived experience.

Table 1 – Summary of research questions and methods used

Research question	Data collection methods and sample size	Data analysis methods
1. What does existing international research tell us about current responses to end of life care for people with substance problems?	<ul style="list-style-type: none"> • Rapid Evidence Assessment 	<ul style="list-style-type: none"> • Systematic mapping • Thematic narrative synthesis
2. What practice or care pathways already exist to support adults with substance problems needing end of life care, and the families/carers of these people?	<ul style="list-style-type: none"> • Key Informant semi-structured Interviews Sample size: n = 21 	<ul style="list-style-type: none"> • Template analysis
3. How many people with substance related chronic or terminal illness are receiving, or in need of, end of life care in the UK?	<ul style="list-style-type: none"> • Secondary analysis of existing datasets in substance use and palliative care 	<ul style="list-style-type: none"> • Review of current national mortality data • Critical reading of reports on mortality and morbidity estimates
4. How do people with substance problems , past or present, experience end of life care?	<ul style="list-style-type: none"> • PEM (Person-Centred Evolving Method) Sample size: n = 11 	<ul style="list-style-type: none"> • Thematic Analysis (Braun and Clarke 2006)
5. How do family members, friends and carers (FMFCs) , experience the care and support provided to their loved one? To what extent have services been responsive to FMFCs own support needs?	<ul style="list-style-type: none"> • Secondary analysis of qualitative data (SAQD) – ESRC dataset on families bereaved through alcohol and drug use. Sample size: n = 102. • Individual unstructured interviews Sample size: n = 18 	<ul style="list-style-type: none"> • SAQD and template analysis • Template Analysis
6. What are the challenges and opportunities professionals face supporting people with substance problems and chronic or terminal illness?	<ul style="list-style-type: none"> • Online or paper-based survey. Sample size: n = 113. • Focus groups. Sample size: n = 7 groups (43 people) • Individual semi-structured interviews. Sample size: n = 10 	<ul style="list-style-type: none"> • Descriptive analysis of numerically coded survey data. • Thematic analysis of narrative survey data • Template Analysis

Appendix 3. Acknowledgements

The Research Team

The research team for this project comprised 10 academics from Manchester Metropolitan University, two independent research consultants with extensive experience of research in the substance use field and a specialist in community partnerships and co-production. Team members represented a range of disciplines and varied methodological preferences. At different stages of the project the team comprised:

External team members

- Lorna Templeton – Independent Research Consultant, Bristol
- Amanda Clayson – Founder, VoiceBox Inc
- Dr Fiona Duncan – Independent Research Consultant, Manchester

Manchester Metropolitan University: Department of Psychology

- Dr Jo Ashby – Head of Department of Psychology

Manchester Metropolitan University: Department of Social Care and Social Work

- Professor Sarah Galvani – Professor of Adult Social Care
- Dr Gemma Yarwood – Senior Lecturer in Adult Social Care
- Dr Cherilyn Dance – Research Fellow
- Dr Sam Wright – Senior Research Associate
- Dr Marian Peacock – Senior Research Associate

Manchester Metropolitan University: Department of Nursing

- Dr Lucy Webb – Reader of Psychosocial Health
- Dr Gary Witham – Senior Lecturer
- Professor Carol Haigh – Professor of Nursing
- Professor Josie Tetley – Professor of Nursing (Ageing and life-long conditions)

Acknowledgements

We thank the Big Lottery Fund for their support of this project from its inception to its completion and beyond.

We thank the Project Advisory Group for their support, ideas and reflection and our Project and Community Partners Group for their partnership working and willingness to practically support this research.

Project Advisory Group	Project and Community Partners Group
Viv Evans OBE, CE, Adfam	St Trinity's Hospice, Blackpool
Annette Fleming, CEO, Aquarius	St John's Hospice, Lancaster
Dr Sean Hughes, University of Lancaster	St Catherine's Hospice, Preston
Andrew Misell, Alcohol Concern	Aquarius, Midlands
Alison Colclough, St Luke's hospice	ADS, Manchester and Oldham
Chris Clarke, Joint Commissioning Manager, Solihull Drug and Alcohol Action Team	VoiceBox Inc
Tony Bonser, Hospice UK (formerly NCPC)	
Marcus Green, Age Concern	
Leza Quate, Palliative Medicine Specialty Doctor, Queen Elizabeth University Hospital, Glasgow	
Additional contributions from:	
Richard Rodgers (Strategic Lead -Specialist Services Network, GM Mental Health NHS Foundation Trust) and Dr Jonathan Dewhurst, Lead Consultant	
Tony Ryan, Tony Ryan Associates	
Max Vaughan, Commissioner (Substance Use), Public Health England, Birmingham	
Fiona Duncan, Trustee, St Catherine's hospice	
Pete Smith, Commissioning Manager, NHS Fylde and Wyre CCG, Preston	
James Armstrong, Phoenix Futures	
Alistair Sinclair, UK Recovery Foundation	
Sammie Weston, Inspire Lancaster	

Finally, we would like to thank the People with Experience Advisory Group (PWEAG) for their willingness to listen to what we wanted to do then help us to shape it for the better. Their experiences and voices have been documented as part of the Project's outputs.

