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# RESEARCH REPORT

## Key Informant Interviews:

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

“We need to be developing services [that] provide the same level of care around end of life for people with drug and alcohol problems [as they] would if they were dying from anything else... everybody deserves as good a death as we can help them to have.”

(Frontline Health and Social Care Practitioner)

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July 2018



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## **Acknowledgements**

We thank the Big Lottery Fund for funding this research and the wider project of which this research is a part. We also thank all the interviewees who gave their time so generously to speak with us.

## **Glossary and notes on terminology**

- EoL – End of Life.
- PC – Palliative Care.
- REA – Rapid Evidence Assessment.
- KI – Key informant.
- OST – Opioid Substitution Therapy.
- Client/patient – these terms have been used interchangeably to reflect the terms used by interviewees. They refer to the person receiving the service they offer.
- PWE – Person with Experience. This is the preferred term of the research team for a person with both substance use and end of life care needs who may, or may not, be using a service.

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## Executive Summary

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1. The aim of the Key Informant (KI) interviews was to investigate existing models of practice or care pathways for supporting adults with substance problems needing end of life care, and their families/carers, from the perspective of people who were living or working with these overlapping issues or in close proximity to them. The interviews were conducted at the start of the project so their findings could inform our understanding of some of the key policy and practice challenges faced by those working, and living with, people with substance problems and end of life or palliative care conditions. They also helped to shape our thinking about the wider project design.
2. A total of 17 interviews were completed with 20 people – 16 professionals, one service user and three family members from the same family. The professionals were a diverse group with expertise in palliative and EoL care, and substance use.
3. Template analysis of the interview data identified two overarching themes: i) the wider landscape of EoL care and substance use service provision; and ii) engaging and responding to people at the end of their lives who have a history of problematic substance use.
4. These two overarching themes included seven broad themes: i) the size and nature of the problem; ii) service commissioning and delivery; iii) definitions and perceptions of substance use and end of life; iv) engaging clients; v) (not) talking about the issues; vi) managing and developing care responses; and vii) families and networks.
5. There are six headline findings from the analysis:
  - i. First, current definitions and ways of understanding palliative care, and substance use recovery, do not easily apply to people with current or previous problematic substance use and EoL conditions.
  - i. Second, this group of people is not a straightforward one – there are often complex and multiple physical, psychological and social morbidities which impact upon their identification, engagement with services and the delivery of care.
  - ii. Third, there are significant issues with the fragmentation and inflexibility of service providers which affect the care they receive. However, it is possible to identify the characteristics of a good joined-up and compassionate approach to care.
  - iii. Fourth, substance use receives little attention in national or local policy around palliative and EoL care; and palliative and EoL care receives little attention in national or local policy around substance use.
  - iv. Fifth, prescribing for pain and/or symptom management for people with substance use and EoL conditions is a complex area but good practice is achievable.
  - v. Finally, family members of people with substance problems at the end of their lives can be viewed negatively, and receive little support both at the end of their relative's life and after their death.
6. The KI interviews have given a unique, and hitherto unknown, insight in to the experiences and challenges of working with adults with substance use problems and life limiting conditions. Interviewees identified numerous individual, organisational, and strategic challenges to identifying this group and delivering timely, efficient, joined up and compassionate care. It is clear that there is much to do to better meet the needs of a sizeable, but largely neglected group of adults and their families – these interviews offer constructive suggestions for how care can be improved.

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## Section 1 - Background

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There are growing public health concerns about the morbidity and mortality of people with alcohol and/or drug problems and the care which they receive, the current climate in which substance use treatment services are commissioned and delivered, and inequalities in substance use treatment, palliative care (PC) and end of life (EoL) care (ACMD, 2017; Adfam, 2017; Aldridge et al., 2017; CQC, 2016; Marie Curie, 2015).

The experiences and needs of families of people with substance use problems, including those who have been bereaved by substance use, have also been highlighted (Andersson et al., 2018; Valentine, 2018). Overall, however, there is a paucity of research about EoL care for people with substance use problems and their families, and a lack of policy and practice attention about the specific experiences and needs of these cohorts of patients and families and of the professionals who have contact with them. There has also been a lack of research which has investigated professional views on caring for this group of patients and their families.

Our programme of research on *End of Life Care for People with Alcohol and Other Drug Problems* has six strands. This report presents data from Strand 6, which aimed to investigate existing models of practice and care for supporting people with substance problems needing end of life care and their families/carers. The remaining sections of this report outline the methodology employed to conduct and analyse the interviews, the findings, and a discussion of the key issues.

Ethical approval for the KI interview study was obtained from Manchester Metropolitan University (ethics application 1389). Given the mixed methods nature of the wider programme of research, ethical approval was sought solely for qualitative data collection from key informants for this strand and from strand 5 of the research focussing on professionals working within our partner agencies. Informed consent was given by all participants.

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## Section 2 - Methodology

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### 2.1 Overview

At the start of this project, the research team identified a number of individuals, Key Informants (KI), who worked in this, or a related, area through contacts in both substance use and EoL services and through existing literature on the topic. To ensure the project was asking the right questions, and doing so from a point of some knowledge, we decided to conduct a small number of interviews with these key individuals. This would ensure that, for example, the Rapid Evidence Assessment (REA) was using the correct search terms and exploring all relevant literature. As we spoke to people they told us of others and the group of individuals grew. It was clear that the data emerging from these discussions was hugely informative, particularly given the range of people we spoke to and their varying professional and personal experiences. It therefore became a full additional strand of research and developed into a small semi-structured interview study, rather than simply a consultation to inform the questions and parameters of the REA. The KI interviews also informed the development of Strand 5 of the project which sought to identify what challenges and opportunities professionals face when supporting people with substance problems and chronic or terminal illness.

### 2.2 Recruitment of interviewees

Recruitment was an iterative process which combined purposive and snowball sampling. The aim was to select individuals working both nationally<sup>1</sup> and locally from a range of disciplines and perspectives (policy, practice, research) and from both the substance use and EoL fields. Some interviewees were found through existing literature, others were already known to members of the research team, while the remainder were suggested by KI themselves. The original aim was for approximately 15 interviews – this target was set pragmatically rather than with an aim of data saturation or comprehensiveness, and was deemed appropriate for the exploratory nature of the project.

### 2.3 Interview process

The interviews were undertaken by one researcher<sup>2</sup>. Semi-structured interviews meant that there could be a focus on *a priori* topics identified by the researcher while allowing for flexibility to explore and develop the participants' responses. The interview guide was developed in collaboration with members of the research team based on the project's main research questions. As the KI interviews were at the early stages of the research, the topic guide identified broad questions relating to the person's experience of working, or living with, both substance use and end of life care. These included:

- i. Asking about the key challenges and opportunities people faced when someone had both substance use and end of life care needs.
- ii. Identifying, where possible, current models of practice at individual and organisational levels.
- iii. The relevance of the policy context at regional and national levels.

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<sup>1</sup> Usually in England or Wales although one interviewee was based in Scotland.

<sup>2</sup> The PI (Principal Investigator) completed one interview.

- iv. The organisations people work with or access.
- v. Any awareness of projects already working in this area.

The early interviews led to some minor changes being made, for example the order in which topics were explored in the interviews. Interviewees tended to speak freely about their experiences and views meaning there was a need to refine the questions to prompt for more, or different, data.

All the 17 interviews were conducted face-to-face; 15 in person and the remaining two conducted by an internet-based telecommunications system, Skype. All interviews were audio-recorded and transcribed by an external transcribing agency, which had signed a non-disclosure agreement with Manchester Metropolitan University prior to the project starting.

## 2.4 Analysis

Qualitative analysis was undertaken using template analysis (King, 2012), with some use of thematic networks to help visualise the emerging codes and themes (Attride-Stirling, 2001). QSR NVivo 10 was used to organise the data. Template analysis is a form of thematic analysis which combines structure with flexibility and is most commonly used to analyse individual interviews (King, 2012). It can combine 'top down' with 'bottom up' analysis, and allow the use of both *a priori* themes and themes which emerge from the analysis itself. Template analysis has been used in a qualitative study which explored family carers' experiences of out-of-hours community palliative care (King, Bell & Thomas, 2016) so it was known to be appropriate for this area of research. Figure 1 summarises the application of template analysis to the dataset of KI interviews and the final analytical template is in Appendix 1.

A small number of broad *a priori* codes were considered when starting the analysis, based on discussions with the researcher who completed most of the interviews, the interview topic guide, and broad knowledge of the area and some of its literature (for example, through the REA). Examples included commissioning, asking about substance use or EOL, and uncertain illness trajectories. As the analysis evolved these *a priori* codes were integrated in some way as major or minor themes. Analysis was challenging because of the diversity of the interviewee cohort. This diversity meant that the early stages of analysis involved more reading of the transcripts so that the most representative template could be developed (King, 2012). Some codes were more common across the whole dataset while others were relevant to subsets of interviewees (for example, according to their area of expertise and their focus).



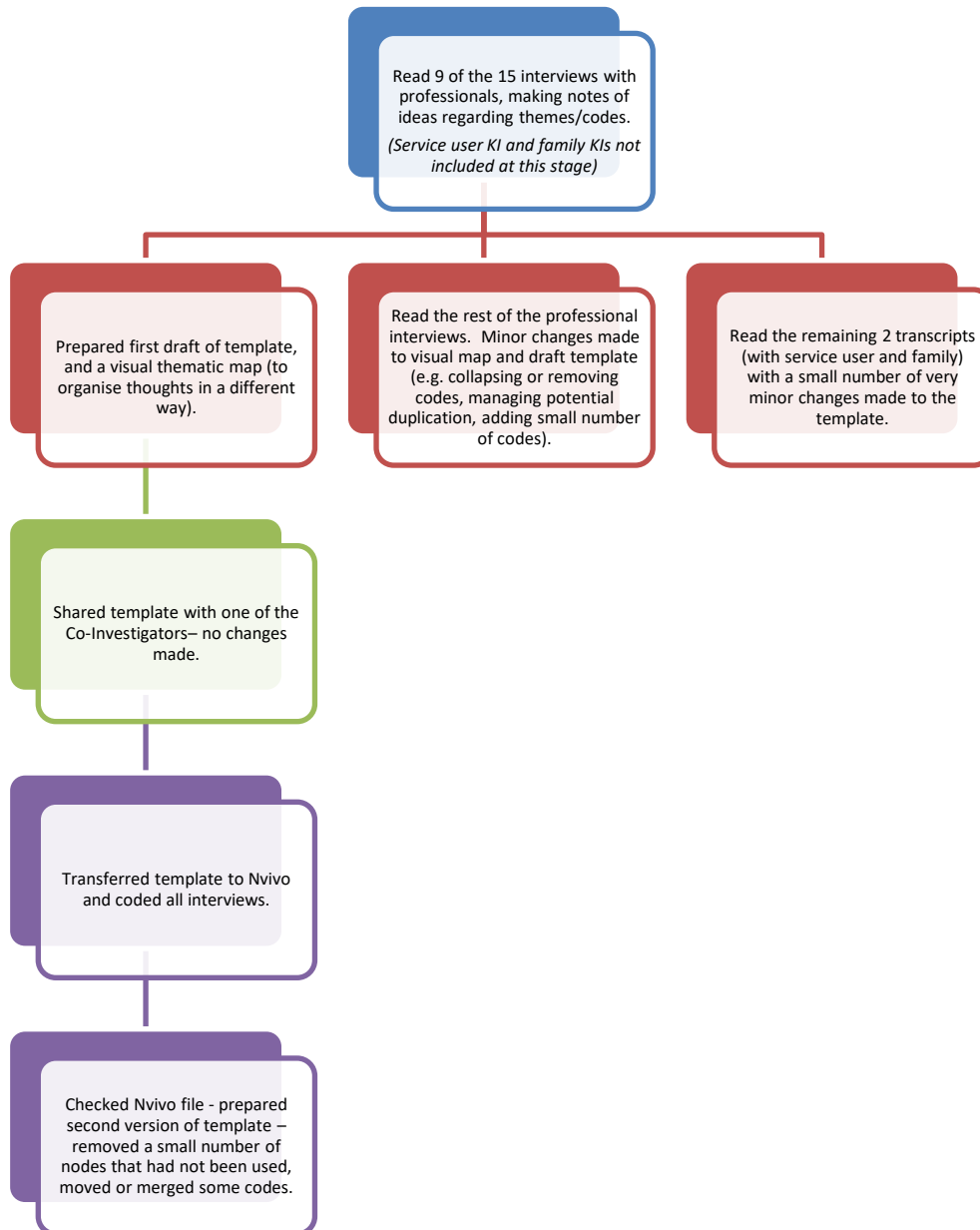


Figure 1: Application of template analysis to KI interviews

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## Section 3 - Findings

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### 3.1 Description of the KI interview sample

A total of 17 interviews were completed with 20 people. Interviewees consisted of 16 professionals (two were interviewed together), one person with lived experience (PWE) and three family members (FMs) from the same family who were interviewed together and talked about the same relative who had died. The 16 professional interviewees were a diverse group who can be broadly grouped as follows:

1. **Group 1 (n=8)** - Frontline health and social care professionals (HSCP) working at a local level – a GP (also a regional lead for substance use), a specialist EoL social worker, three clinical nurse specialists, a homelessness nurse specialist working in a hostel, a prison worker, and a specialist in EoL care and homelessness at a homeless charity.
2. **Group 2 (n=4)** - Senior health and social care professionals working at a local level – a CEO of a drug/alcohol treatment service, a palliative care consultant, a consultant hepatologist, and a registered premises manager (bail hostel).
3. **Group 3 (n=2)** - Those working nationally in policy or commissioning – one in substance use and one in palliative and EoL care.
4. **Group 4 (n=2)** – Other Professionals – a coroner and a researcher.

Analysis identified seven broad themes (see Figure 2 below) which were grouped into two thematic clusters. The two clusters were ‘the wider landscape’, and ‘engaging and responding’. Each of the seven themes will be discussed in turn and illustrated with verbatim excerpts from the interviews (quotes from the professional KI interviewees are classified by the groupings listed above).

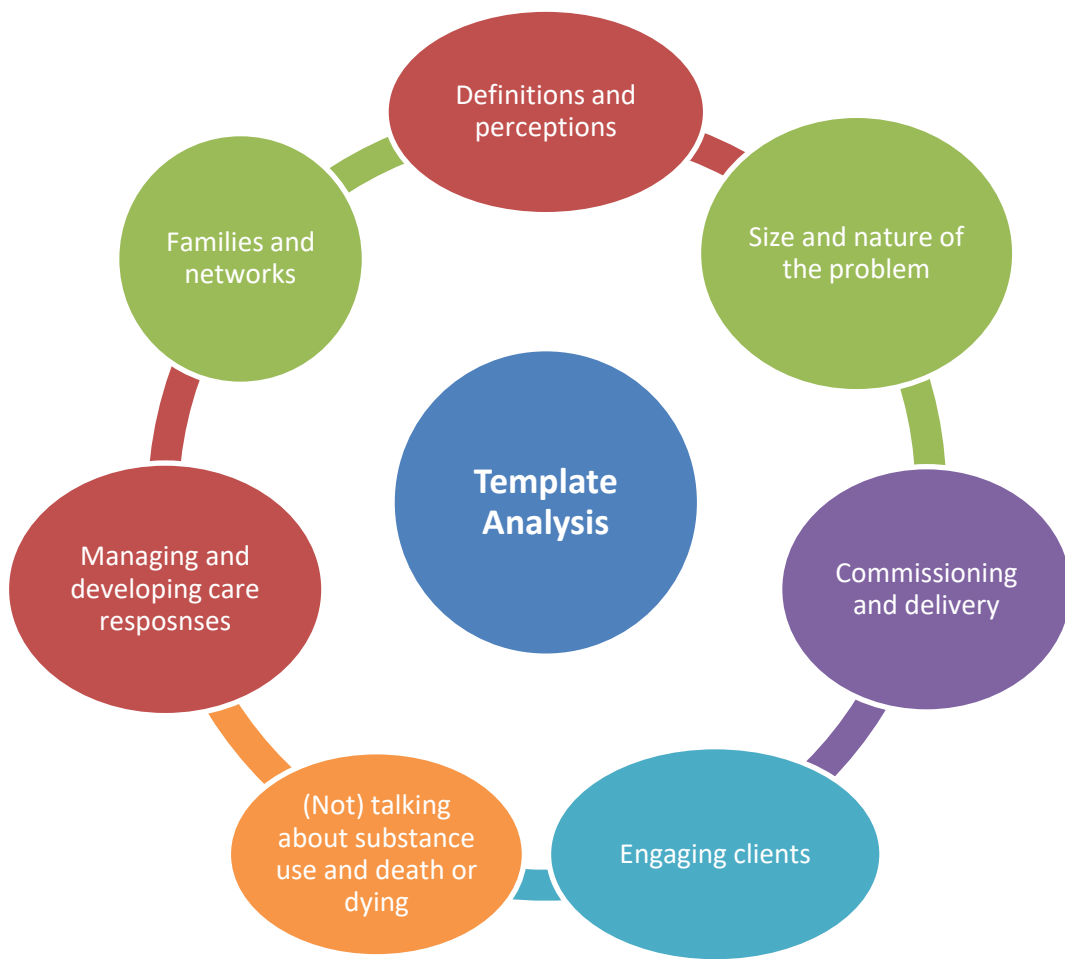


Figure 2: Template analysis broad themes

## 3.2 Thematic Cluster 1: The Wider Landscape

The first thematic cluster was 'the wider landscape', and this covered three broad themes - definitions; size and nature of the problem; commissioning and delivery (Figure 3).

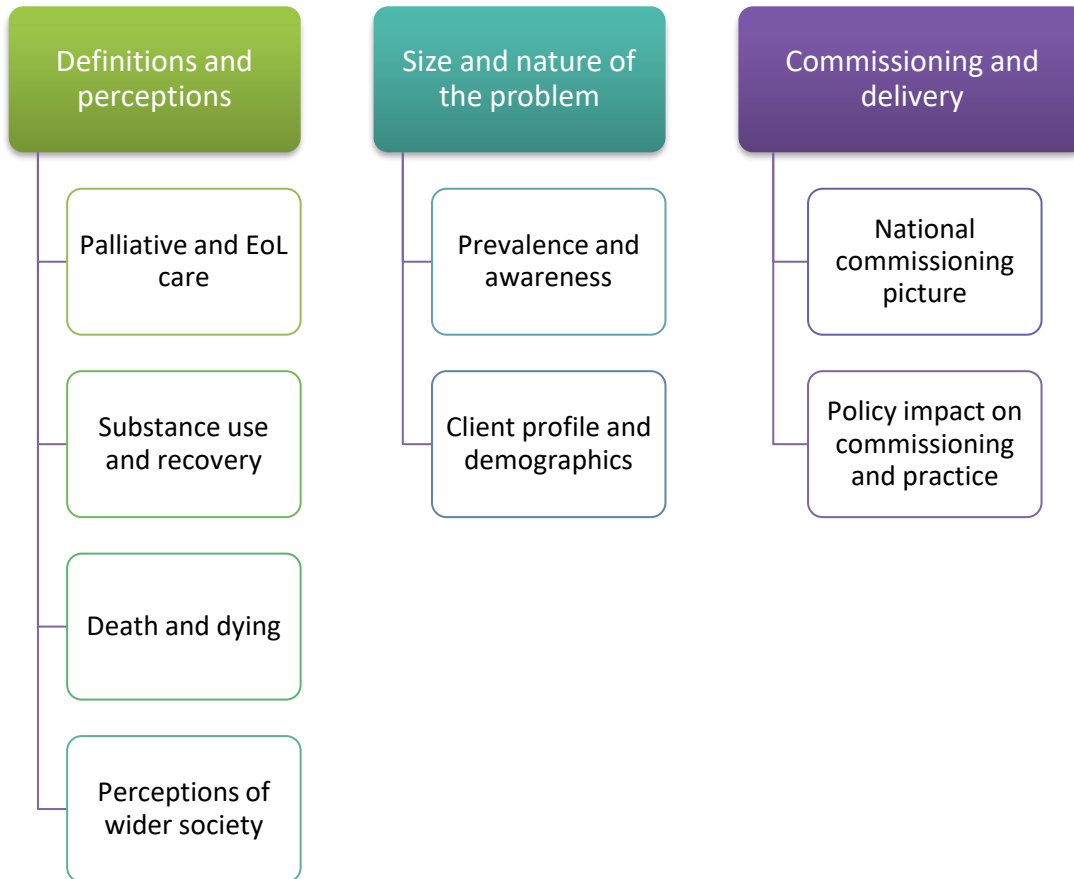


Figure 3: Thematic Cluster 1 - The Wider Landscape

### 3.2.i Definitions and perceptions

Interviewees talked about how palliative and EoL care, substance misuse and recovery, and death and dying, are defined and how these definitions and perceptions can facilitate or impede care. This theme also includes what interviewees said about how society perceives this group of people.

#### *Palliative and EoL care*

Interviewees talked about this at both a general level and with specific consideration of people with substance use problems. At a general level some interviewees thought that palliative care should not be seen in “binary”, i.e. in black and white, terms and as something which is only about dying; rather it should be something that runs parallel to treatment. In the quotes below one interviewee thought that a narrow definition of palliative and EoL care risked ‘giving up’ on some people, while another reflected that it made it harder to argue that palliative care and treatment can be delivered in parallel:

[It feels] like it's giving up which is very much based on this [idea of] you have to stop one sort of care before you start another, but I think that's slowly changing and so it is improving (Group 2 - Senior HSCP)

[It's] harder to push the duality of care message (Group 3 - Policy & Commissioning Professionals)

Other interviewees felt that the term EoL care can be too rigidly and narrowly interpreted. One said that using the term 'palliative care' (for example, when discussing palliative care registers) can be a "*double edged sword*" which can facilitate or damage interactions with challenging and complex patients. Such patients may feel that their situation is completely hopeless and continue with damaging levels of substance use as a result. Another interviewee described their preferred interpretation of palliative and EoL care:

...palliative care is not putting somebody into the side room in the last two days of life and putting on Radio 2, it's about having a serious period of time where you can plan what you want to happen towards the end of your life... some sort of understanding of mortality can be helpful and it's often done intuitively over many, many consultations and I certainly don't think we should sort of be really forcing it down people's throats, some people don't want to see it but at the moment there's just not the toolkit there to do it, if you want to. (Group 2 - Senior HSCP)

Interviewees recognised the need to ensure that the terms palliative and EoL care are defined and understood in ways which ensure that they are relevant to all illnesses and conditions rather than their (often narrow) application to cancer:

...[discussing] palliative care with people with substance use issues needs a bit of a re-brand...it's a huge bombshell to drop on somebody with no plan of action going forward. But I do appreciate that it can, on the one hand, have very detrimental effects but...we need to ensure that people can make informed choices about their future as well...it's a person-centred approach that palliative care/end of life care, needs to take... (Group 1 - Frontline HSCP)

At least one interviewee emphasised the need to consider how to best adapt the definitions of palliative and EoL care for conditions like liver disease because of the unpredictability of the condition:

So the steady decline that you see in malignancy, which is where palliative and end of life care developed as a specialty and a lot of the evidence base is around that, is not there in liver disease, so that unpredictability of the trajectory, which can sometimes even result in survival from the disease, makes it very difficult. (Group 2 - Senior HSCP)

Some interviewees also identified a need to be clearer about the role of key professionals and services in the delivery of palliative and EoL care, such as Macmillan nurses, palliative

care nurse specialists and hospices. Although not directly mentioned, the implication from this is that there needs to be a greater understanding that such professionals do not just work with cancer but are there to work with groups such as people using substances.

### *Substance use and recovery*

When thinking about substance use and addiction, interviewees tended to focus on the recovery paradigm which is currently dominant in UK alcohol and drug treatment<sup>3</sup>. There was consensus from many interviewees that the general definition of recovery and its application to treatment does not apply to those with EoL issues and that this disconnect makes the delivery of care extremely difficult. As one interviewee said, “*dead people don’t recover*”. Another interviewee talked about the focus of substance use treatment being on prevention, management and recovery and, as a result, ignoring the fact that some of this group will die:

So there is something about the end of life care prospect that is invisible to this group of people...the talk never gets to the fact that people die, so the talk is always about prevention, self-care, best management and I keep having to say but they will die at some point so when are we going to deal with this?...I wonder if that is also what happens in the addiction clinics...all the services that have contact with this group of people, whether actually the focus is all on that first bit and not about, or not even acknowledging that last bit and I wonder why. (Group 3 - Policy & Commissioning Professionals)

Interviewees discussed the relevance and appropriateness of recovery-oriented approaches within EoL care for those who cannot or do not want to ‘recover’ from their substance use. Some people would rather be supported to drink or take drugs at the end of their life, or they are not able to address the other issues which are often the focus of recovery and associated service targets. A focus or insistence on recovery can alienate clients:

...within the drugs movement now, there is this big push around recovery, recovery... for some people who find it impossible to come off drugs, whether just because they see that the big push is around recovery, that even more marginalises them because they think, ‘I can’t recover and what do I do?’ so all these services are badged ‘recovery’, it’s all about recovery and someone is coming in thinking, ‘I don’t know if I can get there, I’m not there yet’. (Group 2 - Senior HSCP)

...the majority of services really are focused on recovery – so if you’ve got somebody with liver disease that realistically isn’t looking very likely to recover, all of the services are directed at detox and at rehab, whereas there’s certain people [where] that’s not going to happen or it’s unlikely to happen. (Group 4 – Other Professional)

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<sup>3</sup> In recent years stemming from a consensus statement which defined the process of recovery from substance use as characterised by “voluntarily-sustained control over substance use which maximises health and well-being, and participation in the rights, roles and responsibilities of society” (UK DPC, 2008 – see <http://www.ukdpc.org.uk/publication/recovery-consensus-group/>)

However, one interviewee wondered if recovery was misunderstood and interpreted too narrowly:

...what they see is a very abstinence oriented, recovery focused policy and we've been trying, we've been at pains since 2010 to point out that that isn't the policy, the policy is still one of balance, that you should have more ambition for people's recovery but that that isn't the same as curtailing treatment or keeping people out of it. (Group 3 - Policy & Commissioning Professionals)

### *Death and dying*

Interviewees talked about how death is perceived, usually in Western societies as something to be feared and ignored and not talked about, and how this impacts upon notions of what is a 'good death' and where the right place to die might be. There was general acknowledgement from a small number of interviewees that there is discomfort in acknowledging that death occurs within this group of people:

As soon as you come to see me, because you've got decompensated cirrhosis in a liver clinic, your chance of dying is high the second you walk in the door. We don't really face up to that. (Group 2 - Senior HSCP)

Interviewees voiced concerns that the nature of this group of people (their substance use, their other illnesses, and their wider personal/social circumstances) can make some professionals and patients question whether in fact a 'good death' is possible for them. As will be seen later in this report, it is important that those providing care open channels of communication with their patients so that such feelings can be expressed and discussed:

People that traditionally are taking drugs, have got a higher tolerance [of medication] and they're terrified when they come to end of life of being in pain and not being given enough drugs... A lot of people just want reassurance that their end of life will be as comfortable as it can be. Again, it's just getting people to voice that concern and that it will be addressed. (Group 1 - Frontline HSCP)

Often people towards the end of life, if there are any outstanding issues, they become really agitated and restless and things and you can tell that things are mulling over in their mind and that might be something that they can be quite honest and say, 'I wish that...didn't happen', 'I wish I could have done things different' and sometimes it's enough just to have had a conversation around that and acknowledge how difficult that must be for them. (Group 1 - Frontline HSCP)

Interviewees debated what a good death and the right place of death might be for this group of people. Some interviewees talked about how the circumstances of the group, and how their self-perceptions (or their belief in how they are perceived by others), can influence where they die and their views about that:

...all the stories that involve hospices, palliative care, end of life care, the 'nice' end of that is never associated with unpopular groups; it's never associated with the homeless, people in prisons, people with substance abuse, it's always about people who are dearly beloved, lots of family and friends, children, almost as though that's too precious for this other group...a beautiful hospice may feel very alien to somebody who is not used to that, for whom life is completely alien now anyway with facing a life threatening condition. (Group 3 - Policy & Commissioning Professionals)

Further, the circumstances of some patients may mean that a hospice or home are not the best places for dying, and that a hospital might be the best place for EoL care and death (for example, when complex clinical care is required for someone with liver disease at risk of variceal bleeding). However, some interviewees thought that hospital staff must be able to provide personal and compassionate care alongside such complex medical care:

We're a hospice and we think everybody should die in a hospice because that's the place to die...or at home preferably...but actually, from what I've seen, the gentleman who's poorly, if he dies on the ward where he goes in and out of all the time, that would be okay because he knows them, people are kind to him on there...how cocky of a hospice worker to think they shouldn't die in a hospital. When I was a hospital nurse, I'd have been really annoyed if somebody felt that I couldn't provide that care and some of the nurses and doctors are absolutely superb, so why not? They will die with dignity in a hospital but what I'd like to see and what my bosses would like to see is choice and that's not what they're getting, they get no choice. (Group 1 - Frontline HSCP)

Other interviewees also discussed the applicability of hospice care for some sub-groups of people such as younger patients, homeless people or those who wish to continue drinking or taking drugs. For example, the service user interviewed talked about attending a hospice in his mid-40s, saying that he felt he was in the "*wrong place*", a view echoed by one other interviewee:

... there's only one other person here that's even remotely near my age... I feel almost too young to be here but obviously there's no age limit to illness...[I'm] definitely in a minority (Service user)

...where do you place a young man who's 35 years old, who meets the criteria for a care home but the care home criteria is that he has to be 65? And even if there wasn't an age criteria, is that a dignified place for care for someone who's young...there's a massive gap in services for people with substance use issues because they're younger, they don't fit the bill for mainstream services. (Group 1 - Frontline HSCP)



Another important element of a good death highlighted for this group is whether or not they are able to, and can be supported to, continue using substances when they are dying (this is discussed on a few occasions throughout this report).

#### *Perceptions of wider society*

A small number of interviewees talked about how wider society can perceive this group of people. They spoke of the impact that the perceived negative perceptions held by other people towards them can have on their accessing care. Some interviewees expressed strong views that society sees this group of people as undeserving of help and that such perceptions are a vicious circle with patients simply reinforcing the labels that society places on them:

...people are just like whatever, not interested. They deserve to be locked up and they can die in prison. That's the kind of attitude. (Group 2 - Senior HSCP)

I think that stigmatised people often behave in a stigmatising way because of that, they carry the label. Therefore, their willingness to engage can be low...they feel that they're going to be stigmatised and therefore it's easier to avoid that. (Group 1 - Frontline HSCP)

One interviewee suggested that wider societal views even go so far as to blame or scapegoat such groups of patients for the pressure which has been placed on health and social care systems in recent years:

...whether the system sees this group of people as being a group that needs to be looked after properly, further upstream, in order to prevent this or whether it simply sees it as a problem we need to kind of get rid of... (Group 3 - Policy & Commissioning Professionals)

Such perceptions can influence how this group of people engage with services, because they have carried on self-medicating with substances or view themselves as undeserving of treatment (such as a transplant) compared to others:

I think sometimes it can make people less willing to engage because they don't feel they deserve the service, so they just carry on self-medicating. (Group 1 - Frontline HSCP)

In summary, interviewees debated the application of the common definitions of palliative care, EoL care, and recovery from substance use to people with substance use problems who have EoL concerns. Interviewees also recognised that it remains difficult to talk about death and dying, that views of what constitutes a 'good death' may also need to be thought about differently, and that societal attitudes to substance use can affect access to care.

#### **3.2.ii Size and nature of the problem**

The second theme in the 'wider landscape' cluster covered the size and nature of the problem of co-existing substance use and EoL care needs. Interviewees talked about the

scale of the problem and the characteristics of those with EoL and substance use problems. Regarding the scale of the problem, interviewees talked about prevalence and awareness, covering national and local prevalence of alcohol and drug use and associated mortality, challenges with measuring and reporting prevalence, becoming more aware of the extent of the problem, and thoughts on future prevalence.

#### *National and local prevalence*

Overall, interviewees recognised that there had been an increase in both alcohol- and drug-related deaths, with liver disease deaths particularly highlighted by one interviewee. However, as a counter to the majority view of increased prevalence, one interviewee thought that liver disease deaths had plateaued in recent years, while another hinted that the increase in prevalence might be associated with improvements in reporting rather than an actual increase. A couple of interviewees reflected on the increase in heroin deaths in recent years, particularly among younger populations who may be unaware of the heroin epidemic of the 1980s and 1990s. Some interviewees commented on prevalence within particular populations, such as deaths in prisons, and deaths among those who had a 'deprivation of liberty order' because of their inability to look after themselves. One interviewee said that this is primarily associated with Alzheimer's but can also include alcohol- and drug-related deaths. A third interviewee discussed prevalence in terms of where deaths occur (with specific reference to alcohol liver disease), commenting that most of deaths take place in hospitals rather than hospices.

Several interviewees gave localised examples of prevalence (see Box 1 below). Their examples illustrate geographical and professional diversity.

#### *Box 1 - Local examples of prevalence*

- A 'High number' of clients using a service for older drinkers had alcohol liver disease.
- Scoping 6 hospices in one Scottish city – 2-4 patients a month with addiction issues and, overall, a significant but not huge number of patients are in their 20s.
- Specialist EoL social worker in a major English city - 5-10% of patients at any one time have substance use issues – excluding those drinking or using cannabis non-problematically.
- This group of people are commonly seen in bed and breakfast accommodation in one English city.
- One English homelessness charity found that 75% of residents had substance use issues.

In talking about prevalence some interviewees thought that official data were just the 'tip of the iceberg' and did not offer a true reflection of the full extent of the problem:

I think probably a bigger issue is knowing that the need is a great deal more out there than we ever see and how we reach that is an issue. (Group 3 - Policy & Commissioning Professionals)

Some interviewees thought that deaths among an ageing population were also affecting the accurate reporting of prevalence:

...we are seeing more people dying while they're in treatment and those aren't necessarily the people dying of the drug misuse deaths, they are people just getting older, iller, frailer, some of the long-term consequences of their drug use like Hepatitis C...[and]...smoking. (Group 3 - Policy & Commissioning Professionals)

Some interviewees talked about the challenges associated with reporting the prevalence of substance use related mortality which generally means that it is under-reported. Examples given by interviewees included:

- Narrow parameters set by the Office for National Statistics (ONS) for measuring the prevalence of drug-related deaths, and which do not cover deaths both in and out of treatment, or deaths directly or indirectly associated with drugs.
- Limited categorisation of deaths by coroners as resulting from substance use – for example, substances may be named on a death certificate if they have directly contributed towards a cause of death (CoD) but not if this is unclear.
- Decisions made by GPs as to what to put down as the CoD on a death certificate – particularly where substances are more indirectly linked to death. Similarly, under-reporting by GPs who may not connect CoD with the longer-term history of substance use (particularly if the person was not drinking/using when they died).
- Cancer caused by alcohol – this can be labelled as cancer rather than alcohol-related disease.
- Cases where substance use may be at lower levels/non-problematic, or where someone is using cannabis for pain relief or is on methadone substitution therapy.
- Disconnect between the numbers of people dying of liver disease and the significantly lower number who receive a transplant. Overall, many people with liver disease do not reach the attention of key professional groups such as hepatologists.
- Cases where families do not want substances to be named on the death certificate as contributing to the cause of death.

Several interviewees thought that there had been growing awareness in recent years about people with substance use problems and EoL issues:

I saw it as such a huge area of unmet need... the group that we haven't paid that much attention to as an end of life care group, are the people who are dying from liver failure. (Group 2 - Senior HSCP)

...we've [hospice] recognised we need to do something about it, which is why my boss grabbed me two or three years ago and said, 'let's look at this'. (Group 1 - Frontline HSCP)

A small number of interviewees gave specific examples about the greater recognition being afforded to this issue. For example, one interviewee said that EoL and liver disease had been recently included in a British Liver Conference programme for the first time. Other interviewees talked about specific gaps in awareness of EoL issues among people with substance use, at both national and local levels. One person thought that awareness was lacking because of a more fundamental lack of attention to EoL among many populations who have long-term conditions, including people with substance use problems:

...we're talking about long-term conditions and the talk never gets to the fact that people die, so the talk is always about prevention, self-care, best management and I keep having to say, 'but they will die at some point so when are we going to deal with this?'... (Group 3 - Policy & Commissioning Professionals)

For three interviewees, they each had an experience with one of their patients that 'made me think'. As a result, they became more aware of this patient group and the need to improve their care:

I presume it was one poor patient who was really struggling, but it made you realise that there is a gap in provision there. (Group 1 - Frontline HSCP)

I think my involvement has been less of a planned thing, it's been based on really thinking about someone's individual experience and how awful that was really...it just makes me stop and think, 'What are we doing about that?', 'What is anybody doing about that?'. (Group 2 - Senior HSCP)

I've niched the market really...we had a patient with addiction issues and cancer pain and none of us really knew what to do or how to manage her...I realised that it wasn't just us...it was kind of everyone locally didn't know where to ask for help. (Group 2 - Senior HSCP)

Another interviewee thought that awareness was growing because of the need to understand why the UK health and social care system is under so much pressure:

I think the awareness is slowly increasing...because people are looking for why is the system under pressure? ...so if suddenly the system pays attention to people who are frequently turning up to A&E, these people become more obvious so it's a slightly odd societal attitude (Group 3 - Policy & Commissioning Professionals)

Interviewees also gave their views on future prevalence. Generally, interviewees were likely to express views that prevalence would increase, partly through changes and trends around substance use (the rising problem of the use of novel psychoactive substances [NPS]; Spice was particularly mentioned), and wider societal and cultural changes such as the ageing population and the closure of pubs:

I think in another ten years, we'll see a different picture, there will be more people with more problems, there's a lot more people with psychological problems because life has got tougher for a lot of people and the resources aren't there to help people when they've got psychological issues. (Group 1 - Frontline HSCP)

I think they are going to become a bigger population within the NHS...in the next 10-15 years in terms of like the hepatology patients, the head and neck, lung cancers and the COPD and all the things that go with that, so I think it's a huge time bomb...they are only going to become a bigger number of patients and the problem will become bigger. (Group 2 - Senior HSCP)

One interviewee wondered if the purchase of drugs via the 'dark web' would influence patterns and prevalence of use. However, some interviewees had more mixed views about future prevalence. Some thought that prevalence in some areas may fall, for example when the 'bulge' associated with the heroin epidemic of the 1980s-1990s runs its course, although the current resurgence in heroin use may cause problems in the future. One interviewee thought any future predictions were difficult to make because of uncertainty around the long-term use and problems associated with things like the use of NPS:

I think it probably is too early to say quite what is going to happen with younger people going forward because their patterns of use and misuse are quite different and still developing, as some of the newer psycho-active substances, their harms start to emerge, things that people just hadn't predicted. (Group 3 - Policy & Commissioning Professionals)

Interviewees talked about the impact of increasing prevalence on workload, and of the influence that the availability of resources has on the capacity to adequately respond to this growing problem.

#### *Client profile and demographics*

Interviewees discussed a number of characteristics of people with EoL and substance use issues, including gender, age, substances used, complex presentations and multiple morbidities. Overall, while some broad patterns emerged, interviewees generally thought that it was a diverse population which does not meet one consistent pattern or stereotype:

It's very varied. It is never one group, it's never one solution. But the commonality is that they probably don't get a very good service, they have differing needs. (Group 2 - Senior HSCP)

Interviewees made few clear comments about **gender** and wider gender identities beyond male and female were not mentioned. For example, one interviewee thought that the problems were more common among men while another thought that there were no gender differences, and a third commented that homeless women have less entrenched problems and are perhaps more likely to have support around them.

Interviewees talked more about **age** and a generally mixed picture emerged. On the one hand, several interviewees commented on the increasing presentation of those in younger age groups. The family said that their relative was 37 when he died, while the service user interviewed was in his mid-40s. Some interviewees commented specifically on the age of those dying from alcohol liver disease which one interviewee described as “horrendously low”. Interviewees also commented on younger people presenting with, for example, Wernicke-Korsakoff syndrome<sup>4</sup>, heroin use and COPD<sup>5</sup>, substance use and Hepatitis C, the impact of overdose or intravenous drug use, and the consequences of the use of NPS. Further, two interviewees indicated that some care settings (for example, hospices or other forms of residential care) can be inappropriate for those in younger age groups including where there are serious conditions like Wernicke-Korsakoff syndrome.

On the other hand, interviewees also discussed the characteristics of those in older age groups:

...the population is getting older and you’ve got to have that in your framework, in terms of working with people. (Group 2 - Senior HSCP)

Two main issues around those in older age groups were discussed. First, problems in older age groups as a result of ageing and age-related conditions, which may be directly or indirectly associated with their substance use. Second, the current ‘bulge’ of deaths as a consequence of the drug (heroin) epidemic from the 1980s-1990s. One interviewee commented that the ageing substance use population is a paradoxical outcome of the success of substance use treatment.

With regards to **substances**, there was consensus among interviewees that alcohol tends to be the dominant drug in populations of people with EoL and substance use issues. However, interviewees also talked about a range of other substances which they saw through their work. They listed opiates and heroin, benzodiazepines, cannabis, cocaine, ecstasy, prescription medicines, steroids and fentanyl. Six interviewees commented specifically on NPS and problems associated with its increasing use, with one describing it as “the absolute drug of choice at the moment”, although one interviewee thought that their ban (introduced in May 2016) had led to some improvement:

We don't know very much about [it]...I've been in that many prisons and the ambulances are being called four/five/six times a day. It's shocking stuff, it's awful...It's going to be a big one. (Group 2 - Senior HSCP)

Oh my word, I can't tell you, I have never in my life rung 999 so often, it's been really bad. (Group 1 - Frontline HSCP)

Interviewees were clear that substance use and EoL rarely presented in isolation and discussed a number of commonly co-existing health and social conditions. With regards to **health conditions**, cancers, smoking and COPD, and Hepatitis C were most commonly

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<sup>4</sup> Severe brain damage as a result of long-term and chronic alcoholism.

<sup>5</sup> Chronic Obstructive Pulmonary Disease – an umbrella term for a range of progressive lung diseases often associated with smoking.

mentioned. A small number of interviewees mentioned other health conditions; for example, heart problems (including the service user who had endocarditis), HIV, and pancreatitis. Interviewees talked about many cancers, including lung, gastric, bladder, breast, bowel, head, neck, liver, and oesophagus. Lung, head and neck cancers were the most commonly mentioned. One interviewee thought that cervical cancer was being missed because women are often in chaotic situations and do not attend for screening. There was recognition that cancer may be associated with the substance use and its associated lifestyle but also a recognition that it may be separate and unrelated to it (although there might be increased susceptibility). Interviewees also commented that cancer diagnoses could often come late because of client chaos resulting from their substance use (and possibly also other co-existing issues such as mental health problems) and that, as a result, the cancers might be quite advanced.

Smoking and COPD, and associated cancers (particularly head, neck and lung) were seen as an *“increasingly common”* problem, particularly among drug users. One interviewee thought that smoking (and hence associated problems) in substance users had been overlooked:

There’s been such a focus over decades of drug treatment on treating the illicit drugs and just leaving the smoking alone because that’s just too difficult and so you help people to recover from their drug misuse, only for them to then die of tobacco related disease...it’s kind of taken us a while and the treatment system quite a while to realise that that is not really acceptable. (Group 3 - Policy & Commissioning Professionals)

Finally, Hepatitis C (associated with both injecting drug use and alcohol use) was also seen as an increasing problem, but one that is hard to treat because of the late identification and presentation of patients (often despite frequent admissions to hospital) and the complex nature of patients (for example, Hepatitis C is common among homeless people).

With regards to **social conditions**, interviewees highlighted traumatic pasts (particularly a history of abuse or being in care), mental health (including disabilities and cognitive impairment which may or may not be associated with the substance use), being homeless (or residing in a bed and breakfast or hostel), and social deprivation and isolation. A number of other issues were also mentioned, including being a prisoner and bereavement:

There’s a lot of tri-morbidity – physical health, mental health and addiction issues – so it’s a very complicated picture for people. (Group 4 – Other Professional)

Our client group have a huge complexity of need that needs to be addressed and substance use very often comes hand in hand with mental health issues, so it’s such a difficult thing to look at in isolation. (Group 1 - Frontline HSCP)

Overall, there was some consensus among interviewees about the impact on the delivery of care when trying to support those who are presenting with complex and multiple problems.

One interviewed commented on the challenges of care when the system seems to be increasingly fragmented. Interviewees also talked about the challenges of working with a group who are isolated, including because they isolate themselves, and disadvantaged:

These people are already disadvantaged in society. (Group 1 - Frontline HSCP)

We have people who socially isolate themselves from everyone and usually, those people who socially isolate themselves have either got a drug or alcohol problem and have been estranged from family members for years...[they're] anonymised and not known to people. (Group 1 - Frontline HSCP)

A few interviewees talked about the challenging living conditions of some clients and how this can impact on both their engagement with services and on the provision of care in the home by professionals:

[They] end up living in dire circumstances with no support to actually look after them at their end of life... they don't even have anybody to go to the shop to buy a pint of milk...it's very dirty, they haven't got anything, they haven't even got the basics, some people haven't got a bed. (Group 1 - Frontline HSCP)

In summary, interviewees recognised the increasing prevalence of mortality among people with problematic substance use, and of the problems seen in recent years with the growing use of drugs like novel psychoactive substances. Interviewees highlighted several common characteristics of this group, including their younger age, increasing problems in older people often because of co-existing health conditions, and of the multiple physical health, mental health, and social issues which many patients present with. Overall, this is a group of people who present many challenges for health and social care professionals.



### 3.2.iii Commissioning and delivery

Interviewees discussed two main aspects of commissioning and delivery. First, the national commissioning picture in both substance use and EoL care, and second, how policy issues impact on commissioning and practice.

#### *National commissioning picture*

Interviewees talked about the national commissioning of both drug and alcohol services, and palliative and EoL care. With regards to drugs and alcohol, interviewees gave generally negative views about commissioning, including the shift from protected to localised budgets, the increased frequency of recommissioning cycles, and having integrated drug and alcohol services. At least two interviewees described alcohol commissioning as *disastrous* and *“a complete disaster”*. One interviewee criticised the move to localisation while another criticised disintegration and the lack of continuity between services:

Care has shifted to local authorities who maybe have different priorities and as their money's got really, really tight, they're looking at ways in which they can save money, if that means shortening treatment, hastening people out, then the story is certainly that that is what's happening. (Group 3 - Policy & Commissioning Professionals)

There's no continuity from the hospital into the community, they're seen as two separate entities and then it's shopped out to the person that can provide it the cheapest in the community...it's more disjointed now than it's ever been with alcohol...I feel very angry about the way alcohol services are being disintegrated...the 'any willing provider stuff with alcohol might work fine if you're booking heart [appointments], CAMHs or something, it doesn't work fine for this because it's far more complicated than that. (Group 2 - Senior HSCP)

There was a general sense that alcohol loses out through integrated commissioning as drugs are prioritised and differences between alcohol and drugs are insufficiently recognised. One interviewee commented that commissioning teams are often smaller and tasked with working more generically, meaning that commissioners no longer have adequate specific understanding about things like addiction. Some interviewees also felt that addiction is not prioritised as a commissioning issue:

Within most local authorities, I don't think addiction is one of those things that local authorities would prioritise, there's no statutory requirement so when the pressure is on child protection and vulnerable adults with disabilities and all those things, I think this is a service provision that will get squeezed even more as well. (Group 2 - Senior HSCP)

I think unless we get commissioners wanting to see this built into service specifications, then really we're left with those GPs who are prepared to be engaged...So unless we get the pathways commissioned it really is going to be about trying to convince GPs to incorporate this client group into their current palliative care arrangements. (Group 1 - Frontline HSCP)

However, a small number of interviewees gave examples where palliative and EoL care is being recognised within drug and alcohol commissioning. For example, some of the bids submitted to run one treatment contract mentioned palliative care pathways; EoL care is one of five strands of the Pan London health initiative for homeless people; and EoL care is being increasingly recognised as a key issue for those with liver failure. One interviewee said that the updated clinical guidelines on drug misuse and dependence will refer more to pain management, although someone else said that there is nothing about palliative and EoL care in the revised *'Orange Book'*<sup>6</sup>.

With regards to national commissioning for palliative and EoL care, interviewees said that there is no national commissioning (commissioning is led at a local level by Clinical Commissioning Groups) and no specialist palliative care commissioning. There was also a sense that commissioning is biased towards pain management rather than broader aspects of care. One interviewee said that the needs of substance users have been recognised but that funding constraints means that a national programme of work is not possible, adding that there is a need to think more creatively about how to integrate this issue with other national programmes of work such as mental health, homelessness and prisoners:

...rather than is there a piece of work for this group of people, it's how can we raise awareness about this sub-group of people within each of those other areas?...[we] can only champion so many things...but certainly I think substance abuse as a precursor to all kinds of conditions, all kinds of diseases, that lead to end stage and death and dying, is an obvious path.  
(Group 3 - Policy & Commissioning Professionals)

Overall, interviewees suggested that substance use policy does not sufficiently address EoL care, and vice versa, and that this population needs to be addressed in both areas of policy:

So I do think that there needs to be written within both policy frameworks... something specific to this...I think any agenda around liver needs to have that in. (Group 2 - Senior HSCP)

Interviewees went on to outline three key, overlapping, challenges that they think are greatly affecting national and local commissioning and practice. Namely, fragmentation, inflexibility, and being stretched in terms of both capacity and financial resources. In talking about these challenges, several interviewees made comparisons with how things used to be, generally feeling that aspects of practice are not as good as they used to be. For example, there used to be more district nurses and hospital Matrons, GPs had lower workloads, shared care with GPs in relation to substance misuse was more common, substance use was included in local GP contracts, and there were more 'dry' hostels.

First, interviewees talked about **fragmentation** nationally (including geographical variation), locally, between sectors and between organisations/services. At a national level, many interviewees felt that there was quite wide geographical variation in commissioning,

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<sup>6</sup> A Department of Health publication which guides all practitioners across the UK in the treatment of alcohol and drug dependence.

practice, attitudes and, hence, care. Some interviewees felt that things are often too London-centric and not always transferable to other localities. Variation between London boroughs, and between urban and rural areas, was also discussed:

Perhaps an advantage of working in a more localised area is that in a big city, you've got people that access four, five different hospitals and have different networks, we have one mental health team, we have a drug and alcohol contact, we share a building with the district nurses so the pathways are easier in a way than they are within a big city. (Group 1 - Frontline HSCP)

The family described the polar extremes of care that their loved one experienced by two different hospitals a few miles apart in the same city. Other interviewees talked about the challenges of operating in a more localised way. On the one hand it can be harder to identify and find out about good practice at a local level while, on the other hand, one interviewee felt that a more localised approach can breed, *"a growth in creativity, innovation, energy...diversity"* (Group 3 - Policy & Commissioning Professionals). However, a more common view was to discuss the local impact of national decisions and cuts and the resulting fragmentation which many interviewees felt affected commissioning:

Our hospital [has] six separate commissioning groups, all of which have a separate alcohol provider, some of which don't have any at all because they've not chosen to fund it, none of which are attached to the inpatient hospital service that used to coordinate the whole journey through. (Group 2 - Senior HSCP)

Some interviewees also thought that cuts and fragmentation had increased competitiveness rather than collaboration:

Alcohol services do not flow, secondary care and primary care are disparate, often competing for the same resources in this any willing provider nonsense. (Group 2 - Senior HSCP)

This same interviewee had also experienced a lack of continuity between services, and between professionals working for different services:

...no continuity between the two and so, from the person who comes in from their acute medical emergency, where they need secondary care services, to the community which is going to stop that emergency happening again, there's no link, there's no thread...it's all disparate, separate services and there's often not one overseeing physician...and so the whole thing becomes just fragmented to the extent that it's entirely ineffective. (Group 2 - Senior HSCP)

We're no longer in the hospital, again because of recommissioning and cuts, so there was a very large hospital team that we had across the four general hospitals in [City] and we lost that contract but the current

provider of the contract cut an awful lot in terms of finances...there's a notional hospital presence but nothing like before so I guess all those pathways and everything that we set up, disappeared...it's destabilised. (Group 2 - Senior HSCP)

Interviewees went on to talk about how a fragmented system affects referrals and care. For example, it brings challenges with sharing information and caseloads, and with offering the holistic and person-centred response which can respond to multiple morbidities/ needs:

Multi morbidities seem to be becoming more common so it's not only physical health but mental health and the need to be able to treat all of those as people approaching the end of life and the difficulties doing that, when services do seem to be increasingly fragmented. (Group 3 - Policy & Commissioning Professionals)

Moreover, professional colleagues in the community become more anonymous and depersonalised and work more generically than specifically. It is interesting that the two examples below both make comparisons with the past:

The alcohol nurses used to work with us, they used to do clinics next to us so we could talk to them and ask them and we both managed the same patient that we had a cup of tea and talked about at the end and that's gone now...we've lost their expertise, they've lost ours, it's gone to someone in the community that I've never met, will never meet. (Group 2 - Senior HSCP)

We used to have quite small, dedicated district nursing teams...you would know your patients inside out and they would be reviewed regularly by the district nurse sister with experience and you've now got massive teams with less experienced team members and [they're] even talking not about these patients, people go in and you don't know what they don't know so they're not picking up cues and managing things more effectively so you will go into see a patient and find that you're picking up problems that you thought another health professional should have perhaps seen. (Group 1 - Frontline HSCP)

Second, interviewees viewed services as often being **inflexible** and not set up to ease access for these vulnerable and chaotic patients:

A health service that is designed around schedules and appointments, don't necessarily work for people who have more chaotic lifestyles and the slack has gone out of the Health Service. (Group 3 - Policy & Commissioning Professionals)

Certainly, if you've got somebody who's older and who's a drinker and who's got no literacy, what's the point in sending them letters? They're not going to go to those appointments. (Group 2 - Senior HSCP)

One interviewee thought that specific initiatives, like payment by results (where a service is paid according to targets met or outcomes achieved), breed inflexibility:

...[it's] a sort of tariff-able intervention...we get the generic letter saying, 'patient x has received a 40 minute alcohol-related intervention, they didn't turn up so we've not given them another appointment, I hope you enjoy seeing them in ITU in two weeks' time. (Group 2 - Senior HSCP)

Some interviewees talked about inflexibility in terms of differing ways of working between professions:

I've probably seen about five patients jointly with the hospital addictions team and we come at it from a very different...we might have to do this a bit differently, they're still very stuck in their regimented old school. (Group 2 - Senior HSCP)

Where you're trying to get organisations to be flexible when they themselves are over-run and they have just certain ways of working and you need to fit the bill...it can be a real, real challenge. (Group 1 - Frontline HSCP)

Third, interviewees felt that the overall system is **stretched**.

[It]'s a resource issue and it's a staffing issue and it's a time issue and it's a needs issue and it's a demands issue... (Group 2 - Senior HSCP)

A small number of interviewees were more optimistic, thinking that their community palliative care team, clinical nurse specialists, and aspects of hospital liver care were quite well resourced. One interviewee said that palliative care "*pulls on the heart strings*" and can be "*quite marketable*". However, overall, most interviewees talked more pessimistically about an overall lack of resources and the negative impact this has on care:

It's sad because you're under-resourced for what you do and the end of life should be the best and we now have to go with good enough. (Group 1 - Frontline HSCP)

We always like to give a gold standard and sometimes you have to accept that you need to do a silver standard because you haven't got the time to do the gold. (Group 1 - Frontline HSCP)

The difficulty is, that none of us have got the resources that we need to best meet the needs and to quickly meet the needs to save going round and round in circles...If the provision was there in the first place it should be straight line A to B job done. But because provision isn't there we just have the chaos that we do. (Group 2 - Senior HSCP)

One interviewee felt that the group of patients they were talking about (homeless/substance use) are just not popular and so do not attract resources:

When resources are tight, him who shouts loudest gets heard, this group of people don't shout in terms of 'Look after me'. (Group 1 - Frontline HSCP)

Interviewees also thought that there was a bias towards London when allocating resources, but also that substance use and EoL care are competing for resources with a number of other areas (many of which overlap with substance use and EoL), including mental health, prisons and housing. Overall, interviewees talked about several ways in which they felt things were stretched. These included increased competition for smaller budgets, recommissioning, being asked to make resources stretch further, lack of pooled budget arrangements, less ability to focus on prevention and early intervention but "*firefighting*" and working reactively, the move to community focused care, and the reduction in aspects of care such as specialist palliative care nurses and district nurses. Such restrictions can impact upon waiting lists, hospice beds, access to housing, and a care market which one interviewee described as "*collapsing*". One interviewee described a liver clinic as stretched and wondered what would happen if the patients who are currently not seen (for example, because they have not been identified or they do not attend) also started attending such clinics.

#### *Policy impact on commissioning and practice*

Interviewees highlighted several policy directives which they felt affected both national *and* local commissioning and led to challenges for practice. Namely, policy agendas that are too mainstream and cancer focused; the need for integrated and/or specialist commissioning; and debates as to whether care should be centralised or community focused. In practice, they identified the need for dedicated roles, services and champions; a lack of local direction and guidance in how to work when the two issues overlap; and gaps in workforce development.

First, some interviewees felt that palliative and EoL care is still **overly oriented towards mainstream issues** such as cancer:

I do think at the moment the end of life agenda is very dominated by the mainstream. (Group 3 - Policy & Commissioning Professionals)

One interviewee said that, as something of an experiment, they gave a group of hepatologists two case scenarios of patients with end stage liver disease, one of whom had a better prognosis despite also having cancer. Despite the prognosis being worse in the non-cancer patient, a referral to palliative care was approximately twice as likely with the cancer patient. This interviewee further commented on the dearth of referrals of people with liver disease to hospice care:

The fact is it's the third commonest cause of death in working age adults and you go to a hospice and no-one's ever seen liver disease, [it] is a real indictment of the state we're in with it. (Group 2 - Senior HSCP)

However, another interviewee, talking about hospice care, felt that there was a shift towards engaging more with groups of patients who do not have cancer:

I've actually found that hospices are the most understanding...but I think although it is generally overrun with cancer, more and more I think that is shifting which is really great to see. (Group 1 - Frontline HSCP)

Second, interviewees talked about the need for **integrated and/or specialist commissioning**. They felt that this would tackle identified problems with the lack of continuity between hospital and community; problems with integrated alcohol and drug treatment services; the lack of integration between substance use and palliative and EoL care; the need for better integration with GPs; and the fragmentation between health and social care:

I think unless we get commissioners wanting to see this built into service specifications, then really we're left with those GPs who are prepared to be engaged...so unless we get the pathways commissioned it really is going to be about trying to convince GPs to incorporate this client group into their current palliative care arrangements. (Group 1 - Frontline HSCP)

So what it needs is for health and local authority commissioners to be working together, to ensure that there are the pathways to the services they can help with those broader physical and mental health problems that drug treatment services are in an ideal place to scream for and to support and to refer onto and to support people to, but can't actually do themselves. (Group 1 - Frontline HSCP)

Some of the specialist, partnership, services that interviewees talked about can only happen if there is integrated commissioning:

We need a hostel type environment that has the expertise and the resources of a hospice...that's not going to be achieved unless we have integrated commissioning from Health and Housing and Social Care. (Group 4 – Other Professional)

Third, interviewees talked about **centralised or community focused care**. There were views in favour of each approach:

The cuts have meant that we spent all the years moving out to a community based model and it's now shifting back to more of a centralised model, so I think it then reduces those opportunities [to engage with clients and build trust]. (Group 2 - Senior HSCP)

There's a massive push nationally for people to be looked after at home, get away from acute settings and there's a lot more targets being set in the community, without the funding. (Group 1 - Frontline HSCP)

A number of interviewees saw potential in moving services to a range of community settings such as homeless hostels, needle exchange or job centres:

I haven't got any evidence to back any of this stuff up but I have got evidence that my patients don't turn up to clinic after I've seen them in hospital, the next time I see them is when they come in vomiting blood to A&E. (Group 2 - Senior HSCP)

However, there are also challenges with community focused care which overlap with the issues of fragmentation, inflexibility and resources discussed above. There needs to be careful decisions about what can and cannot be delivered in a community setting.

In terms of practice implications, interviewees highlighted the need for **dedicated roles, services and champions**. Some interviewees commented on the positive impact of specialist roles such as a palliative care coordinator for homeless people, the only such role anywhere in the UK, and multi-disciplinary pathway teams in hospitals which can develop holistic care packages for homeless people. Such roles can bring much needed time, expertise and dedication:

To hear the impact that she's had for staff compared to people that don't have that service has been very striking...initiatives like that that are much more person-centred and are kind of advocating for homeless people in those settings, so that people feel that they have someone on their side when they go in... a phenomenal initiative which I think is also shown really good benefits. (Group 4 - Other)

Examples of other specialist services or roles suggested by interviewees included specialist support within prisons, outreach or inreach from hospices to hostels, hospices beds in hostels, and specialised services for homeless people or those with substance use issues. The family said that they would like to see specific hospital wards for people with alcohol problems (for example, for draining), and for specialist facilities so this can be done on an outpatient basis.

Next, interviewees talked about the need for more **local direction and guidance** when the two issues of substance use and EoL overlap. Several interviewees held the view that there was an overall lack of guidance, particularly at a local level, for caring for this group of people including around specific issues such as prescribing and pain management. One interviewee, a specialist EoL social worker, said that there was no guidance on joint working with drug treatment services. The family felt there was a need for hospital ward staff to be trained in how to care for people with substance-related conditions such as liver failure. One interviewee said that they set up a multi-disciplinary working group to see if they could develop local guidelines or a group of interested skilled professionals so, "that if we didn't know what to do, we could at least ask somebody 'what would you do?'" (Group 2 - Senior HSCP). Another interviewee suggested the need for some kind of policy hub or coordinator to pull everything together for ease of access, while another commented on the dissolution of national organisations like Drugscope and Alcohol Concern and the loss to the sector as a result of the information, expertise and training functions that they provided. Finally, one



interviewee suggested that there was a need for greater involvement of ‘people with lived experience’ in developing responses and care:

We create solutions and we often are very good at co-designing solutions but we’re also used to co-designing solutions with people who think they know what the problem is rather than with people themselves. (Group 3 - Policy & Commissioning Professionals)

Finally, some interviewees talked about gaps in **workforce development**. Overall, interviewees thought that there was a need for more training in working with this group of people. Further, each profession needs to receive training that best meets identified gaps – for example training those in the substance use sector to work with people with EoL care needs. Training needs to cover a range of things including identification and asking questions, planning and talking about care, getting to know the patient to deliver a person-centred response, and issues around management of medication including alongside any ongoing substance use. Another area for workforce development is around the development of pathways to encourage and facilitate collaborative working, and guidelines to support care. The family felt the need for hospital staff to be better trained because there were aspects of their relative’s clinical care that they felt were poorly managed:

The staff there need training in people skills for one, that would be a massive thing for them, they need training in how to deal with bereavement because I don't think they've got a clue, sympathy and empathy and the whole, ‘we know how you feel’, ‘no you don't because this is just another number to you’. They shouldn't ever, in my opinion, turn around and say, ‘We know how you feel’ because you don't. (Family)

In summary, interviewees had a generally negative view of the commissioning of both substance use treatment services, and palliative and EoL care services, and of the impact this has on delivering care to people with substance use and EoL concerns. Overall, interviewees suggested that substance use policy does not sufficiently address EoL care, and vice versa, and that this population needs to be addressed in both areas of policy. Interviewees outlined a number of key, overlapping, challenges that they think are greatly affecting national and local commissioning and practice, namely: fragmentation; inflexibility; being stretched in terms of both capacity and financial resources; agendas that are too mainstream and cancer focused; the need for dedicated roles, services and champions; the need for integrated and/or specialist commissioning; debates as to whether care should be centralised or community focused; a lack of local direction and guidance; and workforce development.

### 3.3 Thematic Cluster 2: Engaging and Responding

The second thematic cluster was entitled ‘engaging and responding’, and this covered four broad themes - engaging clients; managing and developing care responses; (not) talking about substance use or death and dying; and families and networks (Figure 4).

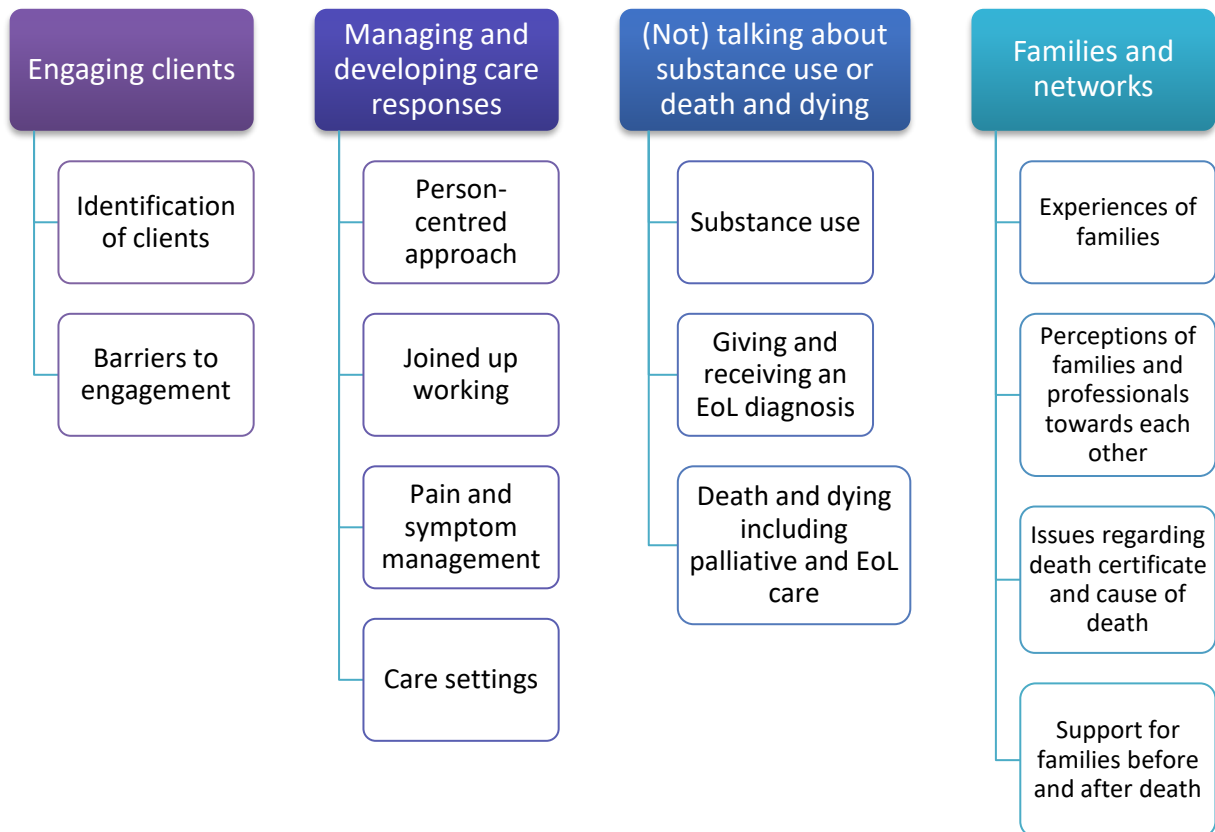


Figure 4: Thematic Cluster 1 - Engaging and Responding

#### 3.3.i Engaging clients

This theme covers two areas, namely identification of clients (covering screening, assessment and referrals) and barriers to engagement.

##### *Identification of clients*

Interviewees talked about the identification of clients’ substance use problems, and the identification of other problems (such as cancer and COPD) which may or may not be associated with the substance use, as well as the identification of EoL itself. Some interviewees suggested that the focus on other problems and illnesses can mean that issues related to the substance use are missed. Late identification can affect care and communication, including because of impaired or limited capacity associated with the circumstances of some people when an EoL diagnosis is given (for example, because of alcohol-related brain damage). Additionally, a small number of interviewees indicated that in some cases referrals are not made (and hence identification does not happen) because professionals are “just simply not thinking about it”. One interviewee explained how their

discussions with a local hospice, supported by reciprocal training, led to both sides recognising just such a gap:

When we were starting the conversations with two key hospices, they went 'oh, I never thought about that'...but similarly, I think some of our staff went, 'never thought about palliative care' either, so there was that 'ooh' moment, realising we haven't thought about this. (Group 2 - Senior HSCP)

Interviewees talked about the challenges they faced in asking clients about substance use or EOL. For example, interviewees from palliative or EoL care professions expressed their discomfort with asking about substance use, with one saying that they do not feel "*competent*" to ask about such issues and have concerns that it will disrupt patient relationships:

We're already happy to talk about death and dying and your plans and how you might die...we can talk about that all day long and not be upset about raising those questions with patients but yet I'd probably have palpitations ...asking, 'have you been injecting heroin again or what have you been drinking?' (Group 2 - Senior HSCP)

Having information about substance use included in a referral can make such conversations easier. This makes identification simpler because someone already comes with "*that label*" or it emerges through the conversations which accompany a referral, although it was acknowledged that time is often needed to build trust for such conversations to be had and for honest disclosures to be made. Two interviewees highlighted the importance of open and honest dialogue with clients; for example, emphasising to a client the need for honesty to assess and make decisions around prescribing for pain control. Other interviewees talked about knowledge of caseloads providing opportunities for identification, including an awareness of "*red flags*" (such as someone who says that they go to the pub every day) when talking to clients. The role of "*intuition*" and "*gut feelings*" was also mentioned.

Interviewees talked about things which made identification difficult, including uncertain illness trajectories (such as alcohol liver disease); the possible masking of symptoms; the crisis, chaos and complexity which can often accompany this group of people; patients moving areas or being homeless; social isolation; denial; and not engaging with services:

Thinking of a chap last year, he was just about at death's door...he was just used to not turning up to appointments and defaulting and didn't want to go for tests or investigations, so they will have poorer outcomes. (Group 1 - Frontline HSCP)

There are also issues around, I guess, compliance with treatments, turning up to treatments, a more chaotic lifestyle inevitably means that things will get missed. (Group 3 - Policy & Commissioning Professionals)

Furthermore, interviewees suggested that professional attitudes towards people with substance use problems can also hamper timely identification. Overall, it seems that opportunities (often multiple opportunities over long periods of time) for identification of EoL conditions in this patient group are missed and then often happen very late:

I think they are hugely disserved...they present frequently, they're not listened to, they're diagnosed late...I think they're often not heard, they present often. (Group 2 - Senior HSCP)

A few interviewees suggested that the chaos, denial and difficulties people have in engaging with services means that their needs are not identified through primary care routes or community services, but through (often frequent) admissions to emergency departments. One interviewee said that the frequency of such emergency admissions should trigger opportunities to improve identification of EoL and start conversations with people about their care. However, even when individuals are in frequent contact with services, opportunities for engagement are still missed and interviewees cited several reasons for this including a narrow focus and attitudes, such as one interviewee who talked about a man who was misdiagnosed for eight years because he was viewed as a "malingerer":

Sometimes that contact is wasted...an opportunity to deliver quite a number of interventions...The people who had seen him had put the 'it's a drug problem' head on, rather than 'I am a GP, this is a person' head. (Group 1 - Frontline HSCP)

They see all kinds of hospital doctors, they see all kind of substance abuse clinics, why are we not getting referrals from them? (Group 3 - Policy & Commissioning Professionals)

The family key informants said it took a number of years, multiple symptoms, and a high number of GP and hospital appointments and admissions, before the severity of their loved one's condition was recognised:

There was a few times where we had to go to the doctor's 'cause he'd be complaining that he was passing fluid from his back passage and this went on for three or four years didn't it?...he was in that much pain...we got to a point where he did start to deteriorate and we noticed he was [be]coming ill...nothing was diagnosed for sure...and then we noticed the yellowing of his skin and his eyes and this was where he kept saying, 'I feel so terrible'...he was always complaining he'd got back pain...his stomach was out there. (Family)

The masking or misdiagnosis of symptoms can present further missed opportunities for identification. For example, one interviewee drew parallels between the symptoms of 'cold turkey' (i.e. the abrupt cessation of substance use, usually with no medication to aid withdrawal) and peritonitis (inflammation of the tissues that line the abdomen wall) meaning that one can easily be mistaken for the other.

With regards to alcohol-related liver disease, the unpredictable trajectory of the illness (which can last many years) can make identification of the illness, and when it becomes EoL, extremely difficult:

He went nearly a whole month and everybody thought he was fine...and overnight, something happened because he was in here on the settee and he was screaming with pain...he was crying. (Family)

You can have somebody who actually is deemed palliative or at very end of life and they'll leave the hostel and be admitted to hospital, everybody has been told they're going to die and then they come back in a couple of days' time good as new almost, just about and they're here for another five years. (Group 1 - Frontline HSCP)

[The] fluctuating nature of the symptoms and the illness [of liver disease]...and it's identifying at what point should palliative care get involved. (Group 4 – Other Professional)

One interviewee explained the challenges with identifying EoL in people with liver disease compared with other conditions such as cancers, adding that there are similar challenges in predicting terminal illness in people with Hepatitis C or who are injecting drug users:

The trajectory of death in liver disease is inherently unpredictable...I'm speaking simplistically but in metastatic solid organ cancers...you will have this progression of disease and you can plan the end of life with a degree of certainty. With liver disease...the trajectory is very unclear...the period to death is very sudden so it's not like a slow decline...So the steady decline that you see in malignancy, which is where palliative and end of life care developed as a specialty, and a lot of the evidence base around that, is not there in liver disease. (Group 2 - Senior HSCP)

One interviewee talked about the 'green gap' of the Gold Standard Framework for end of life care<sup>7</sup>, saying that this is often the hardest 'group' to identify but is where those with substance misuse and EoL issues might best fit:

In days gone by it used to be the last year of life but these days it's a little bit extended because we don't know what people's last year of life is because of treatments these days...the bit that has to be missing is the Green bit...where there's actually very few people involved in the patient's care in that section and that is probably the harder part of trying to look after people. (Group 1 - Frontline HSCP)

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<sup>7</sup> The National Gold Standards Framework (GSF) Centre in End of Life Care is the UK's leading provider of training in end of life care. The GSF employs a PIG (Prognostic Indicator Guidance) with a 'traffic light' system for the identification of EoL – red is when someone is in the final days of life; yellow is when someone is in deteriorating health and may have weeks left; and green is when someone is unstable and in advanced poor health with possibly months left. See <http://www.goldstandardsframework.org.uk/>

Interviewees talked about how identification can be affected by referral processes. One interviewee said that a hospital was reluctant to make a referral to a hospice because they viewed a hospice as “*where you go to die*”; another said that a local service for mental health and substance misuse would initially not accept referrals from a hospice clinical nurse specialist; and a specialist EoL social worker was banned by one hospice from making referrals because the hospice seemed judgmental about the clients being referred. Another interviewee felt that a segregated system affected referrals to EoL care for people with problematic substance use and subsequently the identification of clients:

The hospital is very good at referring to the addictions team and they’re very good at referring to the palliative care service but I’ve yet [to] find that a patient that they refer to both services...it’s very segregated...I think people focus on one issue. (Group 2 - Senior HSCP)

### *Barriers to engagement*

Interviewees talked about how professionals can perceive this group of people, and about the barriers which clients can experience in accessing services. Both can impact upon identification and care. Overall, client engagement can be influenced by stigma, which can have many forms, and practical access to services. Interviewees also made suggestions about what can facilitate engagement. One barrier to engagement is around whether people can or should continue to use substances at the end of their lives.

### Stigma

Interviewees talked about stigma, both actual and perceived, experienced by this group of people, explaining how this can negatively influence client engagement with services:

I think [stigma] is a significant barrier...stigmatised people often behave in a stigmatising way because of that, they carry the label. (Group 1 - Frontline HSCP)

Stigmatising experiences and attitudes, whether they are direct or perceived, can mean that clients are invisible to services (and hence to EoL care). They can be viewed as difficult, unpopular and non-compliant, perceived and treated differently and often with a lesser priority than most other groups of patients. They can also be considered a nuisance because of the demands that they place on services, and viewed narrowly in terms of their alcohol or drug problem. Many interviewees talked about these barriers and how they ultimately mean that this group of people “get a less good service” through not being afforded the same amount and quality of care as is given to others such as those with cancer:

Our system works for the vast majority of average people, we’re not dealing with average people here and the system is failing them. (Group 1 - Frontline HSCP)

We need to be developing services for that, provide the same level of care around end of life for people with drug and alcohol problems than it would

if they were dying from anything else...everybody deserves as good a death as we can help them to have. (Group 1 - Frontline HSCP)

I think they're left to fall through the net to be quite honest because it's easier. (Group 2 - Senior HSCP)

Interviewees gave examples of how they, or clients they had known, had experienced stigma. These included:

- Interviewees who said that patients (and their families) can be rude and aggressive, misbehave and not conform to the rules of a service like a hospice, which can mean that professionals then expect such behaviour from all families;
- A man whose illness was not diagnosed for several years because he was seen as a malingeringer (by which time it was too late);
- The service user wondering if his late diagnosis of a groin abscess was because a hospital professional "hated junkies"; and
- The family who said that their relative talked about sensing that one of the nurses did not like him because he was a problem drinker.

One interviewee said that some patients can feel that they are less deserving of a liver transplant compared with other people, a view echoed by the service user who wondered if he had been refused a transplant because of his known history of drug use.

Service user: It was sort of insinuated that it was through my drug use that I'd contracted [endocarditis] [an inflammation of the valves or inner lining of the heart].

Interviewer: Are you saying you think that one of the grounds for refusing you [a transplant] might have been a judgment on your drug use?

Service user: I think it would have been the drug use, yes.

It is interesting that this service user then goes on to say that he understands why he might have been refused a transplant:

When you look at some people, how straight they toe the line when they've been told that there's the possibility of a transplant, they live squeaky clean lives, they do everything that's asked of them and if it was due to my drug use that I damaged my heart, then...it sounds a bit blasé, but it was my own fault. (Service user)

It was commonly expressed across the interviews that experiences and attitudes, including of the patient group towards themselves, can leave patients feeling that they are not worthy of care, or the same level of care that is afforded to others, and are often deeply mistrusting and suspicious of professionals:

I do believe the people that maybe are born with congenital heart problems that wait for years for a matching hearts or for young children, who are innocent, they've done nothing wrong and then I go and screw

things up by...but it shouldn't be at the cost of somebody who's not making mistakes, to their detriment, that they get told, 'we did have a heart for you but we've given it to this guy that we're not even sure is going to look after it'. (Service user)

Experiences or perceptions of stigma can reinforce clients' feelings of hopelessness, low self-esteem, guilt, blame and denial. Some also feel that they do not want to bother professionals by asking for help, or are used to looking after and relying on themselves:

A number of these people are actually absolutely lovely and are scared, it's like because they've never been overly loved, they think they deserve nothing and so they don't like putting on people. It's not just about 'I don't want to go into hospital', it's also 'I don't want to mither [bother] them', I can't tell you how many times I've heard this person say, 'You've done too much'. (Group 1 - Frontline HSCP)

There was also recognition that some people are so immersed in their addiction and concerns over where their next drink, or hit, is coming from that this takes priority over everything else. Equally, interviewees felt that some professionals think that there is nothing that they can do for this group of people. In some cases, this is borne out of experience of a 'revolving door' patient who has ignored repeat requests to stop drinking or taking drugs:

It can be very exasperating to work very hard on a patient, to get them through an [intensive care] stay, through a lot of complex procedures to stop them bleeding from the GI [gastrointestinal] tract, have this discussion saying, 'If you go back to drinking, this is going to happen again and the next time we might not be able to save you' and then to see them two weeks later, that can be very difficult for the clinician not to be really angry with the individual. (Group 2 - Senior HSCP)

The impact of this is that professionals can take a very narrow focus of patient care:

I think drugs and alcohol users are an easy target to blame, they don't get much sympathy and no-one seems to look at why people are taking drug and alcohol...and it's just hard to shift that out of anyone. (Group 1 - Frontline HSCP)

Sometimes it can be difficult to like these people, very honestly, but it is really important to look past that and look at the reasons why that person is acting in that way. (Group 1 - Frontline HSCP)

Similarly, some professionals may be less inclined to proactively introduce conversations about palliative or EoL care:

When somebody is in liver failure, even though they're told, 'You are in liver failure, if you don't stop drinking, you will die', they rarely go onto say,



'Right, let's assume that you're not going to stop drinking, then let's look at that and then I can refer you to the hospice, I can refer you to a counsellor, I can refer you to other things' like you and I would access (Group 1 - Frontline HSCP)

### Practical access to services

Interviewees listed a number of practical barriers which can impede clients from vulnerable and chaotic groups (such as those with substance use issues) engaging with services including EoL care. These included:

- Rigid structure of schedules and appointments.
- Literacy problems which can affect reading letters or paperwork.
- Practical and financial issues in physically getting to services that expect clients to go to them.
- Waiting lists and times.
- Social isolation, including people who may not have a next of kin.
- Issues to do with prescribing and substance use e.g. being maintained on methadone, being placed in a wet hostel, ex-users not wanting to be prescribed opioids, services that have a zero tolerance substance use policy.
- Having to keep on telling professionals the same thing because of poor information sharing and co-working.
- Multiple carers meaning that carers do not know or understand a patient.
- Cognitive impairment (e.g. associated with alcohol use).

The circumstances in which some people live can also greatly influence their access to services and make the provision of EoL care in the home particularly challenging:

[They] have chosen that lifestyle, they don't want to move away from that lifestyle and don't want support and then they get to the stage where they can't look after themselves, we then have to see if we can try and get them to accept support from around...But you find generally those that are like that, they do not have even a next of kin, a lot of them won't give you a telephone number, contact details of anybody for you to access help... (Group 1 - Frontline HSCP)

The fragmentation of services discussed earlier can also affect access to, and engagement with, services. Overall, interviewees thought that services are not set-up to meet the needs of groups like this and that services need to be more available and accessible. However, current pressures on the system are barriers to change taking place.

We often talk about 'hard to reach' patient groups, but generally it's 'hard to access' services that have a problem. Because hard to reach means they don't really want to be...we need to make services available. (Group 1 - Frontline HSCP)

The slack has gone out of the Health Service... I just have the sense that our system is under so much pressure, that I suspect a lot of people are just

falling through the net because people are just forgetting they're there.  
(Group 3 - Policy & Commissioning Professionals)

### Facilitating engagement

Interviewees identified what they thought could facilitate engagement, in addition to overcoming some of the practical barriers to access that were outlined above and incorporating substance use into care where desired. Overall, some interviewees identified a change in attitude as key, covering both how patients are viewed but also more conceptually how addiction is viewed:

I think it's once they know that they're not judged, they're actually looked after, they're given a nice wash, a nice bath, a nice dinner, are able to be wheeled outside and go and have a cigarette, that they'll have alcohol on their prescription and nobody is going to stop that when they're here, so because that is allowed and not judged, they become compliant because they're quite often at home thinking that everyone is trying to take over.  
(Group 1 - Frontline HSCP)

I think you really need to take away this implicit guilt...the amount of times you go onto medical admissions units and the sickest patient on the ward is the one with liver failure and they're the ones the nurses shrug their shoulders at because...'they were in last week, we worked bloody hard to get them better, they've just done it to themselves', and I personally think we treat alcohol as...a sort of implicit, something wrong with the individual and something wrong with their character and something morally corrupt, as opposed to addiction being part of the pathology in the same way your encephalopathy is part of the pathology, or your renal failure is part of the pathology. (Group 2 - Senior HSCP)

The service user KI gave two examples of strategies that he employs when engaging with professionals, and which he feels has influenced how he is perceived and the care he receives from hospice and hospital staff. The two strategies that he describes are not talking about his substance use, and ensuring that he is polite to and respectful of hospital staff:

Maybe there's only one or two people that know about my background here. So as far as everybody else is concerned, I'm [Luke<sup>8</sup>] and I've got a knackered heart not "Hi, I'm [Luke], I've got a knackered heart and I'm a recovering heroin addict...my heart thing is why I'm here, I'm not here for my substance abuse, I go somewhere else and I get treatment for that...they don't need to know about it, it's not their business, they're not qualified and they don't have much to offer me in the way of assistance...It could only be detrimental for me to bring it up or make other people aware of it, especially other patients. (Service user)

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<sup>8</sup> Name has been changed.

I've pretty much been of the school of thought that you get treated how you treat people, when I've been in hospital....I'm always polite, I don't make demands... because you will get treated like shit if you talk to people like shit....No matter how much they're trained and how much it's meant to be healthcare professionals, you can only push people so far and I think a select few ruin it for people like, not necessarily ruin it but it creates a stigma that affects people like me, they presume a stereotyped behaviour pattern. (Service user)

In summary, interviewees talked about numerous challenges in the timely identification of EoL in people with substance use problems, and the barriers which many people can experience in accessing services. Related to this, interviewees, particularly those working in the substance use sector, discussed how hard it can be to ask questions that might lead to improved identification. Engagement is greatly influenced by stigma, which can have many forms, practical access to services, and whether services support people to continue to use substances while they are receiving EoL care. Interviewees made suggestions about what can facilitate engagement, including building trusted relationships with people, to make difficult questions and conversations possible.

### 3.3.ii Managing and developing care responses

The second theme in this cluster contains four issues on the theme of managing and developing care responses. These are: the importance of a person-centred approach; joined-up working; pain and symptom management, and care settings.

#### *Person-centred approach*

Interviewees talked about the important components of a person-centred approach to care, as well as how care is planned and managed, particularly when dealing with risky and often uncertain conditions. The key components of a person-centred approach identified by interviewees were positive relationships, holistic care, accessible and flexible care, communication, and the provision of personal care. Overall, interviewees advocated for putting the patient at the centre of their care, and for doing this in a way which is comparable with how people with other conditions are supported:

[We need] to listen to what people actually want rather than push what we think they might need. (Group 4 – Other Professional)

It doesn't matter what you do, whether this is self brought on, whether the fact you've been a drinker has brought this problem to you, it doesn't matter, everybody should be treated equally within their rights so what they should have done with [our relative] would have been to have give him the treatment he required in the proper way it was required. (Family)

Interviewees also identified the importance of integrating client wishes around their substance use into a person-centred approach to care:

...letting them know you do care about them and you do want to just help them live....and let them know that 'we do not want to take you away from

this situation at this moment in time, we don't want you to stop drinking, we don't want you to stop living your life how you have always lived it'.  
(Group 1 - Frontline HSCP)

One interviewee who worked in the homeless sector gave an example of care that includes multi-disciplinary case reviews which also involve the homeless person themselves:

[We ask] the homeless person to identify who's important and who needs to be there because it's trying to engage people in that kind of discussion, when often they don't really want to, you're doing what you can with the homeless person and then working around and getting everybody involved.  
(Group 4 – Other Professional)

In one case peer navigators were involved to support homeless people. However, some interviewees acknowledged that person-centred care was not always the reality. For example, one interviewee thought that the recovery agenda that dominates substance use treatment runs contradictory to the key principles of person-centred EoL care.

The way that services are judged to be successful is on whether or not people recover and that doesn't really take into account...the wishes of an individual. (Group 4 - Other)

Perhaps fundamental to a person-centred approach is **the relationship between patient and professional**. Interviewees talked about the importance of being non-judgmental and listening to a person's experiences and wishes, to build a trusting relationship. The importance of this, and the time that it can take, was acknowledged with a vulnerable group of people who may have had very different experiences of services in the past such as being dismissed and not heard:

We break the barrier quite often...because we sit down in a dirty house and don't actually judge them on how they are living, they know eventually we want to help them, so you do break down some of those hard exteriors...we are probably the first people that they've met that haven't judged them. (Group 1 - Frontline HSCP)

I think patients, when they realise that you're not going to condemn them or give them advice to give up, then start trusting you about what other things that they're doing or taking or want to try. (Group 1 - Frontline HSCP)

It is so much about engagement, it is so much about trust-building, so the people who have been drinking for years and may never have sought any help or may have had quite harsh kind of response from their GP or medics, it does take them time to trust and quite often by the time people come to us, they have very low esteem. (Group 2 - Senior HSCP)

Another important aspect of the relationship between professional and patient is facilitating **reciprocal honesty**. Professionals need to be open with the questions they are asking of patients (for example, relating to decision making around prescribing for symptom and pain management which is often of great concern for people because of their historic or current substance use) and what is and is not possible regarding care.:

We seem to be able to build relationships with these types of patients that are not overly honest people...they do seem to show some honesty in the end, we ask them direct questions. (Group 1 - Frontline HSCP)

Equally, patients need to be honest with professionals to maximise the quality of care they receive. Some interviewees suggested that EoL can facilitate honesty from patients that might not have been present before. For example, allowing conversations where someone may wish to talk about the guilt and regret they feel.

Also, central to a person-centred approach is **thinking and working holistically**, and offering a package of care which responds in the right way to what are often complex and vulnerable situations. Interviewees talked about holistic care in terms of both understanding a person's 'back story' and what has brought them to where they are now, and accounting for broader health and social needs:

So then you get to see people as whole people don't you? Not just someone that's stopped treatment and therefore they're okay, they don't need to come back, we were then offering people something else that they could then come to, so you get to learn more about what goes on for them really. (Group 2 - Senior HSCP)

There might be a lot of reasons why they're drinking and without addressing the underlying reasons, to expect someone to stop using substances and have no support to deal with what's underneath that, seems unreasonable to me but at the same time, you need to give people the chance to stop if that's what they want. (Group 2 - Senior HSCP)

Interviewees highlighted the need for services to be **accessible and flexible**, both in practical terms (in terms of barriers and in terms of working with people who are actively using substances, both discussed elsewhere) and in a way which facilitates engagement and the delivery of a more personal approach:

A significant change for [us], from a very much centre-based model focusing on that one to one session, to one which was community-based, visiting people at home...we didn't have a really prescriptive way of how we were going to do it...we discovered different people with different needs and realising that we'd done an all right service but perhaps we could do a much, much better service. (Group 2 - Senior HSCP)

As part of this, interviewees emphasised that work like this requires more time:

We can't seem to cope with the fact that people with complex problems need more time. (Group 3 - Policy & Commissioning Professionals)

Interviewees talked about the importance of **communication** in supporting a person-centred approach, highlighting both the content of what is discussed but also the way in which communications are managed. For example, it is important to find out from someone why they are not attending appointments:

A lot of services would have discharged them because they're not engaging because they're not actively doing what they've told them to do...we don't discharge on those grounds, we actually generally understand that when they're not doing what you advise, people have a choice. (Group 1 - Frontline HSCP)

It is also important to ensure that patients are fully informed about their care options as this can facilitate engagement, even where this may involve difficult but critical conversations. It was acknowledged again that time is needed as well as follow-up conversations.

I think it is really important to be given all that information...we do need to convey the information and ensure that people understand it...I think the way it's delivered sometimes by consultants in a 10/15 minute consultation, with no follow-up or quite often no options or support to actually look at how you could address this issue... although the doctors may think that they've conveyed that information, what that person hears is completely different. (Group 1 - Frontline HSCP)

Poor communication can be very distressing both to those at the receiving end but also to their families. The family KIs were told by hospital staff to provide personal care themselves to their loved one because staff were too busy. That included this interaction:

I changed the bed and I bagged everything up, I got these wipes and she said, 'if you're going to make it, at least make it properly' and I said 'It's not my fucking job'. (Family)

The final component of a person-centred approach identified by interviewees was the need for the provision of **personal care**. Good provision of personal care can facilitate engagement and compliance:

I think it's once they know that they're not judged, they're actually looked after, they're given a nice wash, a nice bath, a nice dinner. (Group 1 - Frontline HSCP)

This absence of personal care was most powerfully illustrated by the family who detailed the amount of personal care that they provided to their loved one, both while he was in hospital (where he died) and in the immediate aftermath of the death, alongside poor communication with hospital staff saying they did not have time to provide such care themselves. Another interviewee said that there were limitations around the personal care

that hostel staff can provide for residents; for example, staff cannot clean up after someone who has wet themselves.

Interviewees talked about two further considerations when delivering person-centred care. Namely, dealing with uncertain illness trajectories like those which usually surround liver disease as identified previously, and the need to proactively (rather than reactively) plan and manage care and risk.

Moving on to planning care, and managing such uncertainty and risk, one interviewee said that the criteria for referrals to palliative or EoL care need to be *“as broad as possible”*. Another interviewee said there are clear markers of deterioration in patients with liver disease which mean that EoL care can be put in place. Overall, interviewees talked about the need for care to be proactive rather than reactive and suggested ways in which this can be achieved. For example, one interviewee said that, *“you hope for the best but you plan for the worst”*, while another said that, *“we aim to be one step ahead of the game”*. Interviewees suggested conducting risk assessments, and talking openly with patients, families and other professionals about potential or actual risks and how they can be mitigated. Such considerations can be particularly important when organising community or home-based care, including medication requirements and communication with families:

I think some of the examples I can think of where we've worked really well, is where from the start, we've said 'this is going to be a problem patient' from the point of view of it's more complex, 'what are we going to do to manage that?'...I think if you have all the health professionals who are willing to make it as good as it can be, then that's a great way to do it and it is like having the risk assessments in, it's talking to staff that feel a little bit anxious about things and from the outset, they've worked really well.  
(Group 1 - Frontline HSCP)

We have built a good relationship with a lot of hospices...they really are quite proactive in trying to understand what the challenges are....to understand why that person may be presenting in such a challenging way and to try to look past that and look at the reasons for that. (Group 1 - Frontline HSCP)

Overall, interviewees acknowledged that resources, time and fragmentation can affect the provision of such planning and proactive care.

### *Joined up working*

Interviewees identified collaborative working as crucial to EoL care. The role of commissioning in this regard was discussed earlier so the focus here is on practice. One interviewee said that it was the absence of *“wraparound support”* for a client which triggered the need to do something to improve care for this group of people. Interviewees discussed five issues in relation to joined up working; namely, treatment and palliation in parallel; tackling fragmentation; reciprocal expertise and knowledge; communication; and clarifying who is responsible for care. Throughout this section the many challenges to joined-up working are also discussed.

Several interviewees highlighted the importance of professionals working together so that **treatment and palliation** could be delivered in parallel. One interviewee thought that guidelines on advance care planning could include something to this effect, and that palliative care can be introduced even with patients who are on a transplant register. Such parallel care is important for conditions like liver disease where, without such advance planning, palliative care often only happens in the last few hours or days before death.

Fragmentation has already been identified as a barrier to compassionate and effective care and interviewees talked about **tackling fragmentation**, in some cases giving examples of collaborative working that had overcome potentially disjointed services, such as joint working and joint visits or multi-disciplinary case reviews or team approaches:

Case reviews...for the most complex clients, they're able to get some medical professionals to come to the hostel and talk about what's happening and drug workers and various other people involved in their care...you're doing what you can with the homeless person and then working around and getting everybody involved because that seems to be a real problem with the fragmentation, that people don't really seem to know what's going on and what each arm is doing and there needs to be a much greater sharing of information. (Group 4 – Other Professional)

One interviewee implied that good joined up working practices can minimise the need for information sharing multiple times, and can ensure that care is oriented towards listening to what people want rather than what services think they need – both things which can also facilitate patient engagement. Overall, interviewees recognised the benefits to joint working, and its importance when working with people who often have multiple morbidities and problems, although they emphasised that a lack of resources and the attitudes of some professionals can influence attempts to tackle fragmentation:

If we can all work together....if just one of us of each can come together and keep talking, we're going to do this, we're going to make an improvement, it's never going to be perfect but I believe we'll have choices that will stop...some of the deaths happening in places where they shouldn't happen, it's got to be collaborative, no doubt in my mind. (Group 1 - Frontline HSCP)

I do think that there is a real willingness of staff across all services to work in a multi-agency joined up way. We all understand that, we've all worked like that for years. But the difficulty is, that none of us have got the resources that we need to best meet the needs and to quickly meet the needs to save going round and round in circles. (Group 2 - Senior HSCP)

Another important component of joined up working was the **reciprocity of expertise and knowledge** that can come from collaborative working. As one interviewee said, *"I think each of us has got to admit we're not the expert"*. Interviewees gave examples of skill



sharing within multi-disciplinary teams, training packages, and accessing specialist guidance around prescribing for pain and symptom management:

The patients will be referred to the Pathway team and they act as a focal point and a guidance point, both for the patient and for everybody else involved in their care...I think we're very lucky that we can draw on the support and skills of many different professionals and people can get on board a lot quicker. (Group 1 - Frontline HSCP)

Several interviewees highlighted the importance of good **communication** for effective collaborative working:

I have to maintain good relationships with people, I can't afford to get cross and nasty...I can't afford to alienate people because I want them to work with me and I want them to see what they can't see because their heads are running, they don't have time to think of the niceties. (Group 1 - Frontline HSCP)

Elements of this include understanding the role that each professional or service plays in care, being open and transparent, and managing anxieties that some professionals have about working with this group of patients. Good communication can maximise proactive and compassionate person-centred care. One interviewee thought that good communication, and hence collaborative working, was easier in local areas. An interviewee also highlighted the value of communication in supporting community-based care:

We try and draw on as many people in the community that are already known to the patient as well because sometimes you get a flavour because they've [e.g. pharmacists] always known the patient for a long time because they've been in and collected methadone, they get to know the patient well so they'll pass on information. (Group 1 - Frontline HSCP)

Finally, several interviewees thought that effective joined up working was affected by agreement about who was, or should be, ultimately **responsible** for that person and their care, including who should take the responsibility for initiating and managing conversations and planning around palliative and EoL care:

What was often absolutely infuriating was when you've got somebody who's a drinker, who's got mental health problems, who's got one or two long-term conditions, who's got other needs...Which organisation is going to take responsibility? Which department is going to take the lead responsibility? Who's going to coordinate those services? Who's going to get them to the appointments? (Group 2 - Senior HSCP)

... I think it delays the care that they need at that point because they're too busy saying "Is it you or is it you?" (Group 1 - Frontline HSCP)

A few interviewees thought that some professionals or services were all too ready to push the responsibility on to someone else or another service meaning that, ultimately, people “fall between the gaps” and do not receive a joined-up response. One interviewee cynically felt that some patients are left to fall through the net because it is easier to do that than establish who should be responsible for them.

An interviewee gave an example of a GP who had a patient with cancer requiring palliative care but where the GP was told to pass the care for the person’s substance misuse over to a specialist service which the interviewee described as “bizarre”:

Drug and alcohol users are often seen as somebody else’s problem, so if you're a GP, then their drug and alcohol use is somebody else’s problem. If you're actually the third sector providing the service, or the Mental Health Trust...then their physical comorbidities are somebody else’s problem.  
(Group 1 - Frontline HSCP)

Then there’s the confusion or conflict even over who’s responsible for meeting the needs of somebody who’s terminally ill but is continuing to drink...we’ve had examples of Social Services saying, ‘We can’t help him until he stops drinking’, and you think ‘Is that likely to happen? Probably not so what you're essentially saying is that you can’t help at all because the drinking is not going to go away’. (Group 4 – Other Professional)

### *Pain and symptom management*

This was one of the more prevalent themes in the data and had many elements to it. These include the challenges of managing pain and symptoms alongside substance use including risk management; differing approaches to the problem between professionals; talking about pain and symptom management; education and training; issues related to families and peers; and working together.

Interviewees highlighted many challenges and areas of clinical uncertainty when managing **pain and symptom control alongside substance use**. This is an important area to get right to maximise the person’s engagement with the service and, medication compliance. Issues raised include the following:

- Levels of prescribing may need to be higher because of tolerance from historic drug use. It may not be appropriate to prescribe at the low levels that might be detailed in clinical guidelines.
- Professional reluctance to prescribe opioids particularly to those who are ex- or current users of opioid based drugs.
- Abuse (including divergence) of drugs that are prescribed, and the risk of overdose.
- Professionals need to understand that some people may resist or refuse some medications (for example, opioids) because of their history of substance use, and care needs to be adapted accordingly.
- Managing medication on top of opioid substitution therapy (OST) and any other medications that a person may be receiving linked to their ill-health.

- Managing pain and symptoms with co-existing conditions like cancers including when diagnosis of EoL has come late.
- Some patients will worry that their level of substance use will preclude them from having pain and symptom management at high enough levels.
- Others may not be able to, or want to, stop using for a range of reasons, including unresolved underlying issues such as experiences of abuse or trauma.
- In some cases, it can be advantageous to support someone to continue using (for example, because it can be dangerous to suddenly stop drinking alcohol or because the support is not in place to tackle the trauma behind the substance use).
- Professionals may worry that a drug user has ulterior motives for also wanting medication for their pain and symptoms, including that they will abuse or divert the medication that they are prescribed.
- Practical concerns such as keeping drugs safe in the home, and supporting patients who cannot swallow properly.

Some interviewees gave examples of the sensitive management of ongoing use of substances alongside the management of pain and symptoms. Ultimately, a comprehensive understanding of the patient along with skilled and compassionate clinical input is required:

... I just reassure them that the team will take [their drug use] into account and 'there won't be a limit on your pain relief' and I think that stops people stockpiling as well, if you give guarantees that your pain relief will be the main focus, if you need higher amounts of drugs, you'll get them. (Group 1 - Frontline HSCP)

The doctor said he needed to be sorted out and it was important that he stayed on these medications and he didn't come off them. But the doctor also said, 'This cold turkey idea thing, I don't think it's fantastic... Ideally he needs to still drink but nowhere near as much, even if it's only one glass a day'. (Family)

There were a small number of examples where the attitudes and perceptions of professionals affected the approach to pain management with this group of people:

We talk about the pain...what the patient tells you it is but that doesn't seem to apply to this group in terms of other people, 'so they're looking for drugs, they've asked for it four hourly', whereas if it was a wee old lady who was 80 who was asking for extra painkiller, they'd be paging us going, 'She's really sore, you need to come and do something about it'. (Group 2 - Senior HSCP)

I guess where we hear about things that are of concern clinically will be things like people being afraid to prescribe analgesia properly, particularly if somebody has a heroin or some kind of a drug related abuse...my clinical experience is that some people, particularly with heroin abuse or related drugs, have a very high tolerance for the drug and therefore they need really big doses...people are really afraid of really big doses and so I think

that there is a tendency to underserve this population. (Group 3 - Policy & Commissioning Professionals)

Examples of steps that had been taken to manage such identified risks included arranging with a chemist for the daily delivery of drugs to a home, safe storage boxes for medications in the home, and a pub landlady who looked after the medication for one isolated pub regular:

His next of kin was the [pub] landlady...she kept the 'just in case' medications<sup>9</sup> for use and they were the ones that kept out for his safety because they were aware when he didn't come in, so there are inbuilt support mechanisms from that. (Group 1 - Frontline HSCP)

A challenge to the management of pain and symptoms can be the differing views and approach of professionals. One interviewee said that professionals do not worry that a cancer patient will become a morphine addict and that there should be no difference when talking to substance use patients about the right titration of medication for them. One area where opinion was likely to differ was whether a person should be asked or told to stop their own substance use to receive medication for pain and symptoms, particularly opioid medication. This can cause difficulties with substance use treatment services who often advocate for abstinence. One interviewee described a three-way reluctance re opioid medications at times:

I think there is a reluctance for doctors to prescribe opioids, there's a reluctance for patients who might be off opioids to want to take it if you think that's appropriate...I think there's reluctance from nursing staff to give opioids. (Group 2 - Senior HSCP)

A small number of interviewees mentioned specific drugs and the challenges posed when medicating for pain and symptoms. This included managing someone who stopped cannabis use because of the way it blocked their pain, suggesting the need for a more creative use of Librium in the community, and the use of Naloxone<sup>10</sup>:

It would not be appropriate to give someone who has palliative care and cancer pain, a huge dose of Naloxone and reverse all the opioids and so for me, there was some education [needed for] the team that I was working with in terms of how we use it, they hadn't heard of it and used in a different way. (Group 2 - Senior HSCP)

As has been identified elsewhere, interviewees highlighted the importance of **talking about** the dual issues of pain/symptom management and substance use, and of the need to be well informed to have such conversations:

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<sup>9</sup> 'Just in case' medications are prescribed by a GP or nurse for use in the event of people experiencing pain at night or during the weekend. They can be given in tablet or injectable form.

<sup>10</sup> Medication which can block the effects of opioids such as heroin and which is commonly used when someone overdoses. Take home naloxone programmes are widespread across the UK, targeting both drug users and carers in the emergency administration of Naloxone.

We do tell them that we're not being judgemental...[but]...we are going to need to take this into account when we are looking at things to control your pain. (Group 1 - Frontline HSCP)

I wouldn't be averse to having a conversation...saying, 'this is what we're giving you, what else are you taking in the day that we don't know about, be honest with me because we need to try it' and titrate doses accordingly. I need to have some kind of a baseline to make those decisions on and actually if you've got that kind of relationship, that's normally okay isn't it? (Group 1 - Frontline HSCP)

Interviewees talked about the need for professionals to be adequately educated and trained in the issues surrounding pain and symptom control and how to discuss it with this group of patients. One interviewee said that the complexity of liver disease pharmacology means that prescribing requires expertise and careful management.

I suppose [liver specialists] we could provide better guidance for hospices in terms of pharmacological management of patients with liver disease at the end of life, because I think hospices are very nervous of liver disease. (Group 2 - Senior HSCP)

Another interviewee said that a patient with dual addiction and cancer issues triggered a realisation that they did not know how to manage their care and that there were no local guidelines in place to help with this. Someone else commented on the vagueness of British Pain Society guidelines and their focus on analgesia. Another interviewee said that drug treatment clinical guidelines were being updated to include more on pain management. They also mentioned a resource from the Faculty of Pain Medicine called *Opioids Aware* to help guide good practice around prescribing of opioid medications. Overall, there was recognition that this is an area where more specific guidance would be valuable.

Several interviewees recognised the need for greater **awareness of the involvement of families and peers** around the patient and whether they can positively support, or actively disrupt, care plans around pain and symptom control. For example, the presence of other drug users in a household is an important consideration when needing to prescribe (and potentially also store) drugs in the patient's home, but can also bring temptation for ex- or active users or the risk of people stealing or diverting medicines:

Thinking about families and the whole dynamics around someone dying and opioids may be coming into the house and what that throws up for the family, if they've gone through a drug misuse episode and someone's recovered and then opioids are coming back...there may be other people in the family who are at risk of misusing the medicines that are coming in. (Group 3 - Policy & Commissioning Professionals)

A lot of old friends that they've known from over the years find out that they're unwell, these people... start to come into the household when

actually they've not seen that person for a while. (Group 1 - Frontline HSCP)

Concern about the family, particularly where there are identified risks, can be stressful for the person who is dying:

The person who is dying usually is quite stressed about it, if they are aware of the substance misuse of their relative, it causes an awful lot more trauma for them, they're a lot more unsettled, quite often find there's lots of fights amongst the family and police involvement and things when somebody is actually dying, which then you're trying to support everybody. (Group 1 - Frontline HSCP)

Interviewees talked about **working with other professionals** to handle this issue, giving both examples of good practice in this area but also examples of difficult situations. Examples of good practice included working with pharmacies around dispensing of medications where there might be risks for taking such medications in to the home; liaison with other professionals led to one patient moving from legal highs for pain to receiving a pain patch; joint working between hospital and addictions team to agree the most appropriate prescribing; working with GPs who might be the focal contact for prescription management; and Consultant expertise where required:

We will get our consultants to see these patients at home or in clinic here, just so that we can actually get them to say this is the appropriate dose for this patient because if a nurse was saying this is the appropriate dose, that wouldn't be deemed right...when we know we're going to have somebody who we are going to need to use bigger doses, we will get the consultant to see them and we're lucky because we have the ability to actually take them to their homes. (Group 1 - Frontline HSCP)

My experiences of doctor and nurse prescribers are really good and really creative and not formulaic...when people say 'I'd rather drink than take morphine', he'll say 'you can take both', rather than 'yeah you're right'. So they work with the patient and that's what I've experienced. (Group 1 - Frontline HSCP)

Interviewees also gave examples of difficulties in this area. This included one interviewee who talked about GPs who were reluctant to agree to drugs going in a patient's home because of their substance use history, and another who said that patients were being sent back to hostel from hospital without the medication that they needed. The service user described a confusing incident when he said he would *consider* moving on to a different drug, and then found out when he next went to collect his methadone that his prescription had been stopped and he would be starting the new drug but would have to go a day or so without his methadone. This made him cross and frustrated.

### *Care settings*

Interviewees talked about many key services that this group of patients come in to contact with and the successes and challenges in working with each. This included GPs and primary care, drug and alcohol treatment, hospitals, hostels (and other forms of accommodation for homeless people), hospices, mental health services, social care, criminal justice system, and pharmacists. There were also one-off references to other professional groups.

### GPs and Primary Care

Broadly, interviewees recognised the potential for, and importance of, GPs being at the heart of a developing response, but equally recognised the challenges with this. One interviewee said that the loss of shared care and local GP contracts had negatively impacted upon primary care work with substance users and work with treatment services. Most people have good access to their GP and, even though some people with substance use problems engage poorly with services like primary care, when they do present they can often place high demands on GPs which means that opportunities for improving care (including palliative and EoL care) are there:

I haven't yet met someone who has gone to their GP once with significant symptoms and been referred in, they tend to have presented over months and months. (Group 2 - Senior HSCP)

However, identification within primary care is hard or does not happen and the knock-on effect of this is that people with problematic substance use (and potential EoL issues) are not identified (or are not identified in a timely way). This means that some people will not be placed on the primary care palliative care register with one interviewee saying that registers should be extended to capture end stage liver failure or COPD in drug users, in the same way that they extended from cancer to include COPD and heart failure. The reasons behind these identification and referral challenges include: the stigmatisation of this group of patients by GPs who do not feel that there is much that they can do for them, GPs who push for abstinence from substances which can alienate patients, practical issues for those patients who move around a lot or who do not have or do not engage with their GP. Two interviewees highlighted the way forward for primary care and the key role that it can play because of access to both the patient group and a wide range of local services:

So unless we get the pathways commissioned it really is going to be about trying to convince GPs to incorporate this client group into their current palliative care arrangements....[there is a] key coordination role for general practice. (Group 1 - Frontline HSCP)

The family key informants generally had a good experience of GPs who were trying to help their relative, including stepping in when they could see that care from other professionals (mainly hospitals) was not adequate.

### Drug and Alcohol Treatment

As seen earlier, interviewees talked about the impact of the disintegration of drug and alcohol services. For example, one hospital professional talked about having more distant relationships with services and their staff (including hospital-based alcohol nurses) which

makes it harder to co-work patients. Another interviewee said there was very little access to substance use treatment services in their area while another suggested that treatment services are segregated from other services. There was also a sense that substance misuse treatment services are less well informed about EoL issues and are not adequately set-up to be able to respond to the needs of this group. Similarly, there was a sense that treatment services are inflexible, largely through their focus on recovery, the pressure to meet targets (including payment by results), and the rigid structures around prescribing. However, a small number of interviewees cited examples where good joint working around prescribing is possible, and both the service user and family KIs talked positively about the help they had received from drug and alcohol treatment services.

### Hospitals

Interviewees talked mostly about three main aspects of hospital care for people with co-existing substance use and EoL care needs; namely, liver consultants and teams (this was most talked about), A&E departments, and palliative care teams. Generally, as has been seen elsewhere, people with substance use problems can be a difficult patient group to identify and then work with because of the unpredictable trajectory of their conditions (usually discussed in relation to liver disease). They place pressure on hospitals because of their (often frequent) hospital attendance and admissions, particularly to A&E. Some interviewees suggested that this group of patients do not always listen to hospital advice and so can be viewed negatively by hospital professionals:

[It] can be challenging for hospital staff, if you've got someone that's coming in and discharging and going and having a can and coming back, it can be quite disruptive and if you're very stretched time wise, services are extremely stretched, if you have someone that's particularly challenging to work with, it's not always met with the same compassion that you would hope for. (Group 4 – Other Professional)

Some interviewees felt that hospitals are not always adequately set up for the delivery of palliative care. However, some interviewees were also clear that, for some patients, hospital is the 'right' place for them die. There were mixed experiences of links with hospital-based palliative care teams, with the following positive example of collaboration between the two sections of hospital care:

The complications of liver disease can be dramatic towards the end of life...it's often quite ghastly and we can make it better and we work very hard with our palliative care physicians within our hospital. We're very lucky to have very strong links and very good palliative care physicians to do that. (Group 2 - Senior HSCP)

A couple of interviewees said that it can be really difficult to introduce conversations about palliative care and EoL with patients, particularly younger patients. However, it was also recognised that hospital professionals have a key role to play in initiating conversations and that, overall, hospitals can do better when responding to liver disease:



If we want to make a start about actually improving the death, hospital is the place to start. (Group 2 - Senior HSCP)

One interviewee (not a hospital professional) talked about the importance of having good links with hospitals in order to work with clients using substances but said that fragmentation between hospitals and substance use treatment services can affect such work.

As will be seen later, while the family KIs mentioned one or two hospital professionals who provided good care to their relative, they (and their relative) were much more likely to have had negative and distressing experiences of hospitals - before, at, and after, the death of their loved one. The service user KI also talked about his poor experiences of hospital staff when they told him about the severity of his condition. He also felt the way he was told that he had been turned down for a heart transplant was not handled well.

#### Hostels and accommodation for homeless people

It was widely recognised by a number of interviewees that health and social care services face particular challenges in caring for homeless people. Their needs can be complex, often accompanied by chaotic and isolated lifestyles. The negative ways in which they are often perceived can greatly affect the identification of their needs and their engagement with appropriate services even though the potential for timely intervention is there because of their frequent engagement with some services, for example, hospitals:

Even just the label of homelessness, it can be quite difficult to access some services. (Group 1 - Frontline HSCP)

Interviewees identified a number of challenges around working with this group of people. These included availability and choice around dry or wet hostels, finding accommodation (including for those who are still using substances), liaison with treatment services who often focus on recovery, low staff: resident ratios, and difficulties in delivering the clinical care and personal care usually required because of the limitations of hostel care:

I think really the big challenges that we've found have been for people that are drinking or using substances, who are extremely ill...the very physical nature of a hostel is not set up to cater for the kind of needs that somebody with serious prolonged substance misuse might have. (Group 4 – Other Professional)

One interviewee described how they had adapted a training pack for hostel staff working with EoL care in homeless populations to also cover substance use. Overall, this seemed to be a sector where there was greatest recognition of the needs of people with substance use and EoL care needs, and of steps being taken to tackle the multiple issues which arises for them. Interviewees highlighted the importance of a collaborative, multi-disciplinary, proactive and creative approach to intervention with the client at the centre of care.

## Hospices

Generally, KIs recognised that hospices remain very cancer dominated and are not set-up to meet the complex needs of people with substance use and EoL care issues. Some key informants believed that people also assume that hospice care is not the right for them or that they will not be accepted:

Hospices are not necessarily set up for patients with addiction issue and are not necessarily set up for the social chaos that often comes with families with alcohol [problems]... . (Group 2 - Senior HSCP)

However, a small number of interviewees suggested that there is something of a sea change happening. They stated that hospices are an under-utilised resource with a positive impact on patient behaviour and quality of life, and can support people with ongoing substance use:

They do a remarkable job of managing people with complex symptoms... they are considered the masters of symptom management and generally they do manage, even with behaviour problems and it's amazing how their behaviour becomes more compliant in a setting like this. (Group 1 - Frontline HSCP)

The service user KI, who attends a day hospice, talked in mostly positive terms about his experience of hospice care but was clear that he does not want to disclose his drug use (particularly to fellow residents) because of how he thinks he will be viewed:

It has no need to rear its ugly head... so there's no stigma stuck to me.  
(Service user)

He also commented about feeling 'out of place' because of his younger age, suggesting that there could be (for example) support groups tailored to younger people in hospices.

## Other

A small number of interviewees talked about other services that have contact with this group of people, such as social care, the criminal justice system, and pharmacists. There was almost no mention of mental health services, which is perhaps concerning given the high association between mental health and substance use, and the potential role such services could have in supporting this group of people with EoL care needs. Similarly, few interviewees talked in any detail about social care. Those who did mention social care described it as a system under great pressure and therefore unable to do much for this group. This lack of social care involvement was perceived to be because of high thresholds for social care intervention resulting in late identification of needs and delayed care. Multiple carers were identified by one interviewee as affecting care because such inconsistency meant that carers did not fully know the patient and understand their needs. Two interviewees talked about prisons although one very briefly. It was also seen as a system under pressure, and a system which, culturally, does not sufficiently recognise the needs of this group of people and is not in a position to do very much by way of response.

Four interviewees talked briefly about pharmacists, and usually did so in positive terms. It seemed that this was an area of care with untapped potential. Pharmacists had a particular role to play in offering both community-based support and in supporting the safe provision of medication, including in cases where it is unsafe for medicines to be going in to the home:

We have some pharmacies that are very good, some pharmacies that are 'no, we won't deliver to the hostel, sorry, they have to come down and pick it up'...when you do have great relationship with pharmacies who are really flexible and understanding and work well together, that usually comes down to having a compassionate or lovely pharmacist who managed a service, or somebody who is championing the cause of homeless people or people with substance use issues, rather than it being a blanket service level understanding of the need for flexibility with this client group. (Group 1 - Frontline HSCP)

There was almost no mention of some key professions in the EoL sector such as MacMillan nurses. One interviewee mentioned district nurses, saying that they are stretched profession and an under-utilised resource. The family KIs talked about a poor experience when a district nurse visited their relative but was unable to meet the person's needs and essentially "*turned round and walked out the house*". On the other hand, the family recounted positive support from the coroner. One interviewee said that there is a lack of good psychological support for this group of patients:

We've got a lot of people who've got those substance misuse problems and already have a past that chases them on top of major regrets...they will sometimes offload that onto you so you carry that burden for them and quite often, it can be things that they don't want others to know...I'm not trained to deal with that level of psychological problems, so you do end up using an awful lot of time trying to deal with that side... (Group 1 - Frontline HSCP)

In summary, interviewees talked about some of the key issues which influenced the delivery of care, particularly a person-centred approach, joined-up working, and pain and symptom management. The key components of a person-centred approach identified by interviewees were relationships, holistic care, accessible and flexible care, communication, and the provision of personal care. In relation to joined up working, interviewees highlighted the importance of treatment and palliation in parallel; tackling fragmentation; reciprocal expertise and knowledge; communication; and clarifying who is responsible for care. Pain and symptom management was one of the more prevalent themes in the data and interviewees discussed the challenges of managing pain and symptoms alongside substance use; differing approaches to the problem between professionals; talking about pain and symptom management; education and training; issues related to families and peers; and working together. Interviewees also talked about their experiences of care in key settings including primary care, drug and alcohol treatment, hospitals, hostels and hospices.

### 3.3.iii (Not) talking about substance use or death and dying

The third theme in the 'Engaging and Responding' thematic cluster centred around the topic of talking about substance use or death and dying. Interviewees described three areas where conversations could be difficult to have with people with EoL and substance use issues: substance use itself; giving and receiving an EoL diagnosis; and death and dying including palliative and EoL care.

#### *Substance use*

Interviewees discussed if, when, and how to, talk about substance use to those with EoL issues. Some KIs stated they had difficulties asking people about their substance use, particularly for those working in palliative or EoL care. The main issue debated by interviewees was whether people should be asked, or told, to stop drinking or taking drugs at the end of their lives, or whether their wish to continue using substances should be heard and accounted for when planning EoL care. Two interviewees explained that they and their service were happy to work with people regardless of their substance use:

The fact that we recognise that there will always be some people who can't stop drinking and we will always offer them a hand of support and that is different and yes, I think it therefore makes it philosophically easier for us to work with continuing drinkers, even though we know that they are at the end of their life whereas some people would not do that, they could take a harsher view I guess. (Group 2 - Senior HSCP)

I certainly am very flexible, if you want to change, that's fine, if you phone someone up and you're really drunk, fine, I'll see you tomorrow, so there's no pressure, if I said 'if you want to cancel and go and get drunk, go and get drunk'. (Group 1 - Frontline HSCP)

However, for other interviewees, continued substance use can be a barrier to engagement. One interviewee said that they were aware of cases where social services had refused to work with people until they stopped using while another commented that some patients are told to stop smoking which they implied was pointless under the circumstances.

So now they've got to cope with withdrawing from nicotine as well...you see them really struggling and you think it's not going to [make] a blind bit of difference and if you get relief from it, just go for it...we're quite relaxed towards it. (Group 1 - Frontline HSCP)

The family said that their relative could not cope with going 'cold turkey' (from alcohol) particularly as he received no medication to help the withdrawal symptoms. Subsequently, a doctor said that this was not a good idea and that he should continue to drink but try to keep to very small amounts. Interviewees also discussed the pros and cons of giving or receiving 'wake-up calls'; in other words, clear messages that if they continued using then they would die. Some interviewees, including the service user KI, could see the benefits to such an approach:

[My addiction's] just been a crutch that I've not fully been able to kick until this has happened...I suppose it does take something drastic before you really do wake up and smell the coffee and that is what's happened. (Service user)

Sometimes that wakeup call that they got from the doctor will scare the bejesus out of them and they'll be going, 'Right, I need to change my life, turn it around, get me into detox', they attend all of the alcohol groups, they really engage with services, they go to detox, they go to rehab. (Group 1 - Frontline HSCP)

However, other interviewees identified drawbacks with such a 'shock tactics' approach, including the loss of hope which such a message might give and experience of knowing patients who have received a wake-up call yet survived which can make such messages meaningless, "like water off a duck's back":

It's a wakeup call...and sometimes that can work but quite often, people would turn the other way and have their hope removed entirely, so if they have no hope then what else is there to do but continue to drink or do the things that bring them some relief? (Group 1 - Frontline HSCP)

Every time they come in, a different doctor tells them, "If you don't stop drinking, you're going to die" and then they don't die and they keep drinking, they come into hospital again and they believe it slightly less the next time. (Group 2 - Senior HSCP)

Several interviewees said that their preferred approach was to attempt to discuss substance use openly with people (in the context of their illness[es] and any prescribing requirements), and then listen and try to cater for their wishes, rather than to demand abstinence. Within such conversations it can be possible to discuss the disadvantages of continued substance use, while emphasising that care or medication will not be withdrawn or limited if substance use continues, rather it will be adapted accordingly. For some KIs it seemed that how messages are communicated, and how client choice is supported, were more important than the messages themselves. Delivery, content and follow-up are all important:

Let them know that 'we do not want to take you away from this situation at this moment in time, we don't want you to stop drinking, we don't want you to stop living your life how you have always lived it', what we want to do is support you. (Group 1 - Frontline HSCP)

if you planned assuming people would continue to drink instead of believing that they won't because they've told you, I think you could improve care. (Group 2 - Senior HSCP)

Some interviewees, within the context of debates around recovery, questioned the legitimacy of expecting abstinence for someone clearly at the end of life. Another

interviewee made a similar point by describing how they tackled such conversations with patients by shifting the focus away from substance use and choice.

I've found an interesting approach that worked for me....'Okay, we've seen you twice this last six months, you've had several alcoholic hepatitis, you've had a variceal bleed, your kidney function's deteriorating, obviously stopping drinking is not something that's possible for you'. And then you take that off the table straightaway, you don't ask them to stop drinking, you sort of take alcohol away and say '...so now because this addiction is part of your illness, we need to start thinking about how we're going to plan the end of your life'....you take away the, 'If you don't stop drinking, you'll die'....and change the focus to 'Drinking is part of your pathology, we need to deal with that in the same way as we need to deal with your liver chemistry'. (Group 2 - Senior HSCP)

Following on from this some interviewees gave examples of 'good deaths' for people who had been supported to continue taking substances right up until death. One interviewee talked about a patient who was prescribed anti-nausea medication before and after drinking so that she could continue to drink. Other examples were:

Someone who died last week, sitting up in bed sipping whisky, someone a couple of weeks ago said, 'what are you eating and drinking?', she said 'red wine and smoked salmon', perfect! And I think that's as important as end of life drugs. (Group 1 - Frontline HSCP)

There's one guy who's just died in the hospice, he was having two bottles of wine a day and he was just like a big sign up, do not disturb before 11 o'clock' ... and that's where he wanted to die and what's what he wanted to do. (Group 1 - Frontline HSCP)

The hospice have allowed them to continue to drink, although they can't officially say that, the drinks trolley will come round twice a day for them rather than just once and so there is that flexibility and person-centred approach. (Group 1 - Frontline HSCP)

Finally, the service user KI felt that a possible solution would be to warn people to not get involved with substances in the first place, using the real-life examples of people like him:

[I'd] warn them against getting involved with drugs because it's an absolute mug's game, it's virtually killed me and it's a game of roulette...So I'd just advise people to think twice. Don't be like me and let it run your life for 20 odd years... something that you take which is meant to make you feel good and have a good time, ends up nearly killing me, pretty much ruining my life, and then walks away laughing at me for being a mug. (Service user)

*Giving and receiving an EoL diagnosis*

Somewhat surprisingly this area did not feature greatly in the data. One interviewee, a liver consultant, said that such conversations often did not happen because the focus of some professional groups was on saving lives and getting people well (including through transplant) adding that there can be a particular reluctance to diagnose EoL in young people:

Your instinct is not necessarily to palliate, it's to save, often to a ridiculous degree. (Group 2 - Senior HSCP)

Another interviewee asked who was best placed to have such conversations, particularly with vulnerable and complex populations like homeless people. The service user KI, who had been attending a heart clinic for about six months, talked about the 'bolt out of the blue' when he was told that he would die and was asked about hospice admission. He had also been refused a heart transplant:

'How do you feel about going there?' .... I was scratching my head thinking, why do I need to go to a hospice?...Then almost in the same breath, the nurse explained, she said 'you know you're very ill?...you're really ill...you could have as little as a year to three years to live' ....it felt like a kick in the stomach. (Service user)

#### *Death and dying including palliative and EoL care*

Building on findings presented above around how to manage client choice around substance use at the end of life, a number of interviewees talked about the importance of a proactive and collaborative approach with patients, which focused on what they want for their end of life:

So rather than talking about treatment preferences, it's more about your preferences generally, like what do you want for the rest of your life? What do you want it to look like? What can we change? (Group 4 – Other)

It's a person-centred approach that palliative care/end of life care needs to take, it's so where are they now and...how can we improve where you are or your end of life experience, how can we make that what you want it to be? (Group 1 - Frontline HSCP)

One interviewee talked about improving care in the hospital setting in order to facilitate conversations about dying because that is where the majority of people with problematic substance use will die. The family described an example of appalling hospital care for their loved one and for themselves, including an absence of conversations about their loved one's death. For example, at one point when the family suggested that their loved one needed to be in a hospice, hospital staff said that "there's nothing we can do about that":

However, importantly the service user KI emphasised that there should also be awareness about when someone might *not* want to talk about their death:

It's in the forefront of my mind, no matter how many times I push it to the back and it might not be healthy to [keep] pushing it all at the back but at this particular stage, it's how I feel comfortable coping with it and I feel that I'm reminded of it regularly enough, that I don't need to be moping about it or mulling over it in my own head, it's dragged to the surface and as I say, almost on a weekly basis, in one form or another. (Service user)

In summary, interviewees described three areas where conversations could be difficult to have with people with EoL and substance use issues: substance use itself; giving and receiving an EoL diagnosis; and death and dying, including palliative and EoL care. Interviewees discussed the importance of choice around substance use, rather than demanding abstinence, that 'wake up calls' often do not work, and the importance of a proactive and person-centred approach to discussing end of life with someone.

### 3.3.iv Families and networks

The fourth theme that emerged in this thematic cluster has a focus on families and social networks. Not all interviewees talked about families and networks, and those who did, did not do so at great length. The exception is the three family members who were interviewed together about their son/nephew and his end of life care, and who offered an insight into the potential experiences of families. Topics covered under this theme include the experiences of families, the perceptions of families and professionals towards each other, issues regarding death certificates and the official cause of death, and support for families both before and after death.

#### *Experiences of families*

Only a few professionals made any comment that indicated that they were aware of the ways in which families can be affected by having a loved one with a substance use problem, and how they can continue to be affected at the end of life:

The family that are around will have had a lot of, or a bad time with them over the years and quite often, through guilt, will continue to look after them but will have been treated quite badly. (Group 1 - Frontline HSCP)

I just think families is going to be one of those, a big issue for our client group as they approach the end of life. (Group 3 - Policy & Commissioning Professionals)

In terms of how families can be affected, professionals mentioned anger, guilt, strain, conflict, estrangement, and blaming their loved one. One professional made a specific comment that encephalopathy<sup>11</sup> "is deeply unpleasant for families to deal with....gastro intestinal bleeding at home is not nice". Several interviewees commented that clients are often isolated and estranged from their family. Some family members may themselves be ex- or current users, which can bring complexity and chaos to already difficult situations.

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<sup>11</sup> A general term to describe brain disease or damage.



Inevitably, the family KI talked at great length about their relative's addiction and subsequent ill-health which led to his death. They described the impact of multiple interactions with health professionals (mainly GPs and hospital staff) over a lengthy period of time and while they described some good and compassionate care what dominated the interview was an upsetting chronology of poor care of their relative, covering the time before death, the death itself and the period afterwards. For example, they described how quickly their relative's health deteriorated when multiple symptoms emerged seemingly overnight and he became very ill. There were then numerous distressing incidents while their loved one was in and out of hospital and during his final admission when he died. This included a drain being put in back to front (which led to blood poisoning; the person was still waiting for a transfusion when he died), the mother describing how much personal care she delivered to her son after being told that hospital staff were too busy (washing and changing him, shaving him, cutting his toe nails, changing the bedding), and a DNR (do not resuscitate order) not being put in place so that attempts were made to resuscitate him which caused great discomfort. Moreover, poor communication from the hospital meant that the family was not able to be with their relative when he died, and they had to cope with knowing that he died alone and in great distress, and that he was not in a private room:

He was definitely in pain when he died...he was definitely struggling...  
(Family)

Poor care continued after death as the body was not looked after (the mother's personal care of her son continued) and it was several hours before it was taken away. Additionally, there was misinformation about the post mortem, and the family had to get chaplain themselves despite several requests, which the hospital said they never received. Together, what this family says illustrates the great stress and strain which the family was placed under. While they highlight that some professionals showed more compassion towards them and their relative (GPs, one nurse and the coroner), they experienced more poor care and, ultimately, hold the hospital responsible for 'killing' their relative and want them to be held to account. However, the family's complaints were all disputed by the hospital, which only added to their grief. The family knew that their son was dying but know (largely from the coroner) that he did not need to die at that time and in such a distressing way. Ultimately, the family felt that he was not afforded the same care and rights as someone without substance use problems.

#### *Perceptions of families and professionals towards each other*

Interviewees gave examples of how families could either positively or negatively impact upon the dying person. Overall, interviewees were more likely to talk about how they, or others, perceived families and networks negatively, giving examples of how families and networks can have a negative impact on the dying person and on the care that is given to those who are dying. Examples included causing disruption in hospital, being physically and verbally aggressive towards hospital staff, disagreement within families and with hospital staff about their loved one's care, airing views that the person had brought their problems on themselves, and wanting the focus to be on them, and how they are suffering rather than maintaining focus on the person who is dying, and blaming professionals for their loved one's condition and death. Interviewees also expressed concerns about the presence of drug-using family members or peers which can impact upon care, particularly in the home,

for example, concerns about other people's use of the person's prescribed medication. A more positive perspective came from the family KIs who described all the love and care that they tried to offer to their relative particularly in the absence of the poor care that person was receiving in hospital.

In terms of how families view professionals, insights again came only from the family KIs. They gave examples of both good and poor care, thereby presenting mixed views about the numerous professionals they, and their relative, had contact with. The family described good care from GPs, some nursing staff, and staff/volunteers at an alcohol service:

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)

I think that the work they've [alcohol service and volunteers] done has been absolutely fantastic with this family. (Family)

However, on the flip side the family were extremely distressed by the poor care and attitude of the majority of staff at the hospital where their loved one died and referred to a letter they received from the hospital in response to their complaint:

I can't understand where all these apologies are coming from because she's put, '[Matron] would like to apologise for any undue distress caused to yourselves and your grandson on arrival at [the ward], it was not our intention to cause upset', well if it wasn't your intention to cause upset then why did you neglect it in so many different ways and when we actually came to speak to you, did you not be empathetic? Why did they always have a stern, cold exterior to everything that they said? Whenever you spoke to them, it was so abrupt and there was no feeling, there was nothing there...I know sympathy and empathy are two very different things but they should at least empathise with the family. (Family)

#### *Issues regarding death certificates and the official cause of death*

A small number of interviewees talked about families who feel very strongly that they do not want alcohol or drugs to be named on a death certificate and hence the official cause of death of their loved one:

Families do not like alcoholic liver disease, so they do not want that putting on the death certificate, so there's pressure on doctors who've got a family that's recently bereaved...Quite often, they don't mind the fact that he was an alcoholic during life but they don't want it putting on his death certificate. (Group 4 – Other Professional)

One interviewee described in more detail how this situation might play out, and the impact this can have on official statistics:

The junior doctors always get phoned up by the bereavement office the next day, to say they've seen a death certificate, the family really don't like it, please can you take the word alcohol off? That's a very common phenomenon, the number of alcohol-related deaths are probably under-reported because of that...you've got a grieving family that often aren't brilliantly emotionally equipped to deal with that in a sort of calm way, and you can see something that will immediately reduce their grief, and there are ways around it, you can write 'decompensated hepatic cirrhosis', none of that's a lie, you can dress it up and that sometimes makes people happier. (Group 2 - Senior HSCP)

One interviewee said that it can be difficult for families if a death has to be referred for a post mortem or to a coroner because that family "think they've done something wrong or someone's over prescribed, the police have to come and it's horrendous". The family KIs described helpful communication with the coroner about their loved one's death, which helped clarify key things like the time of death and that such a distressing death could, and should, have been avoided.

#### *Support for families before and after death*

Interviewees talked about the need for families to be supported both before and after the death of their relative. One interviewee talked about the need for more pre-bereavement counselling for families and children while another also highlighted an absence of psychological support to families who have been treated badly by their loved one yet who may feel guilt for what has happened:

There is a massive need for them to get psychological support, to actually deal with it...there's limited availability in the area, we don't have Level 4 psychological support, so it's us who supports them to look after and it can be very difficult because there's two needy people there who are needing access to support. (Group 1 - Frontline HSCP)

Interviewees also talked about supporting a person who is at the EoL to connect with family before they died. For example, as a result of EoL training, staff at one hospital were proactive in helping a man find and reconnect with his estranged family before he died:

By the time this gentleman died, he had contact with his family which he hadn't had for many years. (Group 1 - Frontline HSCP)

The family KIs experienced positive support from a number of sources, including the vicar, their local community, a spiritualist and, particularly, one non-statutory alcohol service who continued to support them after the death:

[The alcohol service] are the only people that have been an absolute rock to this family since [relative's] passing, [volunteer] I couldn't thank him enough, I will be eternally grateful to [volunteer] for what he's done...from the word go when they first come here, they put themselves out that much

to do things for [relative and us], they took us both in like family and helped us right the way through... they've provided after-care to the family that have been bereaved and they need to be recognised for that. (Family)

Through this alcohol service the family was also able to attend a bereavement support group and talked about what they found helpful about this:

We talk to [another lady]...she had the same thing, she had the same loss, more or less identical to [us] and we had a talk with her and a cry, you know, but she feels exactly the same, let down by the hospital the same as we feel...neglect, sheer neglect, nothing else. (Family)

In summary, interviewees talked about the experiences of families, the perceptions of families and professionals towards each other, issues regarding death certificates and the official cause of death, and support for families both before and after death. Overall, families were more likely to be viewed negatively, and there was limited recognition and discussion of the needs of families both before and after the death of their loved one.

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## Section 4 - Discussion and implications

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The headline findings from the qualitative analysis of the KI interviews are summarised below (see Box 2):

*Box 2: Headline Findings from the KI Interview Analysis*

1. Current definitions and ways of understanding palliative care, and addiction recovery, do not easily apply to people with substance use and EoL concerns.
2. The patient/client group is not a straightforward one – there are often complex and multiple physical, psychological and social morbidities which impact upon identification, engagement with services and the delivery of care.
3. There are significant issues with the fragmentation and inflexibility of services which affect care – however, it is possible to identify the characteristics of a good joined-up and compassionate approach to care.
4. Substance use receives little attention in national or local policy around palliative and EoL care; and palliative and EoL care receives little attention in national or local policy around substance use.
5. Prescribing for pain and/or symptom management for people with substance use and EoL concerns is a complex area; but good practice which facilitates someone to continue drinking or using drugs if they wish is possible.
6. Families can be viewed negatively, and receive little support, either alongside their loved one and/or in their own right and both at the EoL and after death.

Overall, the interviews identified similar issues at both national and local levels, and across substance use and palliative and EoL care. At times it makes for bleak reading, with interviewees talking about professions and systems under enormous multiple pressures and which, along with stigma and prejudice, mean that this group of patients (and often also their families) is unlikely to receive the right care at the right time and delivered in the right way.

However, the interviews also contain optimism and hope for how the needs of this group of people should be best met. Characteristics of good care, and pockets of good practice, were highlighted, all of which could be harnessed to raise awareness, encourage more good practice and tackle stigma.

In talking about the characteristics of this group of people, the diversity that interviewees discussed means that a ‘one size fits all’ response will be insufficient. Rather, the developing care response must cater for a group of people that has a very wide ranging demographic profile who are most likely to present with multiple, and often chronic and longstanding, physical, psychological and social problems. Interviewees were more likely to discuss groups such as homeless people and those in lower socio-economic groups, suggesting that while concepts such as the alcohol harm paradox (e.g. Bellis et al., 2016) must be accounted for, care must be taken to not overlook, for example, the sizeable number of people in the middle and higher socio-economic groups who have alcohol problems. Furthermore, it seems that this is a group of people who receive unequal care and it is unfortunate that they are not listed as such in EoL inequalities agendas (e.g. CQC,

2016). For the most part within EoL care there is a continued focus on cancer, and within substance use services on recovery. The analysis of this dataset suggests that these two dominant paradigms are impeding the development of the most appropriate response to people with co-occurring substance misuse and EoL issues.

Pain and symptom management was one of the most dominant themes across the interviews. This aligns with a key finding of the Rapid Evidence Assessment undertaken as part of the wider research project on EoL care for people with substance problems within which these interviews took place (Witham, Peacock, & Galvani, 2018). It is, inevitably, an important area of care and clinical concern, but one which rarely accounts for client choice and either ongoing substance use or the wishes of ex-users (who, for example, may not wish to be prescribed certain drugs). However, some of the interviews gave examples of good practice where patients were supported to continue drinking alcohol or taking drugs, and how this had a positive impact on their care experience.

Across the interviews there was limited discussion of the needs of families and a sense that families/networks are viewed quite negatively by professionals (although not necessarily by the KIs themselves). This aligns with other research which has highlighted the experiences and needs of families affected by a loved one's substance use or who are bereaved by substance use, and of the disconnect between these needs and the amount of help and support that is available (e.g. Adfam, 2018; Valentine, 2018). The experiences and needs of families have been the focus of another strand of this project and are reported in detail elsewhere (Wright et al., 2017; Yarwood et al., 2018).

Overall, interviewees were critical of policy and commissioning, and also identified a number of challenges and barriers which are impeding the provision of timely, holistic and adequate care. These reflect wider dilemmas and challenges which are facing both substance misuse treatment and palliative and EoL care (e.g. ACMD, 2017; Adfam, 2017; Marie Curie, 2015). Given the multiple and complex needs of many people with substance use and EoL concerns, there is a greater need for multi-disciplinary and joined up care and care pathways and for national and local policy and commissioning practice to reflect this. There is also a need for resources and guidance to help professionals, in a range of settings, identify and engage with the dual issues and a programme of workforce development that can support people to feel comfortable and confident to talk about these issues with patients, families and colleagues.

## **4.1 Implications for Research, Policy and Practice**

The analysis suggests a number of implications for research, practice and policy – these are listed below.

### **Implications for Research**

1. How can current definitions and ways of understanding palliative care, and addiction recovery, be better applied to people with substance use and EoL concerns?
2. What might the core components be of an improved national and local policy response to this group of people?

3. How can we better understand the complexities of prescribing for pain and/or symptom management, including for those who wish to continue drinking or using drugs? What are the components and facilitators of good practice and in this area?
4. Given the diversity of the KI sample, there is potentially a need for similar research to further explore the key issues which have arisen and how they might apply to different professional groups across England/the UK.
5. 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?

#### Implications for Practice and Policy

1. There is a need for greater reciprocity in national and local policy, where palliative and EoL policy considers the needs of those with substance use concerns, and substance use policy considers the needs of those with palliative and EoL care needs.
2. Practice and policy, at both national and local levels, needs to be fully holistic in order to better meet the needs of families alongside their loved one and/or in their own right.
3. There is a need for guidance, and improved inter-service collaboration, to support the earlier identification of, and engagement with, a complex group of people who are often reluctant to engage with services.
4. There is a need for guidance on issues surrounding prescribing, and how they can be addressed while not compromising the care of those who wish to continue drinking or taking drugs.
5. Practice guidance is needed to support services to meet the needs of sub-groups of people with problematic substance use and end of life conditions.

### 4.3 Strengths and limitations to the research

There are both strengths and limitations to this KI dataset. A key strength to the dataset is that it has, for the first time, brought together the experiences of a diverse cohort of individuals from a range of settings and disciplines working, or living with, the overlapping issues of problematic substance use and EoL care. In terms of limitations, the diversity of the interviewee cohort was also a limitation and made analysis challenging. There is possibly some interviewee selection bias as interviewees were generally known or suggested to us. It is, therefore, not possible to generalise from these findings alone. However, given that many of the findings align with findings from other strands of the wider project, and with other similar research, some generalisation may be possible.

## Conclusion

The KI interviews have given a unique, and hitherto unknown, insight into the experiences and challenges of working with adults with substance use problems and EoL concerns. Interviewees highlighted numerous individual, organisational, and strategic level challenges to identifying this group of people and delivering timely, efficient, joined up and compassionate care. There is much to do to better meet the needs of a sizeable, but largely neglected group of adults and their families. These interviews offer constructive suggestions for how care can be improved.





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## Appendix 1 – Analysis Template v2

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### THEMATIC CLUSTER 1: THE WIDER LANDSCAPE

1. Size and Nature of the Problem
  - 1.1 National Data
    - 1.1.1 Drug-related deaths (incl. within Tx, out of Tx, overdoses)
    - 1.1.2 Alcohol-related deaths
    - 1.1.3 Accuracy of & challenges with measuring & reporting
  - 1.2 Client profile and demographics
    - 1.2.1 Gender
    - 1.2.2 Age
      - 1.2.2.1 Young
      - 1.2.2.2 Old
    - 1.2.3 Substances
      - 1.2.3.1 NPS
    - 1.2.4 Other conditions
      - 1.2.4.1 Cancers
      - 1.2.4.2 Smoking and COPD
      - 1.2.4.3 Hepatitis C
    - 1.2.5 Complex presentations and multiple morbidities
      - 1.2.5.1 General comments and reflections
      - 1.2.5.2 Traumatic pasts
      - 1.2.5.3 Mental health (incl. learning disabilities and cognitive impairment)
      - 1.2.5.4 Homeless
      - 1.2.5.5 Social deprivation and disadvantage
  - 1.3 Tip of the Iceberg incl. ignored, invisible & increasing awareness
    - 1.3.1 Becoming aware ('one case made me think')
  - 1.4 Local examples of prevalence and worker caseloads
  - 1.5 Thoughts on future prevalence
2. Commissioning and Delivery
  - 2.1 National commissioning picture
    - 2.1.1 Drugs and Alcohol
    - 2.1.2 Palliative and End of Life Care
  - 2.2 The response/the system is...
    - 2.2.1 Fragmented
    - 2.2.2 Inflexible
    - 2.2.3 Stretched (covering staff & money)
  - 2.3 National and local practice and commissioning agendas
    - 2.3.1 Too mainstream – cancer dominated
    - 2.3.2 Need for dedicated roles, services and champions
    - 2.3.3 Lack of local direction and guidance
    - 2.3.4 Geographical variation and postcode lotteries
    - 2.3.5 Need for integrated and/or specialist commissioning

- 2.3.6 Centralised or community/home approaches
- 2.3.7 Comparisons with how things used to be
- 2.3.8 General thoughts on policies, pathways & guidance
- 2.4 Financial considerations
  - 2.4.1 Lack of money
  - 2.4.2 How to attract funding incl. 'hooks' & research evidence
- 3. Definitions and Perceptions incl. one comment re substance use & addiction
  - 3.1 Palliative and End of Life Care
    - 3.1.1 Applicability to substance use/misuse
  - 3.2 Recovery & applicability to SM & EOL
  - 3.3 Death and dying (and conversations about)
    - 3.3.1 Notions of a 'good' death
    - 3.3.2 The right place to die
      - 3.3.2.1 The 4 H's (hospitals, hospices, hostels & home)
  - 3.4 Professional perceptions of the client group
    - 3.4.1 Characteristics
      - 3.4.1.1 Difficult & unpopular, a nuisance and non-compliant
      - 3.4.1.2 Underserved, different & viewed differently to other groups
      - 3.4.1.3 Fall through the net
      - 3.4.1.4 Not taken seriously
      - 3.4.1.5 Don't see the whole person
    - 3.4.2 Impact on professional approach
  - 3.5 Perceptions from wider society

## THEMATIC CLUSTER 2: ENGAGING AND RESPONDING

### 3. Families and Networks

- 6.1 Experiences of families
- 6.2 Negative impact on the dying person
- 6.3 Positives in having around the dying person
- 6.4 Lack of family/support
- 6.5 Connecting with family before death
- 6.6 Negative attitudes towards families and peers
- 6.7 Issues regarding prescribing for pain management
- 6.8 Attitudes of families towards professionals
- 6.9 Issues wrt cause of death and death certificate
- 6.10 Support for families
- 6.11 Bereavement

### 7 Engaging Clients

- 7.1 Screening and assessment
- 7.2 Identification
  - 7.2.1 Uncertain illness trajectories incl. masking
  - 7.2.2 Too late
  - 7.2.3 Crisis, chaos and complexity incl. frequent attenders/missed
- 7.3 Referrals
- 7.4 Client barriers
  - 7.4.1 Resistant to engage
  - 7.4.2 Experiences incl. mistrust/suspicion of profs/services
  - 7.4.3 How perceived by professionals
  - 7.4.4 Access to services
  - 7.4.5 Self stigma, being unworthy

### 8 (Not) talking about.....

- 8.1 Substance use
  - 8.1.1 Continuing or stopping
  - 8.1.2 Different professional viewpoints
  - 8.1.3 Client choice
  - 8.1.4 Zero tolerance
- 8.2 Giving and receiving an 'eol' diagnosis
- 8.3 Death and dying and end of life incl. planning/care
- 8.4 Walk up calls – you'll die
  - 8.4.1 Bouncing back and cheating death

### 9 Managing and developing care responses

- 9.1 Uncertain illness trajectories
- 9.2 Planning & managing including risk, anticipatory not reactionary
- 9.3 Joined up working
  - 9.3.1 Treatment and palliation in parallel

- 9.3.2 Tackling fragmentation
- 9.3.3 Reciprocity of expertise and knowledge
- 9.3.4 Communication
- 9.3.5 Challenges
- 9.3.6 Whose responsibility is it?
- 9.4 Examples of good practice and of joint working
  - 9.4.1 National
  - 9.4.2 Local
- 9.5 Person-centred approach
  - 9.5.1 Relationships – trust and honesty
  - 9.5.2 Holistic
  - 9.5.3 Accessible & flexible
  - 9.5.4 Communication
  - 9.5.5 Providing personal care
- 9.6 Pain and symptom management
  - 9.6.1 Alongside use
  - 9.6.2 Different approaches and views
  - 9.6.3 Clinical uncertainty and challenges incl. risk management
  - 9.6.4 Client attitudes and concerns
  - 9.6.5 Talking about
  - 9.6.6 Education and training
  - 9.6.7 Families and peers (using and non-using)
  - 9.6.8 Working together and the role of other profs
- 9.7 Components of care
  - 9.7.1 GPs (and primary care)
  - 9.7.2 Drug and alcohol treatment
  - 9.7.3 Hospitals
  - 9.7.4 Hostels etc. (i.e. other accommodation for the homeless)
  - 9.7.5 Hospices Mental health services
  - 9.7.6 Social care – incl. housing (or separate??)
  - 9.7.7 CJS incl. police & prison
  - 9.7.8 Pharmacists
  - 9.7.9 Other
  - 9.7.10 Workforce development including limitations & need for training