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Will a new approach to end-of-life care for people who use substances improve their access to, and experience of, palliative and end-of-life care?

Final report – February 2023

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“I'm just very grateful that we’ve got people that are driven by trying to improve care. I think there is a lot of goodwill and recognition about people in this situation trying to get it right for them. I guess it’s just really heartening to see that people from all sorts of disciplines and persuasions are coming together to try and make a difference. So, it’s just really heartening to see there are people in research and clinical practice and in the social care world trying to make a difference. Actually, that people are funding the research for that as well so that’s really positive as well because it could be incredibly hard to get things done.”

(Palliative Care Consultant)

Contents

Dedication

This report is dedicated to the people with lived experience who gave their time and energy to contribute to this research.

In particular, Sandra Richardson, a valued member of our PEAT (People with Experience Advisory Team) who passed away during the course of this project.

It is also dedicated to those who shared their experiences with us but who did not wish to be named publicly. We thank them for their integrity, courage and commitment.

Acknowledgements

We would particularly like to thank:

- Our PEAT (people with experience advisory team) comprising: Dominic Lewington, Kim Eaton, Sandra Richardson, Shelley Cunliffe. Their participation as key members of the Research Team, their openness, insights and constructive criticism has been vital to this project's success.

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- Our partner agencies in Liverpool and Sefton – including practitioners and managers that supported us in the most difficult of circumstances during the Covid-19 pandemic and ongoing challenging practice conditions. These include:
    1. Mersey Care NHS Foundation Trust – Specialist Community Palliative Care Team
    2. CGL (formerly MerseyCare's Ambitions service - substance use) service
    3. We are with you
    4. Marie Curie hospice, Woolton
    5. St Joseph's hospice, Thornton
    6. Royal Liverpool University Hospital
    7. Liverpool City Council Adult Social Care
    8. Sefton Borough Council Adult Social Care (Substance use)
    9. Whitechapel Centre
    10. YMCA homeless (umbrella) services
    11. Brownlow GP Practice

- Our project advisory group comprising:
    - Dr Laura Chapman, Consultant in Palliative Medicine; Medical Director, Marie Curie Hospice Liverpool
    - Dr Cait Taylor, GP Advisor to Mersey Care NHS Foundation Trust and Clinical Director of Central Liverpool Primary Care Network
    - Viv Evans, Chief Executive, Adfam, London
    - Mike Parr, Chief Executive, St Joseph's Hospice, Thornton, Liverpool
    - Dr Steve Brinksman, Medical Director, Cranstoun and Clinical Director, Addiction Professionals
    - Andrew Misell, Director for Wales, Alcohol Change UK, Cardiff
    - Maddy Vaz, Trustee/volunteer, Sanctuary Family Support, Liverpool
    - Maddy Bass, Director of Nursing and Quality, St John's Hospice, Lancaster
    - Dr Lynn Owens, Nurse Consultant Hepatology, Liverpool University Hospitals NHS Foundation Trust and Honorary Research Fellow - The University of Liverpool
    - Ellie McNeil, Chief Executive, YMCA Together, Liverpool
    - Annie Lynn, Services Manager, We Are With You
    - Steve Swede, Community Manager - Central, Liverpool Adult Social Care
    - Dr Debbie Nolan, GP partner with special interest in drugs and alcohol, Brownlow Practice; Training Programme Director for South Liverpool and Birkenhead GPs.

  - Michelle Malone, Social Worker, Sefton Adult Social Care Team
  - Martin Smith, Recovery Lead, Derbyshire Healthcare NHS Foundation Trust
  - Tony Bonser, NHS Patient Experience member, Hospice UK volunteer, NHS EoLC Programme Management Board member and St Catherine's Hospice Trustee (Preston)
  - Jan Herrity, Manager DOLs & Drug Rehabilitation Team, Adult Social Care, Sefton Council;
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- This report has been written and edited by Prof Sarah Galvani with contributions from the project team where stated.

Executive Summary

This research, funded by the National Institute for Health Research (NIHR), took place from October 2019 to March 2023[1]. The research was located in the City of Liverpool and the Borough of Sefton in the North-West of England. Liverpool has one of the highest rates of alcohol-related mortality and drug-related harm in the country. Inspired by earlier research that revealed the dearth of policy and practice on providing care and dignity at end of life for people using substances (Galvani, 2018), it set out to answer two primary research questions:

1. What should a new, co-produced, model of care look like for people using substances needing palliative and end-of-life care?
2. Does the new model have the potential to improve people's access to, and experience of, end-of-life care?

Participatory Action Research to co-create a new model of care

The project worked in partnership with a mixed and complex network of 10 social and health care agencies and the project's PEAT[2] to co-create a new model of end-of-life care for people using substances. This process revealed that little was known formally about responding to substance use at end of life, that more practice engagement was needed ahead of policy and practice change, and there was a need for widespread dissemination of knowledge.

The new model of care

An initial theory of change set out a consensus about the long-, medium- and short-term goals for improving care. Given the project's timespan, the focus was on short-term impact, with four short-term outcomes:

1. Carers equipped to have sensitive conversations about serious and advancing ill health, substance use, and advanced care planning.
2. Consistent advocacy for people using substances navigating health and social care provision to access palliative and end-of-life care.
3. Practitioners and peers feel better supported to work/live with SAIH and substance use.
4. Resources available for family/carers to access information and support.

Research design and methods

Mixed methods research measured the impact of this new model of care[3] through:

i. In-depth individual interviews and focus groups with social and health care practitioners and managers who had experience of supporting people using substances at end of life;

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[1] The original completion date was March 2022. The Covid-19 pandemic took hold in March 2020 resulting in a 14-month delay. The individual and structural impact of the pandemic and its after-effects made completion of all the original aims untenable.

[2] A **People with Experience Advisory Team** (PEAT) was established to support and facilitate the involvement of people lived experience of both substance use and end-of-life care in the project at a place and pace that took account of their needs.

[3] A more comprehensive research design was originally planned but could not be delivered due to the Covid-19 pandemic severely restricting access to key participant groups.

ii. Bespoke questionnaires[4] to capture practitioners' pre- and post-model of care experiences of unmet physical, psychological, emotional, spiritual, information and support needs among people using substances approaching end of life; and
iii. Responsive engagement with a group of individuals with lived experience of substance use and palliative needs to produce a series of case studies.

Research Findings

Practitioner focus groups: These revealed how the complex needs of people using substances at end of life were often unmet due to professional boundary concerns and the lack of cross-agency working. Existing end-of-life care provision placed unwanted restrictions on people using substances, meaning that their wishes were not met. The lack of both suitable training for staff and any specialist accommodation to support choices about place of death created moral challenges for service providers.

Manager interviews: With a common goal of supporting people to die with dignity, these interviews revealed that more needed to be done at an earlier stage to identify people with advancing ill-health and support sensitive conversations with them about their future care. Action is needed to develop: routine questioning; integrated care pathways between agencies; specialist roles to support people and link services; specialist supported accommodation; substance use specific family support (needed to counter stigma) and staff training (for example on: terminal health conditions, having conversations about end of life wishes, Advance Care Planning and supporting people who want to continue using substances). There was clear agreement that dying well involves respecting a person's choices, offering needs-led care, and minimising pain in the environment of their choosing - rather than hospital settings where ongoing substance use and intoxication is not tolerated.

Practitioner surveys: These revealed differences in perception of effectiveness of interdisciplinary working and access to palliative care by job role/type of service provider, revealing a degree of silo working and limited care pathways for social care agencies.

Case studies with people with experience of substance use and palliative services: These revealed people's lived experiences of being 'invisible/dismissed' in dealings with (some) practitioners/service providers, sometimes through the inadvertent activation of past experiences of discrimination. Complexities around handling pain medication require practitioners who move beyond procedural approaches to build trusting relationships grounded in 'points of connection' between practitioner and person.

Case studies with family, friends and carers: Friends in particular tend to play a much more central role in providing end-of-life health and social care for people using substances than with 'traditional' patients or clients. There is a stark need for greater understanding of the family's and friends' support needs and exploration of systemic strengths and challenges around this area.

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[4] Based on the Palliative care Outcomes Scales (POS).

Development of information and training resources

To facilitate the dissemination of the new model of care and to respond to the fieldwork limitations created by the pandemic, website resources were developed to support training for practitioners, and information for families and for people with lived experience. Pilot support forums for practitioners and families were also established.

The website (https://endoflifecaresubstanceuse.com/) comprises more than 40 podcasts and over 17 different publications. It provides worldwide access to the resources and information from this and previous projects for professionals, people with lived experience and family/friends/carers.

The training presentations introduced practitioners to the new model, how it had been developed and the resources in place to support it. 164 people were trained across 11 social and health care providers in Liverpool and Sefton.

Six support forums were held, three for practitioners and three for family members. The practitioner forums ran very well but the family members' forums need to be run by family focussed organisations to maximise attendance and overcome shame and stigma. Discussions are ongoing with partner agencies about co-hosting both forums.

Training evaluation

The training evaluation[5] found that, compared to other services, addictions service staff do not expect to manage end-of-life clients. Whilst general expectations and attitudes towards supporting people with comorbid substance use and end-of-life needs were high among all practitioners surveyed, they reported experiencing difficulties in managing complex clients. There were also differences in relation to practice change beliefs between addictions/ palliative care staff (3rd sector services) and social care/health staff (statutory services) - whereby the latter had less confidence or belief in being able to change practice.

Conclusion

This development of resources and training for project partner agencies showed how little was known about responding to substance use at end of life and how much more thinking and engagement was needed by practice partners ahead of significant changes to policy and practice. There is a need for better knowledge set within a clear policy framework to facilitate clear pathways to better more appropriate care and resources that avoid people facing stigma and unnecessary additional suffering at the end of their lives.

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[5] The training evaluation used a bespoke 25-item questionnaire, originally designed to be completed prior to, (T1) and within six weeks of undertaking training (T2). Once again, Covid reduced the opportunity to conduct a follow-up survey at T2, so only T1 data were analysed. There were 42 trainee responses of which 33 provided complete questionnaire responses.

Chapter 1 - Introduction

This research set out to answer two primary research questions:

1. What should a new, co-produced, model of care look like for people using substances needing palliative and end-of-life care?
2. Second, does the new model have the potential to improve people's access to, and experience of, end-of-life care?

The research questions emerged from an earlier research project (Galvani, 2018) that explored the nature and extent of palliative and end-of-life care for people using substances in partnership with three substance use agencies, three hospices and a grassroots community voices organisation, VoiceBox Inc. Its findings suggested that little policy or practice attention has been given to providing people using substances – currently or historically – with the care and dignity people deserve at the end of life. They face a range of barriers to service access at the end of their lives including negative experiences of care services and a fear of stigmatising attitudes from social and health care professionals. This stigma and marginalisation extends to family, friends and carers. The result is often isolation, avoidance of services and late presentation to services at which point the person's health condition is life shortening and social care needs are complex.

The problem is exacerbated by gaps in policy frameworks. Currently, substance use (SU) receives limited attention in national or local policy and practice around end-of-life care (EoLC); and EoLC receives little attention in national or local policy and practice around SU. This gap results in care provision that focusses on either SU or EoLC, resulting in services and staff who are not equipped to respond adequately to individuals and their family, friends and carers (FFCs), with both EoLC and SU needs (Galvani et al. 2018).

With some notable exceptions - driven by particularly committed and reflective service providers and individuals – the project found that, overall, the landscape of palliative and end-of-life care for people using substances was lacking and, at times, ignorant, stigmatising and harmful.

This research, therefore, set out to determine what could be changed and whether it was feasible within a mixed and complex network of 10 social and health care agencies to create a new approach to care for this group of people who have hitherto been marginalised, at best, and their health needs ignored or dismissed, at worst.

The location for this research was the City of Liverpool, in the North-West of England. Statistical evidence shows the North West has the second highest level of alcohol-specific deaths after the North East (Office for National Statistics, 2021). There is a similar picture for drug-related harm. The North West ranks highest in relation to drug-related poisonings (Office for National Statistics 2022). People in Liverpool are, therefore, proportionally more likely suffer substance-related morbidity and mortality than peers in most other areas in England. Importantly, practitioners and policy makers in the City had reached out to the research team during the first project as they sought to improve their services to people using substances in need of palliative and end-of-life care. They were, therefore, keen to work with us to take our research forward.

This report summarises our approach, our findings and our successes. However, it does not fight shy of detailing lessons learned and the challenges to our ambition, in addition to the negative impact of covid-19 on the research process. This was not an experimental project that excludes different groups of people or services. It was located within the messy reality that is the delivery of social and health care services within a city with a significant number of service needs due to its high morbidity and mortality relating to substance use and within a context of economic austerity and funding cuts to public services. The report concludes with plans for the wider dissemination of the resources developed within the project to national and international levels.

Chapter 2 - Evidence summary

There is a dearth of evidence on substance use and palliative and end-of-life care. The evidence and literature that exists is both wide in scope and limited in focus. The following is a summary of the current evidence.

2.1 Existing evidence *(Author – Dr Gary Witham)*

A Rapid Evidence Assessment (REA) conducted by Witham et al. (2019a) examined end-of-life care for people with alcohol and other drug problems. A thematic analysis of the data identified three major themes. These were i) pain management, ii) homeless and marginalised populations and iii) alcohol-related papers. Sixty papers were identified with, geographically, most evidence stemming from Canada and the USA (n=46/76.7%), the UK (n=9/15%) and then Australia (n=3/5%). This section summarises the findings from those papers and includes later papers published since it was undertaken.

Pain management

The majority of papers related to pain management and were focusing on cancer care. There was a general consensus as to the complexity of managing pain within the context of substance use. There are persistent issues of under-treatment of pain with people using substances at the end of life. This is often derived from prescribing practitioners ʼfears of overdosing a client or needing to counter perceived “drug seeking” behaviours. More recent evidence also suggests that prescribing outside standard pain management protocols also causes challenges for practitioners working in palliative care (Merlin et al., 2020, Witham et al., 2019b, Flaherty et al., 2021). This may need to occur due to a high tolerance to opioid pain killers for people with a previous history of opioid use, requiring higher levels than normal of prescribed pain relief. The call for comprehensive assessment was also evident within most papers to manage pain effectively and identify those people who needed this support. For example, Sacco et al., (2017) found that 68% of hospice social workers from a random sample of hospices from 105 agencies assessed for substance use. However, assessments were not from validated instruments, nor did they differentiate between drug types.

The literature focuses on either abstinence from substances use or risk/harm reduction within end-of-life care. Those papers focusing on abstinence appeared to advocate surveillance as a way of promoting safe opioid use. Surveillance incorporated interventions such as universal screening for substance use, pill counting and urine testing with a focus on using validated tools (Barclay et al., 2014, Carmichael et al., 2016, Childers et al., 2015). There remains, however, limited efficacy for these interventions. For example, the clinical impact or acceptability of these validated tools remain uncertain, with a lengthy time to complete and a lack of direction as to what to do with a subsequent positive outcome (Voon et al., 2017). Urine drug testing may offer limited support to practitioners ʼdecisions around risk identification, but there is limited evidence related to its accuracy in predicting, preventing or reducing substance use behaviours (Becker et al., 2013, Turk et al., 2008). With high potential for false positives, it may be a blunt instrument in assessing risk and several papers focus more on the building of relationship and honesty within communication (Arthur et al., 2016, Carmichael et al., 2016).

Homeless and marginalised groups

Substance use at the end of life for people who are homeless or precariously housed is an area with an increasing evidence base. Substance use is common in this population with Schneider & Dosani (2021) noting 61.9% of their homeless sample (n=63) used substances. There has been an emphasis on examining the gaps in service provision for this population and on the environment of end-of-life care which may be shelter-based rather than at home or a hospice (McNeil & Guirguis-Younger 2012, McNeil et al., 2012). More recent research by Hudson et al. (2017) has explored views and experiences of people who are homeless. They found discussing end of life with others, including hostel workers, was challenging. Their focus was more on the immediacy of day-to-day living rather than future concerns. In addition, many homeless services focused on recovery from addiction which left talk about dying a secondary concern and limited opportunity for engagement (Shulman et al., 2018).

The difficulty of recognising dying in this population also created ambivalence about beginning conversations related to advance care planning. Some papers examined the context and service provision for end-of-life care and homelessness, with Giesbrecht et al. (2018) and Veer et al. (2018) commenting that hospitals were perceived by homeless people as inflexible and paternalistic, with substance use hindering adequate care (Klop et al., 2018). This tended to lead to late presentation of severe symptoms in formalised care settings, with palliative care settings viewed as places to die and to be avoided. It is therefore important to be flexible and more proactively engage with shelters and other non-traditional settings to create joined up care and prevent a siloed system (Stajduhar et al., 2019). Purkey & MacKenzie (2019) also recommend a system change that includes harm reduction and equity-oriented health care, as well as a combination of outreach and inpatient services before palliative care services will be accessible for this population. Some papers discussed concerns about illicit drug use or diversion of opioids in a hostel setting by peers or friends/family. Webb et al. (2018) and Wilson et al. (2020) suggests the use of secure lockable cabinets in hostels for controlled medications, supervised consumption, slow-release opioid formulas and support and training for hostel staff. Effective communication with people who are homeless is a fundamental requirement of good care, as well as the acknowledgement of the commonly experienced stigma, shame and indignity that may be linked to childhood trauma and social isolation (Bazari et al., 2018, MacKenzie & Purkey, 2019).

Within the literature mental health was highlighted as an important underlying concern - with depression and anxiety causing increased symptom burden, particular pain (Barclay et al., 2014). This problem was complex requiring and often intersecting with poverty, emotional and social difficulties as well as substance use (Sulistio & Jackson, 2013).

Alcohol

Papers related to alcohol focused on cancer and liver cirrhosis with problematic alcohol use appearing more common in younger palliative populations who usually have been referred late to end-of-life services (Kwon et al., 2013). The most frequent alcohol screening tool found in the evidence was the CAGE questionnaire (Witham et al., 2019a). Giusti et al., (2019) found in their sample of 117 patients that 10.3% were CAGE positive. Most papers focussed on routine screening. For example, MacCormac (2017) asserts that this is important since there is an increased tendency to experience terminal agitation, high levels of comorbidities and poor social support in people with problematic alcohol use. Mercadante et al. (2017) also makes reference to high symptom burden and the need to refer CAGE positive patients early to palliative and end-of-life care services.

Miscellaneous
Some papers fell into no single category. Ebenau et al. (2019) from their qualitative study highlight both the flexibility needed in adapting end-of-life care services to meet the needs of people using substances and the acknowledgment of the complexity of need and how the person's coping skills operate. There was limited and closed communication with practitioners from a family perspective and this is similar to the findings of Walter et al. (2017). Ebenau et al. (2020) conducted focus groups with practitioners and found that attempting to creatively meet the needs of this population was challenged due to stigma and there was little training available, so care was often experience based. This issue of training was also highlighted by Jones et al. (2022) as an area requiring attention in order address the needs of this population. Pain management was seen as often poor and end-of-life care was only accessed late in the dying phase. Care for caregivers was often de-prioritized without effective service integration or knowledge about who the caregivers were in a person's life (Stajduhar et al. 2020). "Family" caregivers can potentially be a significant support but Stajduhar et al. (2020) conducted an ethnographic study and indicated that they often experienced structural vulnerabilities themselves. They found half of their sample were street family or friends. The lived experience of people using substances, including poverty, house instability and challenging relationships, required them to overcome issues of trust with practitioners in order to create interventions that were meaningful to support end-of-life care.

2.2 - Gaps in evidence

There are significant gaps within the literature and these primarily relate to a lack of research on responses to, and interventions for, people with problematic substance use at the end of life. There is limited development of policy and practice in relation to this population, although the literature examining homelessness at the end of life presents the strongest growing research field in terms of policy implications. The associated substance use often presented within homelessness makes this an important area in terms of people using substances at the end of life. There remains a lack of data outside North America and the UK. Comparative studies are an important area to develop since they would highlight potential cultural nuances that could affect appropriate health and social care responses, within western countries (Owens and Randhawa, 2004) as well as in the majority world.

Few prevalence studies were identified. Therefore, more epidemiological research would provide a wider frame of reference for the further development of policy and practice. There is also a need to extend methodological inquiry to larger scale quantitative approaches to increase data sets on the experiences of targeted populations involved in service provision. This would need to include interdisciplinary teams involved in care delivery for people using substances at the end of life. Further research is required in exploring conditions other than cancer that co-exist with substance use and this extends to both prevalence and incidence as well as to health and social care acknowledgement of and response to these populations. Diverse co-morbidities are associated with substance use - for example: COPD, cardiovascular disease and mental health problems (Shield et al., 2014). There is no existing research identifying models of good practice with people using substances at the end of life apart from work by Galvani et al., (2019). Models of good practice need developing by working with people using substances at the end of life. They also need piloting and evaluating for their effectiveness in primary, secondary and preventative levels to assess need at a population level.

Qualitative inquiry is required to examine family and friends of people using substances at the end of life with more rich description of the cultural, social and demographic context. This will enhance transferability and create greater insight into different populations, allowing for more well designed and appropriate research supporting sustainability (Wilson et al., 2015). There remains limited evidence relating to alcohol use at the end of life. This is particularly important given this is the most commonly used substance. There are a few prevalence studies relating to alcohol use at the end of life, but no significant qualitative exploration of people's experiences, nor of their family and friends.

2.3 - Towards a new model of care

The evidence suggests there is much work to be done both in research and practice on the topic of palliative and end-of-life care for people using substances or with a history of substance use. Combined with work from the exploratory study by Galvani et al. (2018), it suggests that there is much improvement to be made to ensure people (individuals and their families, friends and carers) receive the care they deserve and to help them maximise their quality of life in the final stages of their lives. It provides the context for the research detailed in this report that sought to explore, develop and implement a new approach to care for people using substances and their families as they approach the end of their lives.

Chapter 3 - Methodology

This chapter summarises our proposed approach to the research as well the adjustments we had to make to account for the Covid-19 pandemic.

3.1 - Aims and objectives

The primary aims of this project were to determine what a new, co-produced, model of care should look like for people using substances needing palliative and end-of-life care. It also aimed to establish whether the new model had the potential to improve people's access to, and experience of, end-of-life care.

More specifically, its objectives were to:

1. Develop and implement a new, co-produced, integrated model of care in partnership with people with lived experience of substance use (current or past), and serious and advancing ill health, and with their families, friends, carers (FFCs) and professionals.
2. Establish whether people receiving the new model of care, and their FFCs, have an improved experience of care.
3. Establish whether people in need of care, who sit outside of specialist palliative care and substance use services are more able to access care.
4. Determine whether the professionals supporting people with problematic SU and EoLC needs feel better supported by the new model.

3.2 - Research design

The study set out to deliver two complementary workstreams:

i. a pre- and post-test approach to explore the potential impact of a new model of service provision and access to services
ii. process monitoring to inform our understanding of the key factors relevant to the model's implementation and its rollout.

To achieve these objectives, a participatory action research (PAR) approach was proposed and planned. Participatory Action Research is a way of researching in partnership with a range of people with different expertise from the project's conception. It is driven by all the participants, not the researchers alone. It is used when the intention is to benefit people directly through changes or improvements in care (Pain et al. 2007). This means involvement from the outset of the project in terms of determining the research questions, the tools used for data collection, the model development, the data collection itself, data analysis, and subsequent dissemination. This project, while participatory, was a mixed methods research project combining quantitative with qualitative data.

The approach comprised five steps:

Step one:

- Collation of a) existing research evidence, and b) work with project partners to establish current practice in our partner services and the wider care community (where appropriate) and what might need to change to make a difference.

- Administer quantitative baseline measures and qualitative pre-intervention data collection.

Step two:
- Co-create a theory of change with all project partners

Step three:
- Develop the new integrated model of care and its core interventions

Step four:
- Rollout components of the new model following the three phases of PAR:
    - Action – delivery of first iteration of the model
    - Reflection – consultation with participants
    - Adaptation – of the model following consultation.

Step five:
- Administration of post-intervention measures and analysis from baseline and post-intervention (quantitative and qualitative)
- Analysis of data collected at each phase of PAR identified in Step four above.

Section 3.8 (below) details the extent to which we were able to complete this 5 step process in light of the Covid-19 pandemic that impacted so heavily upon social and health care providers – the agency partners in our project.

3.3 - Quantitative data collection and analysis *(Author – Dr Lucy Webb)*

For the quantitative strand of the project, we developed bespoke questionnaires based on the Palliative care Outcomes Scales (POS) (Hearn et al. 1999; Higginson et al. 2014). A range of validated questionnaires were investigated for suitability for this project strand. However, all were either heavily focused on symptom control or service quality, without addressing the specific factors of service accessibility and quality of integrated care that were key outcomes for our project.

The bespoke questionnaire (18 items on a 5-point Likert scale) retained the domains measured by the POS: physical, psychological, emotional, spiritual, provision of information and support. However, we added items to capture ease of access and inter-disciplinary service working and collapsed psychological, emotional and spiritual domains. The final version included service and demographic descriptors and categorical detail to identify and aggregate physical, social and substance use factors (see appendix 1).

Four versions of the questionnaire were designed for use with professional care staff, patients, informal carers and people with dual needs (substance use and palliative care) outside of services. Only two of the questionnaires were ultimately used to collect data from staff and informal carers, with only the staff survey reaching adequate power for statistical analysis (N=69).

A normality test was performed on each domain (physical, psycho-socio-spiritual, support, information provision, inter-service working, access). All domains showed significance by the Shapiro-Wilk test, indicating non-normal distribution. Individual items were also tested for normal distribution, all demonstrating skewness or kurtosis, indicative of significant findings from the survey's Likert scales.

3.4 - Qualitative data collection and analysis

The qualitative data collection sought to complement the quantitative data with the lived experience of people who had experience of substance use and serious and advancing ill health, as well as those who lived with, or cared for, someone who used substances and had palliative or end-of-life care needs.

Pre- and post-test qualitative data would enable us to reflect people's experiences of giving and receiving care in more depth. It would also allow processes of change to be explored as well as the environmental factors that may influence care provision. Three forms of qualitative data collection were included in the research design:

1. For people with lived experience (PWLEs) receiving EoLC, a Person-centred Evolving Method (PEM) (Ashby et al. 2018) was planned. This incorporated a toolkit of qualitative approaches to obtaining views allowing people the choice of a preferred method. People with experience were to be accessed through end-of-life services, substance use (SU) services and those currently not receiving a service through peer communities.
2. Focus groups of approximately 60 minutes duration were planned for family, friends and carers (FFCs). Participants were to be accessed through the carer and family support groups held across the participating EoLC services, SU services and community networks. The focus groups would also provide participants with the opportunity to spend time together discussing their experiences of a) care for their relative and b) their own experience of receiving care as FFC.
3. Practitioner evidence was collected through of focus groups of frontline practitioners and semi-structured interviews with managerial level staff across EoLC services, SU services and community networks, to discuss their views and experiences of current practice and service provision for this group of people and their FFCs. (See appendices 2 and 3).

The analytic approach adopted for the semi-structured interviews was Template Analysis (King, 2012). This is a transparent form of analysis that acknowledges the line of questioning in qualitative research is likely to influence the findings significantly, rather than present data as if it has 'emerged 'from the analysis process. The process is to develop an initial template of themes based on a reading of a sample of transcripts. This is then used as the starting point for a 'bottom up 'coding process more akin to principles of grounded theory approaches. Thus, template analysis allows for new themes to be identified as well as acknowledging there are likely to be themes based around the questions asked and focus of the interview or group discussion.

The four focus groups were analysed using positioning analysis (Halkier, 2010). Positioning can be understood as an examination of interaction locating both how the person both identifies within an interaction and how that relates to the normative cultural framing of such interactions (van Langenhove and Harré, 1999: 17). Positioning Theory is, therefore, grounded in everyday conversation and involves teller and listener negotiating the construction(s) (or attempted construction(s)) of action mediated towards social practice. It addresses features related to the local context and is focused on highlighting the explicit and implicit patterns of reasoning that are generated in the ways that people act towards each other. This supports a critical analytical framing of interaction in, for example, focus groups where participants relate to each other through multiple positionings, rather than through unambiguous identities and norms (Davies and Harre, 1999: 52). Positioning occurs in dialogue and as such is a discursive process. The focus group recordings were listened to twice and the transcripts were uploaded to Nvivo 11 software to support data analysis. The transcripts were systematically read through, and annotations were recorded highlighting the positioning of the participants in constructing their discussion. After this process, common constructions and positions were highlighted through an iterative approach and critically related to all four focus groups. Common underlying themes, therefore, were generated based on this approach. The wider themes and positioning of different health and social care practitioners where initially developed by one of the research team and then independently reviewed by a second team member and the findings further discussed.

3.5 - People with experience advisory team (PEAT) *(Written by Amanda Clayson)*

A strength of this project was the partnership with VoiceBox Inc.. Voicebox is led by a co-applicant with lived experience and a longstanding connection with local communities associated with substance use. Our research experience to date has taught us that people with lived experience require a flexible and personalised approach to participate in advisory arrangements (Clayson and Galvani, 2018). As a result of this experience, we established a **People with Experience Advisory Team** (PEAT) to support and facilitate PWE involvement at a place and pace that took account of their needs. A group of five individuals formed the core membership, providing continuity and an integrative approach across all aspects of the project. All members had lived experience of both substance use and end-of-life care. This included personal substance use issues and that of family and friends. The team's experience of end-of-life care was equally personal. One member of the team died during the project. A wider group of individuals contributed on a more flexible basis, bringing a breadth of insight and widened the scope of experiences.

Participation was extensive and impactful. Resourcing of PEAT members 'time and involvement reflected the core role which they undertook. This went far beyond a consultative role, establishing the team as key developers and influencers at every stage of the project. Regular group sessions were complemented by extensive individual contact and support; this enabled people to participate fully in ways and times that worked for them. Recordings, support materials and adaptations proved positive in supporting a deeper connection and level of involvement.

Feedback from each PEAT member is testament to the value and impact their participation has had. There is clear, recognised and communicated evidence of the real and meaningful role the PEAT process has had for those participating, the wider research team and for the outcomes of the project as a whole.

3.6 - Project Advisory Group (PAG)

A Project Advisory Group was established comprising social and health care professionals, community groups, national charity representation and policy makers and commissioners. The PAG's role was to advise and engage in the research process from design, delivery and reflection on the new model of care. Due to the Covid-related challenges faced by this project, the PAG met only twice although individual contacts with various members continued where relevant throughout the project's duration.

3.7 - Ethics and research governance

Ethical approval was sought and received through application to the Research Ethics Committee of the Health Research Authority (HRA) (REC reference 20/WM/0140). The HRA approves social and health care research through a rigorous panel of reviewers. Given the stringency of its processes, no further approval was needed from Manchester Metropolitan University. However, a number of research partners, including hospice partners, and MerseyCare NHS Foundation Trust had additional requirements for research governance and the issuing of research passports. These were duly completed and full approval given after a process lasting 8 months.

At an individual level, fully informed consent was sought from all participants through the provision of participant information sheets (example in appendix 4) and consent forms (example in appendix 5). The participant information sheets provided detail about the storage of data collected in order to meet requirements under data protection legislation.

Ethical considerations were brought to the fore with the onset of the Covid-19 pandemic and lockdown measures. These will be explored further in section 3.8 below.

3.8 - Research challenges

While every research project has its methodological challenges, the time period of this project brought additional difficulties largely resulting from it spanning the global Covid-19 pandemic. Two key challenges have been summarised below due to their importance to the process and progression of this research.

Research in the time of Covid and post pandemic era

Due to the Covid-19 pandemic that started in March 2020, truly participative research with people with lived experience was challenging and became impossible for data collection purposes. Some PAR was possible towards the start and end of the project with the majority of this conducted virtually with a smaller group of people than originally planned. Meaningful research involvement with PWLE requires the building of relationships. This is not done overnight, particularly with people who, at best, have not been served well by their involvement with many service providers and who, at worst, have been dismissed, stigmatised and marginalised by them as a result of their use of substances. This is the real context for the involvement of PWLE in our research. Meaningful involvement is achieved by spending time with people, in spaces and environments that are comfortable and familiar to them. This often involves wider conversations and opportunities for people to 'get a sense ' of the individuals involved in the research, to unpack the focus and if and how they might be involved. Covid-19 put an end to that process. Face-to-face contact was not possible, meaning those relationships could not be built. Even where there were existing relationships (through the Community Partner), the overwhelming impact of the unfolding COVID situation proved to be a primary concern for many people, especially where they were managing their own mental well-being. Although there was some engagement and participation across the span of the project (through online calls and video chats), it was far smaller than anticipated and focused more on how people were dealing with their immediate circumstances. This meant relying on a smaller group of people than originally conceived, however, their involvement was invaluable. We had planned for a much wider involvement and participation of people pre covid, some of whom would have never been asked to participate in a project of this kind before.

This difficulty was also mirrored in our work with family members. All family work in our partner agencies stopped during the pandemic resulting in no access for us to family members, friends and unpaid carers. This family work has only just restarted in some agencies. Coupled with high rates of absenteeism among staff, there continues to be a tentative approach taken to opening up services completely in social and health care. Further, different strains of covid are appearing still, and social and health care agencies are now struggling to meet the backlog of social and health care that lockdown and the pandemic created.

Credit must be given to the practitioners and managers who agreed to participate in online focus groups and interviews during lockdown to enable us to conduct baseline data collection, and to Dr Sam Wright for making it happen with her incomparable social skills and gentle persuasion technique. Numbers were smaller than planned and senior policy makers were absent from much of our conversations as a result of Covid and other political challenges within Liverpool City Council at the time. This lack of senior policy maker involvement put us at a disadvantage in garnering policy support for whatever model of care was developed from this project. It remains an outstanding gap in the regional commitment to improving services.

With the onset of the pandemic and lockdown or contact restrictions, our research moved online. This raised ethical queries in relation to the recruitment of people with lived experience, and their families, friends and carers. Talking with people about such sensitive subjects without being physically present with them did not sit well with the research team. With agreement from two individuals, attempts at telephone interviewing were made, however, one person withdrew and the other comprised a complex discussion over several lengthy interviews. It eventually became apparent that the person did not meet our inclusion criteria, however, ethically, the researcher felt it was important to support the person who was distressed and offer some links to other services. The researcher also fed back to the team that the process of trying to secure remote interviews with people with lived experience felt uncomfortable and inappropriate. Therefore, we agreed to stop attempts to interview people with lived experience at that time.

Systemic issues

The reality of service provision across social and health care is not a simple one. People presenting with multiple needs that do not fit neatly into one service or another often fall through the gaps. Add to this the perceptions that people who use substances are dangerous, violent, dirty, non-compliant, troublesome, to name a few, and the project was always going to meet resistance.

We knew from the outset that this was always going to be an ambitious project. Working with 10 partner agencies across social and health care, in statutory and non-statutory settings, each with significant differences with respect to their systems, procedures, priorities, funding, staff knowledge and development. Given more than 10 years of austerity, we also found highly pressurised working environments, little slack in the system and services under threat of closure or restructure. In addition, the recommissioning of drug services in Liverpool resulted in a change of provider and partnerships with providers need establishing yet again.

This was the reality in which we were asking people to think about and do something new, to learn and add to their existing knowledge base and expertise. And we were asking them to do this for a group of people who they currently are aware of seeing in small numbers – albeit a group whose numbers are expected to grow significantly in the near future as awareness improves.

Chapter 4 –Theory of change and Model of care

Steps two and three of our five step model (see s. 3.2 above) were to:

- Step 2 - Co-create a theory of change with all project partners, and
- Step 3 - Develop the new integrated model of care and its core interventions.

Given the challenges of collecting baseline data created by the Covid-19 pandemic and its impact on all our participant groups, we brought forward the development of the theory of change and subsequent model of care to run in parallel with our ongoing, but slower, baseline data collection with practitioners and managers.

4.1 - Theory of Change

We held four online (due to Covid), half day workshops with frontline representatives from our partner agencies, the project's PEAT members, and two other members of the research team. In between the workshops email was used to communicate early ideas and to ensure that, in summarising the theory, we represented the views of the working group. The groups were co-led by the people with experience lead for the project, Amanda Clayson, the principle investigator and project researcher.

The first workshop involved large group discussion that identified what a theory of change was and how it was created (see figure 1 below). Smaller breakout group work subsequently allowed for discussion of long-term, medium-term and short-term goals and ensuring all voices and views were heard.

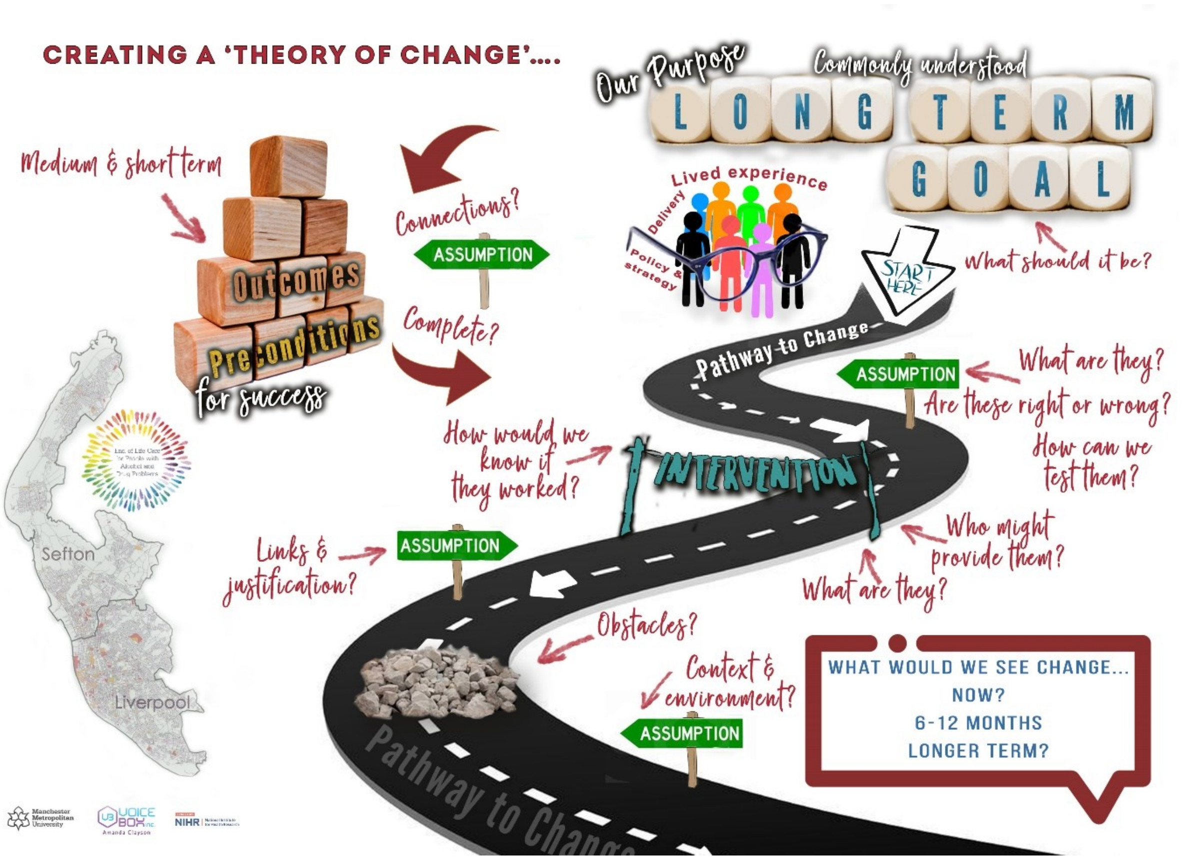


Figure 1: Creating a theory of change – design by Amanda Clayson

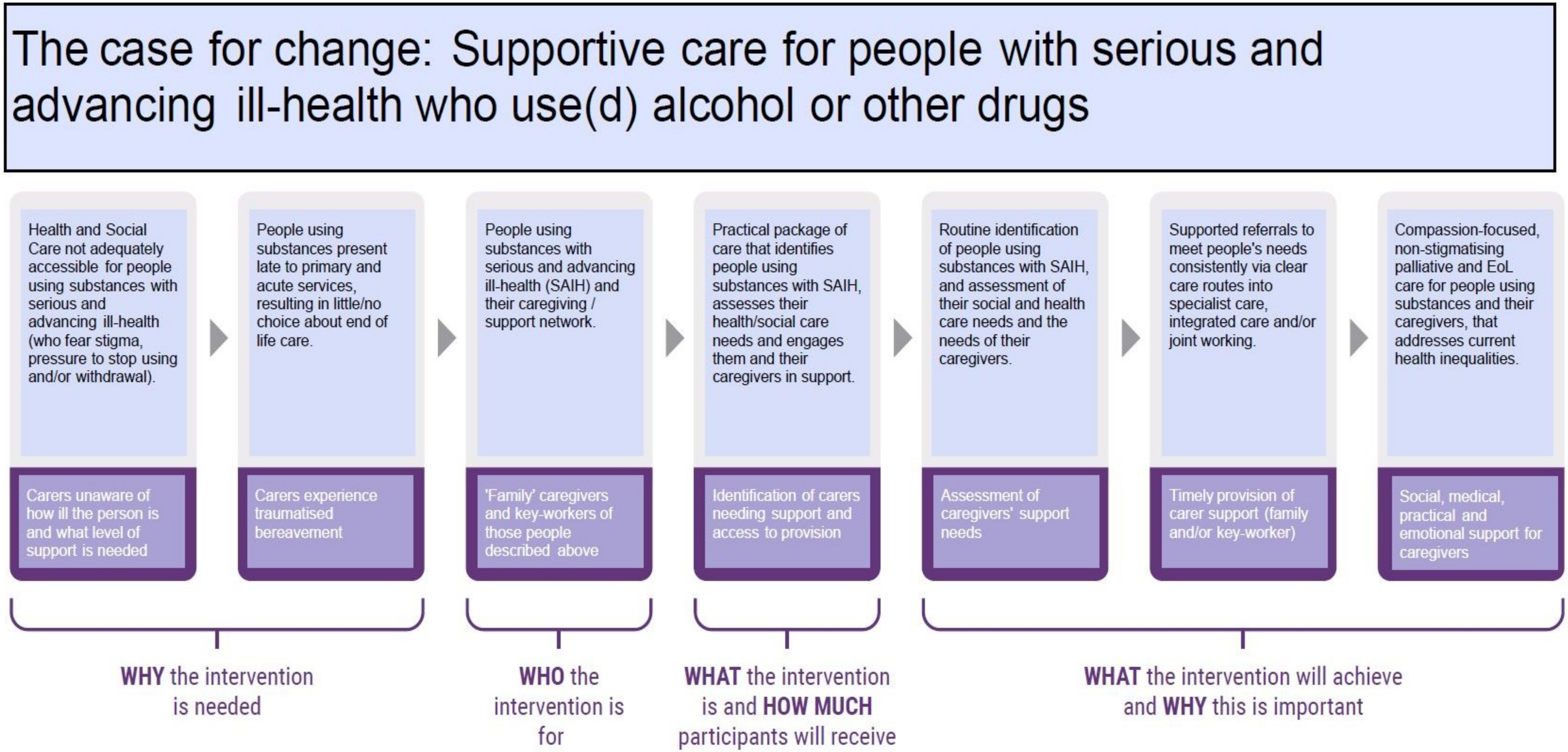
Good practice in developing theories of change and subsequent models of care advises involvement and commitment from policy makers from the outset in order to maximise chances of implementation (Mason and Barnes, 2007). The challenge of the pandemic and a serious policy crisis in Liverpool at the time, resulted in few senior managers and policy makers attending with the potential consequence being our ability to achieve less at a policy level.

Figure 2 below summarises the agreed theory for change. Given the paucity of support or information for carers, particularly family care givers, an additional level was included to record their views and needs. Handwritten notes were taken during all workshops by the three co-leads and distilled into a draft theory of change. This was then shared with all participants and refined accordingly.

Much of the workshop discussion centred around people's negative experiences of care or the absence of care for people using substances when approaching the end of their lives. Subsequently the agreed **long-term goals** of any intervention would be to provide a service that was compassion-focussed and non-stigmatising; one that acknowledged and addressed the health inequalities experienced by people using substances. This, in turn, raised questions about what care pathways existed and whether professionals were prepared for, and able to, routinely identify people who may benefit from palliative care or support around their substance use. Practitioners in the workshop group were aware of their own gaps in knowledge and were keen to know more in order to provide an improved service. These gaps repeatedly focussed on identifying and assessing when someone had overlapping substance use and palliative or end-of-life care needs and practical support to do this. This became the core focus of the summarised intervention in the theory of change.

Similarly, the theory of change for caregivers was mapped across the bottom of the main theory, noting that, ultimately, families of people using substances needed a range of support before and after their relative's death. This required assessment of their needs and timely support offered to them. Also, the previous research (Galvani et al., 2018) identified how practitioners faced an emotional burden that needed to be acknowledged and addressed.

The workshop participants also debated the language used in the theory of change. For clarity and accessibility 'theory 'became 'case 'for change and palliative and end-of-life care became 'serious and advancing ill health (SAIH)'. The change of language was considered to be more accessible and inclusive. Palliative is not a widely understood or used term, and end-of-life conjures up particular images for people. Using SAIH was felt to be more all-encompassing and enabled individuals and caregivers to be more open to reflecting on whether this was relevant to them or the people they were supporting, thereby creating greater accessibility to the resources being developed as part of the new model of care.



The case for change: Supportive care for people with serious and advancing ill-health who use(d) alcohol or other drugs

Health and Social Care not adequately accessible for people using substances with serious and advancing ill-health (who fear stigma, pressure to stop using and/or withdrawal).

Carers unaware of how ill the person is and what level of support is needed

People using substances present late to primary and acute services, resulting in little/no choice about end of life care.

Carers experience traumatised bereavement

People using substances with serious and advancing ill-health (SAIH) and their caregiving / support network.

'Family' caregivers and key-workers of those people described above

Practical package of care that identifies people using substances with SAIH, assesses their health/social care needs and engages them and their caregivers in support.

Identification of carers needing support and access to provision

Routine identification of people using substances with SAIH, and assessment of their social and health care needs and the needs of their caregivers.

Assessment of caregivers' support needs

Supported referrals to meet people's needs consistently via clear care routes into specialist care, integrated care and/or joint working.

Timely provision of carer support (family and/or key-worker)

Compassion-focused, non-stigmatising palliative and EoL care for people using substances and their caregivers, that addresses current health inequalities.

Social, medical, practical and emotional support for caregivers

WHY the intervention is needed

WHO the intervention is for

WHAT the intervention is and **HOW MUCH** participants will receive

WHAT the intervention will achieve and **WHY** this is important

Figure 2 – Theory of change

4.2 - Model of care

Figure 3 (below) shows the new model of care that was grounded in the theory of change. Using a template adapted from Early Intervention Foundation (Asmussen et al. 2019), the model sets out the long-, medium- and short-term goals. *Given the limited time of the research project and lack of regional policy maker involvement, the focus of the project was on the short-term impact.* The four short-term outcomes were as follows:

1. Carers equipped to have sensitive conversations about serious and advancing ill health, substance use, and advanced care planning.
2. Consistent advocacy for people using substances navigating health and social care provision to access palliative and end-of-life care.
3. Practitioners and peers feel better supported to work/live with SAIH and substance use.
4. Resources available for family/carers to access information and support.

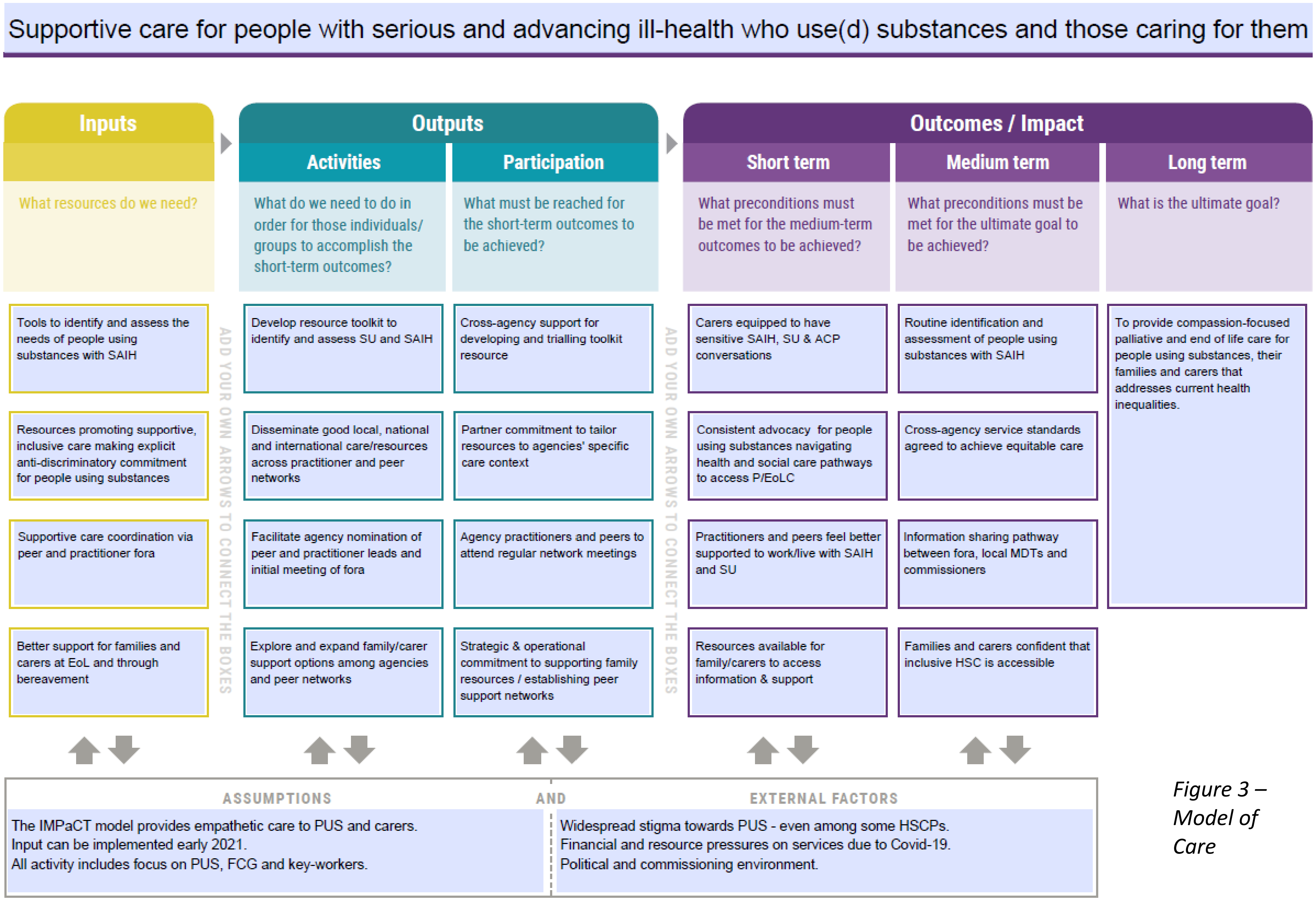
As the model shows, each outcome had resource needs related to it, the activities needed to develop those resources and the participation required from a range of stakeholders to ensure the goals are reached. The overwhelming message from the workshop participants was the need for greater knowledge and information in the form of tools to help them identify and assess substance use or SAIH as well as examples of good practice demonstrating inclusive care. They wanted a multi-disciplinary forum to enable them to share knowledge and challenges and seek support from other specialist practitioners at front-line level. The evidence of a lack of provision for family members also led to the development of resources for family members.

There was one key change to the third outcome as a result of further discussion with frontline services managers at the point of setting up the support forums. They advised the provision of a support forum for family members rather than individuals or ‘peers’. They felt that take up by individuals would be challenging and that there was a gap in family service provision. The resulting resources will be presented in section 4.3 and 4.4 below.

4.3 - Resource development

The new model of care was to be the mid-point of this research. It required the researchers to act on the needs identified by the model of care. The hiatus resulting from the Covid-19 pandemic led to a cessation of participant recruitment, particularly for those with lived experience, either family members or individuals living with substance use and serious and advancing ill health. This time allowed for a greater expansion of the resources for the project than originally envisaged.

In total, more than 50 documents or other outputs were developed in partnership with the PEAT. These targeted the three different groups identified in the model of care as needing better knowledge and support – practitioners, people with lived experience, family, friends and carers. Table 1 below lists the resources developed for each of the three groups as well as those resources available to all.



Supportive care for people with serious and advancing ill-health who use(d) substances and those caring for them

Inputs	Outputs		Outcomes / Impact		
	Activities	Participation	Short term	Medium term	Long term
What resources do we need?	What do we need to do in order for those individuals/ groups to accomplish the short-term outcomes?	What must be reached for the short-term outcomes to be achieved?	What preconditions must be met for the medium-term outcomes to be achieved?	What preconditions must be met for the ultimate goal to be achieved?	What is the ultimate goal?
Tools to identify and assess the needs of people using substances with SAIH	Develop resource toolkit to identify and assess SU and SAIH	Cross-agency support for developing and trialling toolkit resource	Carers equipped to have sensitive SAIH, SU & ACP conversations	Routine identification and assessment of people using substances with SAIH	To provide compassion-focused palliative and end of life care for people using substances, their families and carers that addresses current health inequalities.
Resources promoting supportive, inclusive care making explicit anti-discriminatory commitment for people using substances	Disseminate good local, national and international care/resources across practitioner and peer networks	Partner commitment to tailor resources to agencies' specific care context	Consistent advocacy for people using substances navigating health and social care pathways to access P/EoLC	Cross-agency service standards agreed to achieve equitable care	
Supportive care coordination via peer and practitioner fora	Facilitate agency nomination of peer and practitioner leads and initial meeting of fora	Agency practitioners and peers to attend regular network meetings	Practitioners and peers feel better supported to work/live with SAIH and SU	Information sharing pathway between fora, local MDTs and commissioners	
Better support for families and carers at EoL and through bereavement	Explore and expand family/carer support options among agencies and peer networks	Strategic & operational commitment to supporting family resources / establishing peer support networks	Resources available for family/carers to access information & support	Families and carers confident that inclusive HSC is accessible	

ASSUMPTIONS	AND	EXTERNAL FACTORS
The IMPaCT model provides empathetic care to PUS and carers. Input can be implemented early 2021. All activity includes focus on PUS, FCG and key-workers.		Widespread stigma towards PUS - even among some HSCPs. Financial and resource pressures on services due to Covid-19. Political and commissioning environment.

Figure 3 – Model of Care

Source: Early Intervention Foundation, *10 steps for evaluation success*: https://www.eif.org.uk/resource/10-steps-for-evaluation-success

Table 1 – List of resources developed to inform the short-term goals of the model of care

Practitioners	**Families, friends, carers**	**People who are unwell**
Practice pointers x 6 i. Making palliative care accessible for people using substances ii. Opening conversations with people using substances whose health is concerning iii. Understanding the complex needs of people using substances who have serious and advancing ill health iv. Overcoming stigma for people using substances who have severe ill health v. Supporting the families and friends of people using substances who have severe and advancing ill health vi. Pain and symptom management for people using substances who are seriously unwell.	Leaflet for families, friends and carers, [*'What Families Need to Know'*] co-produced with Adfam and Alcohol Change UK and translated into Welsh	Information poster on 'How do I know if I'm unwell'? This can be displayed in reception areas in agencies.
Pocket guide on supporting someone using substances near the end of their lives	Pocket guide on caring for a family member or friend using substances near the end of their lives	Pocket guide on living with substance use (past or present) and serious ill health.
Good practice case studies	Case studies	Case studies
43 podcasts addressing issues identified through the participatory workshops	4 podcasts specifically targeting family members	4 podcasts geared towards people who are seriously unwell and using substances
List of organisations in Liverpool and Sefton in substance use, palliative and end-of-life care, social care, housing sectors with brief explanations and contact details.	Directory of services to support families in Liverpool and Sefton area primarily and some national helplines included.	List of organisations in Liverpool and Sefton in substance use, palliative and end-of-life care, social care, housing sectors with brief explanations and contact details.
Online support forum – monthly x 3	Online support forum – monthly x 3	

4.3.1 – Online support forums

A clear message from the people in the theory of change and model of care participatory workshops, was the need for better support for practitioners, people with lived experience and families, friends and carers. An online forum was proposed and accepted. The research team undertook to host the first 3-4 monthly forums alongside a representative from social care, substance use services and palliative care. For the family forum we also secured representation from a family focussed substance use service. This would ensure there was at least one person available with expertise in our areas of interest to answer any specific questions that came up. Following further consultation, the team were advised to let go of the forum for people with lived experience because of a range of challenges getting them to attend and participate. This was also a time when services were only just reopening their doors to face-to-face contact, so the timing was not ideal. Thus, two support forums were arranged, one for practitioners, and one for family, friends and carers. They were arranged for one hour over lunchtime and all held online.

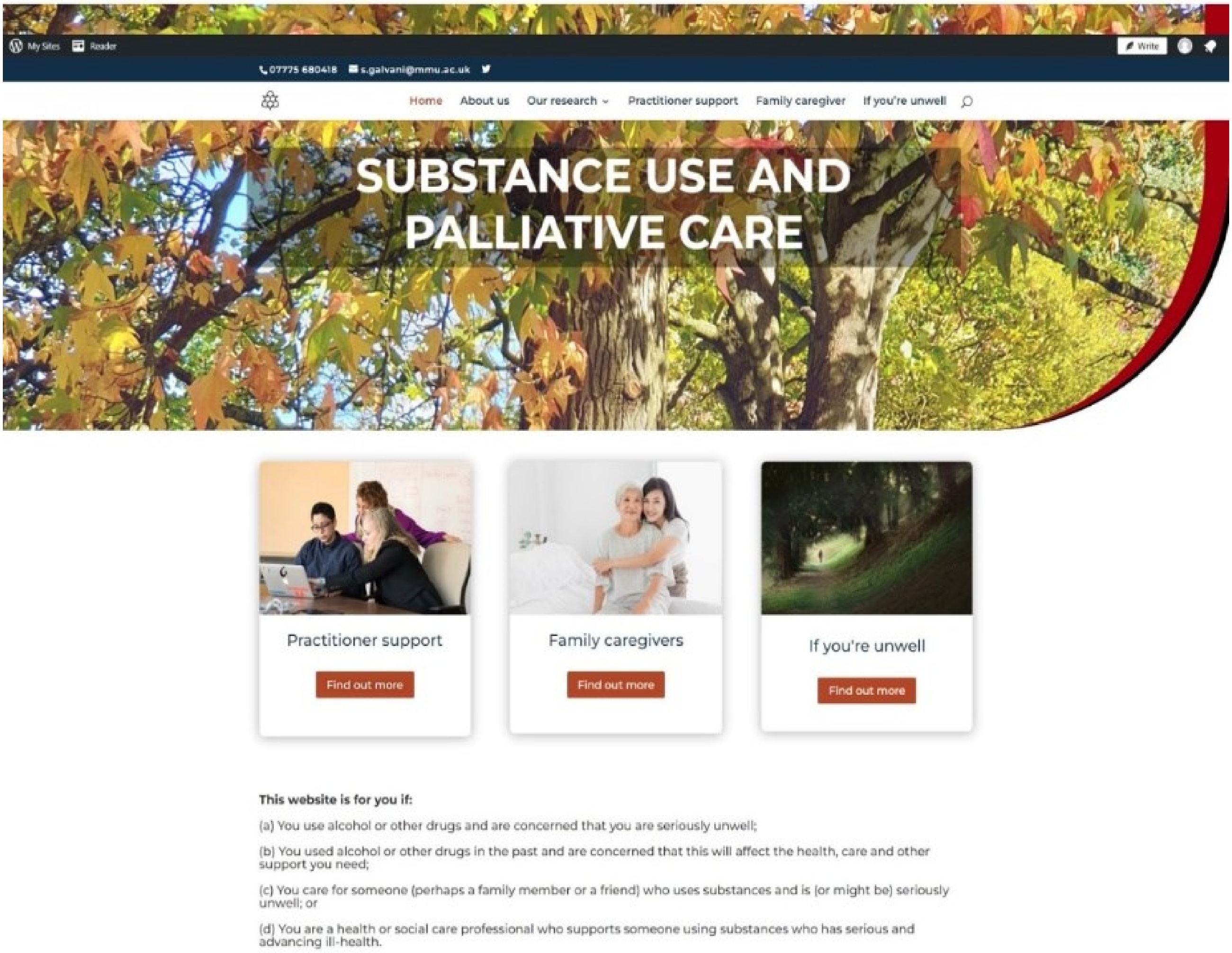
The practitioners ʾforum ran three times between late April and early July 2022 with 20, 23, and 18 practitioners attending respectively, a total of 61 practitioners. The content was to invite a round of introductions, present a short case study or series of questions for people to consider, then open it up to the participants to discuss what they wanted. Some had clearly come to listen, but others presented scenarios they had experienced and found challenging. They were keen for the forums to continue and discussions are underway with partner agencies for them to continue to host them.

The family forum also ran three times during the same time period. No family members attended the first one (outside of the research team and agency representatives), one person attended the second one, and no one attended the third. The timing of the second and third forums was moved to evenings from lunchtime to see if this garnered more interest and availability. This did not work. In discussion with partners, the challenge was accessing family, friends and carers, particularly at a time when partner agencies were not opening doors to them for face-to-face contact. There were suggestions that some people would not have the hardware or software available either. Finally, the research team felt that while a higher education institution probably had some credibility with practitioners, hence the good numbers for the practitioners ʾforum, it was less credible for family members. It was agreed the way forward was for the partner agencies to host the forum and these discussions are ongoing.

Apart from the online forums, all other written, visual and audio resources were placed on the project website.

4.4 - Website – https://endoflifecaresubstanceuse.com and resources

A website was developed to host the resources from this project and material from the original research project. This allowed for national and international access and dissemination beyond the partner agencies in Liverpool and Sefton and has, so far, resulted in contact from colleagues in Canada, India, Australia, and around the UK.



This website is for you if:

(a) You use alcohol or other drugs and are concerned that you are seriously unwell;

(b) You used alcohol or other drugs in the past and are concerned that this will affect the health, care and other support you need;

(c) You care for someone (perhaps a family member or a friend) who uses substances and is (or might be) seriously unwell; or

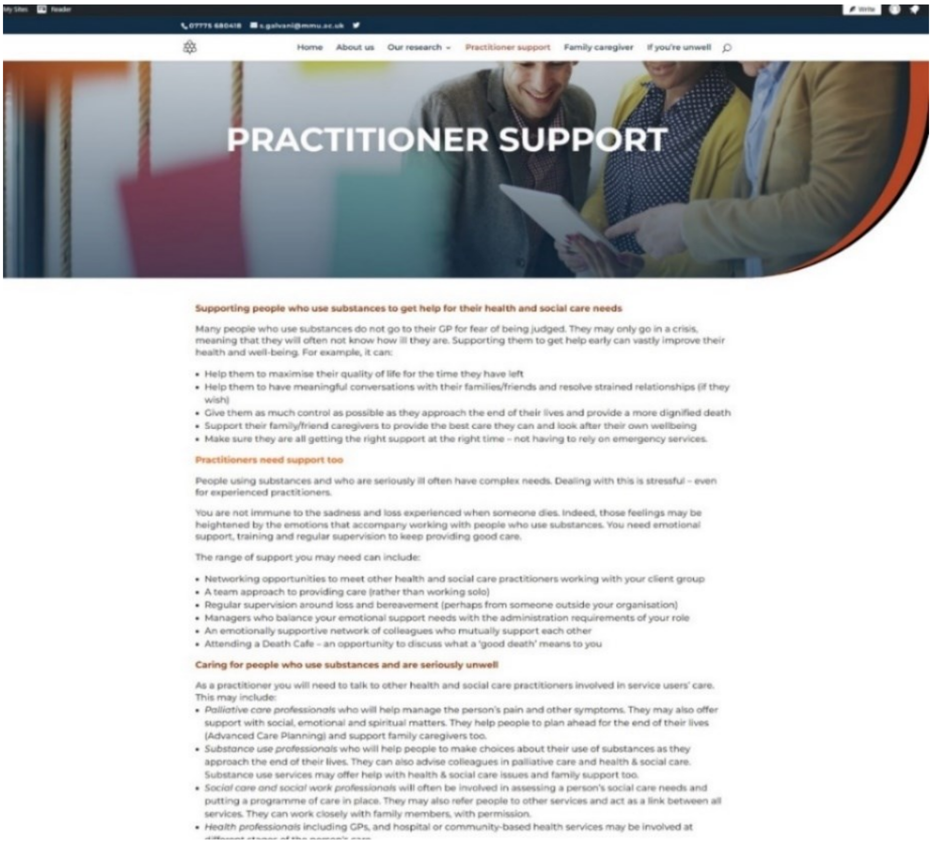
(d) You are a health or social care professional who supports someone using substances who has serious and advancing ill-health.

The website comprises six sections including the home page, information about the research team and project, and a page linking to research from the first project on this topic. The main sections are the three sections focussing on Practitioner support, Family caregivers and individuals living with palliative or end-of-life needs and using substances (‘If you’re unwell’.)

Practitioner support

The practitioner section contains a cover page directly addressing practitioners, identifying key messages for practice, including support for staff and caring for others. This is followed by links to:

- **Six practice pointers** – six single sides of A4 on different topics relating to practice
- **A pocket guide for practitioners** – A6 size that can be accessed online or downloaded. It focusses on identification and assessment as well as key background information and practice concerns.
- **Videos and podcasts** – this section contains over 40 small podcasts that are snippets of conversation with practitioners working in substance use and palliative care. These are grouped by broad theme for example, good practice – identification and assessment, homeless people, supporting families.
- **Case studies** - this contains a number of summaries relating to good practice in substance use services, palliative care, social care and housing.



Supporting people who use substances to get help for their health and social care needs

Many people who use substances do not go to their GP for fear of being judged. They may only go in a crisis, meaning that they will often not know how ill they are. Supporting them to get help early can vastly improve their health and well-being. For example, it can:

- Help them to maximise their quality of life for the time they have left
- Help them to have meaningful conversations with their families/friends and resolve strained relationships (if they wish)
- Give them as much control as possible as they approach the end of their lives and provide a more dignified death
- Support their family/friend caregivers to provide the best care they can and look after their own wellbeing
- Make sure they are all getting the right support at the right time – not having to rely on emergency services.

Practitioners need support too

People using substances and who are seriously ill often have complex needs. Dealing with this is stressful – even for experienced practitioners.

You are not immune to the sadness and loss experienced when someone dies. Indeed, those feelings may be heightened by the emotions that accompany working with people who use substances. You need emotional support, training and regular supervision to keep providing good care.

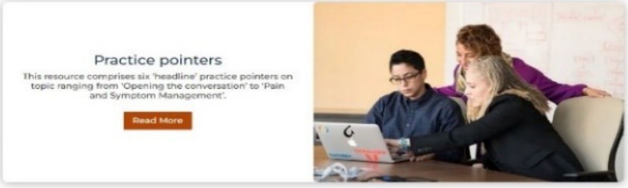
The range of support you may need can include:

- Networking opportunities to meet other health and social care practitioners working with your client group
- A team approach to providing care (rather than working solo)
- Regular supervision around loss and bereavement (perhaps from someone outside your organisation)
- Managers who balance your emotional support needs with the administration requirements of your role
- An emotionally supportive network of colleagues who mutually support each other
- Attending a Death Cafe – an opportunity to discuss what a 'good death' means to you

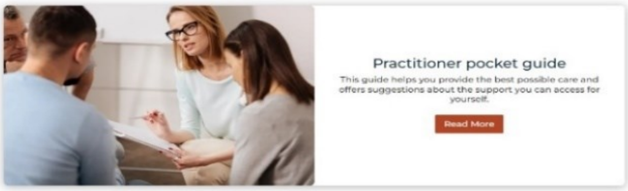
Caring for people who use substances and are seriously unwell

As a practitioner you will need to talk to other health and social care practitioners involved in service users' care. This may include:

- *Palliative care professionals* who will help manage the person's pain and other symptoms. They may also offer support with social, emotional and spiritual matters. They help people to plan ahead for the end of their lives (Advanced Care Planning) and support family caregivers too.
- *Substance use professionals* who will help people to make choices about their use of substances as they approach the end of their lives. They can also advise colleagues in palliative care and health & social care. Substance use services may offer help with health & social care issues and family support too.
- *Social care and social work professionals* will often be involved in assessing a person's social care needs and putting a programme of care in place. They may also refer people to other services and act as a link between all services. They can work closely with family members, with permission.
- *Health professionals* including GPs, and hospital or community-based health services may be involved at


Practice pointers

This resource comprises six 'headline' practice pointers on topic ranging from 'Opening the conversation' to 'Pain and Symptom Management'.


Practitioner pocket guide

This guide helps you provide the best possible care and offers suggestions about the support you can access for yourself.

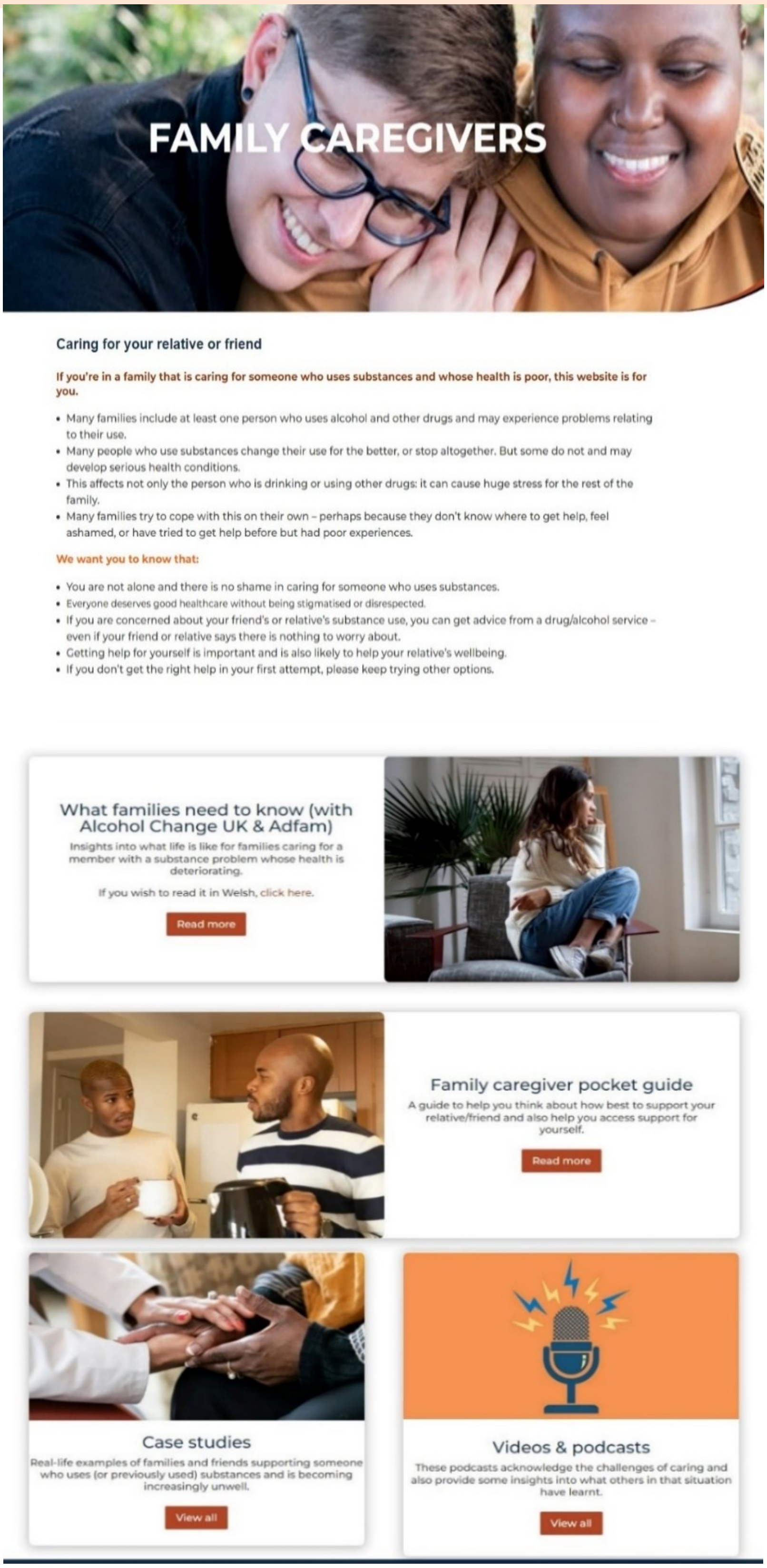

Videos & podcasts

These podcasts have been created by social and health care practitioners supporting people who use substances as they approach the end of their lives.


Case studies

Examples of social and health care practitioners providing support to people who use substances and are seriously unwell.

Family Caregivers



Caring for your relative or friend

If you're in a family that is caring for someone who uses substances and whose health is poor, this website is for you.

- Many families include at least one person who uses alcohol and other drugs and may experience problems relating to their use.
- Many people who use substances change their use for the better, or stop altogether. But some do not and may develop serious health conditions.
- This affects not only the person who is drinking or using other drugs: it can cause huge stress for the rest of the family.
- Many families try to cope with this on their own – perhaps because they don't know where to get help, feel ashamed, or have tried to get help before but had poor experiences.

We want you to know that:

- You are not alone and there is no shame in caring for someone who uses substances.
- Everyone deserves good healthcare without being stigmatised or disrespected.
- If you are concerned about your friend's or relative's substance use, you can get advice from a drug/alcohol service – even if your friend or relative says there is nothing to worry about.
- Getting help for yourself is important and is also likely to help your relative's wellbeing.
- If you don't get the right help in your first attempt, please keep trying other options.

What families need to know (with Alcohol Change UK & Adfam)

Insights into what life is like for families caring for a member with a substance problem whose health is deteriorating.

If you wish to read it in Welsh, click here.

Family caregiver pocket guide

A guide to help you think about how best to support your relative/friend and also help you access support for yourself.

Case studies

Real-life examples of families and friends supporting someone who uses (or previously used) substances and is becoming increasingly unwell.

Videos & podcasts

These podcasts acknowledge the challenges of caring and also provide some insights into what others in that situation have learnt.

The second section focusses on family caregivers as opposed to professionals. Again, it sets out some key messages about caring for someone with substance use whose health is poor and reinforces the point that getting help for themselves is important too.

It links to five sections:

- **An information leaflet** for families co-produced with Alcohol Change UK and Adfam.
- **A pocket guide for family caregivers** to help them navigate the conversations they may need to have with family members and services.
- **List of family support services** in Liverpool and Sefton
- **Case studies** of good practice with family members and what family members found helpful.
- **Videos and podcasts** link to over 40 podcasts including those relevant to family members.

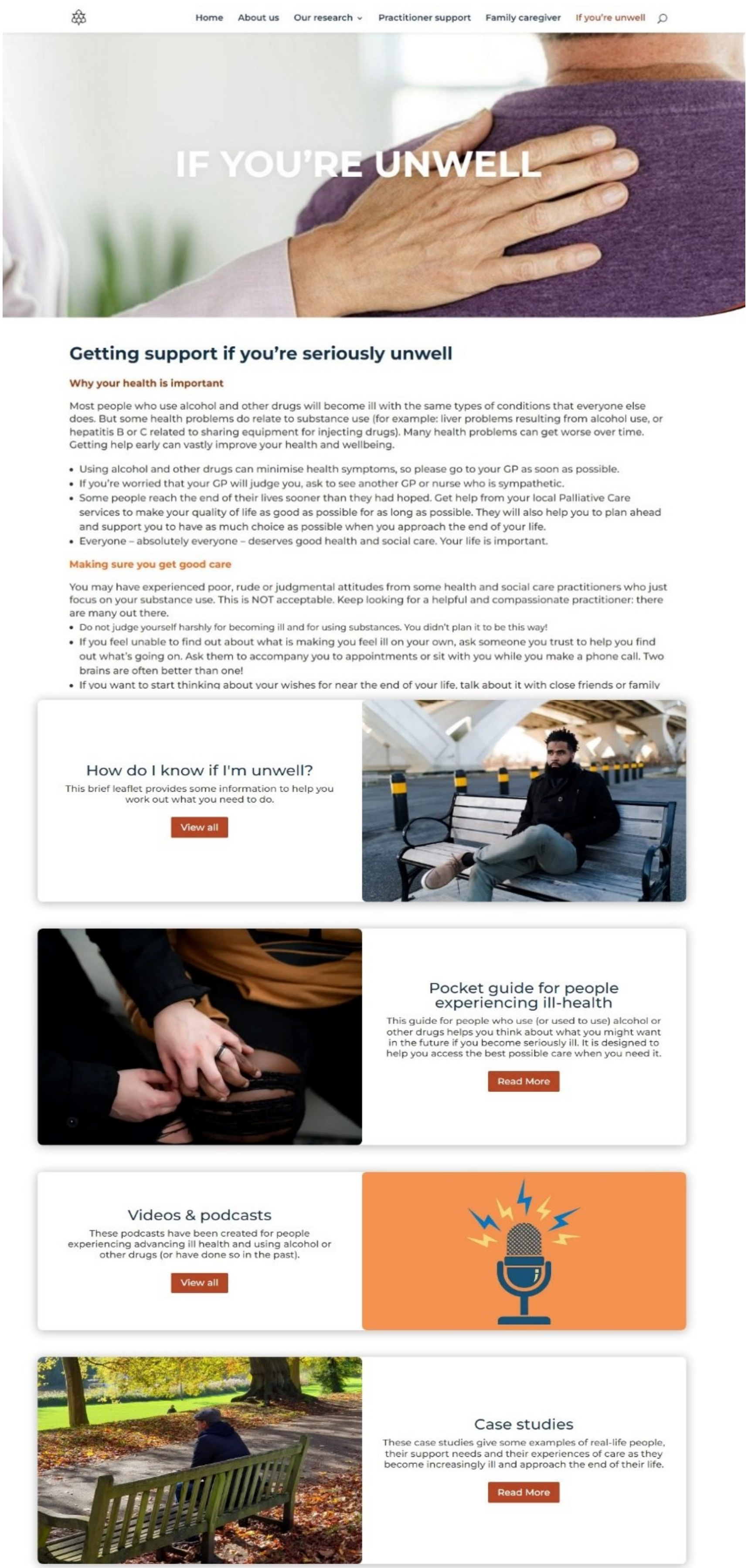
If you’re unwell

The final substantive section on the website is designed for people who have serious concerns about their own health and who use, or have previously used, substances.

The cover page stresses the importance of getting help and not being put off by any negative contact with services. It reinforces the fact that everyone deserves good care, and that sometimes taking someone along with you can help.

The resources include:

- **How do I know if I’m unwell?** – a poster format that helps people to identify if the need to seek medical help. It draws from the SPICT tool used in palliative and end-of-life care services.
- **A pocket guide for people experiencing ill-health** – this develops the principles on the cover page of this section and offers guidance about how to talk to professionals and family members about their concerns and their health.
- The **videos and podcasts** include a selection of podcasts for people who are unwell including ‘how to get good care from your GP’ and ‘the concept of living well’.
- The **case studies section** includes examples of people who have needed or are receiving care and their different needs and experiences of that care.



Getting support if you’re seriously unwell

Why your health is important

Most people who use alcohol and other drugs will become ill with the same types of conditions that everyone else does. But some health problems do relate to substance use (for example: liver problems resulting from alcohol use, or hepatitis B or C related to sharing equipment for injecting drugs). Many health problems can get worse over time. Getting help early can vastly improve your health and wellbeing.

- Using alcohol and other drugs can minimise health symptoms, so please go to your GP as soon as possible.
- If you’re worried that your GP will judge you, ask to see another GP or nurse who is sympathetic.
- Some people reach the end of their lives sooner than they had hoped. Get help from your local Palliative Care services to make your quality of life as good as possible for as long as possible. They will also help you to plan ahead and support you to have as much choice as possible when you approach the end of your life.
- Everyone – absolutely everyone – deserves good health and social care. Your life is important.

Making sure you get good care

You may have experienced poor, rude or judgmental attitudes from some health and social care practitioners who just focus on your substance use. This is NOT acceptable. Keep looking for a helpful and compassionate practitioner: there are many out there.

- Do not judge yourself harshly for becoming ill and for using substances. You didn’t plan it to be this way!
- If you feel unable to find out about what is making you feel ill on your own, ask someone you trust to help you find out what’s going on. Ask them to accompany you to appointments or sit with you while you make a phone call. Two brains are often better than one!
- If you want to start thinking about your wishes for near the end of your life, talk about it with close friends or family

How do I know if I'm unwell?

This brief leaflet provides some information to help you work out what you need to do.

Pocket guide for people experiencing ill-health

This guide for people who use (or used to use) alcohol or other drugs helps you think about what you might want in the future if you become seriously ill. It is designed to help you access the best possible care when you need it.

Videos & podcasts

These podcasts have been created for people experiencing advancing ill health and using alcohol or other drugs (or have done so in the past).

Case studies

These case studies give some examples of real-life people, their support needs and their experiences of care as they become increasingly ill and approach the end of their life.

In summary, the theory of change and model of care workshops starkly highlighted the need for information and knowledge and the widest dissemination of this information. Their ask was that we share examples of good practice where possible. The use of case study material was at the core of our training. The subsequent resources and training of project partner agencies showed how ambitious we had been and how there were steps to take ahead of significant practice change. It was clear that little was known about responding to substance use at end of life and how much more thinking and engagement was needed by practice partners ahead of significant changes to policy and practice. However, our hospice partners had already begun this work and have led the way in attempting to change policy and practice. The website was developed to host the resources and information and to provide worldwide access to the information and learning from the project.

Chapter 5. Findings and discussion: baseline survey data

5.1 - Introduction

This mixed-methods research originally comprised a pre- and post-test design using qualitative and quantitative methods of data collection based on participatory action research principles. There were four groups of participants; practitioners, managers, people with lived experience and family members. Section 3.8 above details the changes to design resulting from the pandemic conditions. Therefore, this chapter presents findings from the baseline data collection with practitioners and managers, case study work with people with lived experience and family members, and findings from the online participatory workshops and resulting theory of change and model of care. It also presents the expanded resource development stemming from the model of care's short-term objectives.

To recap, step one of the five step approach adopted for this research (see s. 3.2) comprised two parts:

i. Collation of i) existing research evidence ii) work with project partners to establish current practice in our partner services and the wider care community (where appropriate) and what might need to change to make a difference.
ii. Administration of quantitative baseline measures and qualitative pre-intervention data collection.

The collation of existing research evidence and project partner experience was collected during the early phase of the project. All partners were contacted via email to ask for current good practice and gaps in knowledge or provision. This information was added to our evidence review that was updated from the first project. Our project lead for the involvement of people with lived experience also spoke to the PEAT members. These various sources of knowledge fed in to the design of both quantitative and qualitative tools resulting in the bespoke design of both sets of tools. In relation to the survey tool, there was no previously validated tool that was suitable on its own. Qualitative data also had to build on what we knew from our earlier research in this area rather than repeat it.

5.2 - T1 survey findings and discussion *(Author: Dr Lucy Webb)*

A total of 98 responses were obtained from participants from 14 care settings in Liverpool and Sefton. Thirty respondents worked in social care (30%), 20 in palliative care (20%), 19 in addictions (19%), eight in primary care and hospital care (8%), 12 worked for housing charities (12%), and there was one service commissioner.

Of those who responded (96), 25% described social issues as their client's main problem, and 24% reported palliative care as the main need. Almost 20% identified addiction as the main problem, and 28% identified physical or mental health problems as the main problem.

Domains

Items for each of the six domains (physical, psycho-socio-spiritual, support, information provision, inter-service working, access) were scored with lower scores representing lower problems. Domains with 95% confidence intervals either above or below the central score (2.0) demonstrate definitive findings. The physical domain results indicated that care staff in general rated the physical needs of clients as most likely to present with unmet need, and the psycho-socio-spiritual domain was shown to be the second most likely to present with unmet need (Table 2). Types of physical issues were reported by 75 respondents as withdrawal from substance use (32%), pain (28%) and respiratory problems (21%). Ease of access, information and support given to these clients and their families were rated well by staff members generally. Interdisciplinarity was not rated as either particularly effective or as presenting a problem for staff.

Table 2: Mean scores for questionnaire domains

Domain	**Mean (range 0-4)**	**95% CI**
Support given	1.33	1.10-1.56
Ease of access	1.52	1.26-1.78
Interdisciplinarity	2.05	1.84-2.26
Information provided	1.34	1.13-1.55
Psycho-socio-spiritual	2.37	2.21-2.54
Physical	2.62	2.44-2.78

Comparison of job roles

A comparison of ratings by staff role/service provider revealed different perceptions of the domains by service. Staff in different roles showed contrasting perceptions of domains, where, treated together as above, these differences cancel each other out.

When interdisciplinarity was analysed by staff role, a Kruskal-Wallis H test showed that there was a statistically significant rating difference in interservice functioning between job categories ($\chi^2(2) = 10.042$, $p = 0.18$), with a mean rank interservice score of 45.79 for palliative care, 40.98 for social care, 36.31 for addiction care and 21.75 for housing care, indicating that palliative care staff rated interservice functioning as most problematic for their clients. This counters the overall mean scores for the domains suggesting that other health care staff (secondary and primary care) rated interservice functioning as effective.

Access to palliative care was rated most problematic by social care staff (Kruskal-Wallis H: $\chi^2(2) = 17.627$, $p = 0.001$, mean rank 41.10), in comparison with the palliative care staff rating (mean rank 35.46), addiction care staff rating (mean rank 25.89), and housing services staff rating (mean rank 16.14). Social care staff also rated psycho-socio-spiritual problems for their clients significantly higher than addiction, housing or palliative care colleagues ($\chi^2(2) = 10.999$, $p = 0.12$) with a mean rank psycho-socio-spiritual score of 41.23 in comparison with the addiction mean rank of 29.15, the palliative care mean rank 24.71 and the housing mean rank 22.88.

There was no significant difference between service staff rating for information provided or physical problems for their patients/clients. Numbers were too small to calculate findings directly from staff from other primary care and secondary care, however, such data is considered in its influence on the findings.

Discussion

The main unmet need for clients, as reported by both social and health care staff, was their physical care. This is likely to be a concern among all staff for their clients in need of palliative care, however, these self-report ratings may also indicate staff members' focus on physical care with less regard or awareness for issues such as access to palliative care or family needs. It is interesting to find that social care staff are most concerned with psycho-socio-spiritual care, in comparison with palliative and housing care staff who rate this issue as of least concern. This may reflect the job roles but also the frustration of care workers who may value and recognise this need but who may have fewer resources to address them. This may explain why social care staff rate this as an unmet need more highly than palliative care staff who have more resources to address them. This does not explain why housing staff do not rate this particularly as an unmet need, however, it is possible that practical housing issues may be seen as a key priority for these services or that housing staff have more time to spend with clients and feel better able to support them with psycho-social-spiritual care.

Interdisciplinary functioning was rated differently by staff in different job roles, with those in secondary and primary health care roles experiencing a degree of effectiveness and those in social care and palliative roles finding this a problem. This suggests that care pathways may be experienced as more effective in primary and secondary care, with good referral routes, while referring into health care or across services at tertiary level is experienced as ineffective. With recent focus on integrated care and care pathways within the NHS, these findings may indicate where barriers remain within a whole systems approach to seamless care pathways, especially between health and social care. This is supported by the findings for access to palliative care in which social care, addiction and housing staff find this significantly problematic.

In sum, there is a difference in perception of effectiveness of interdisciplinary working and access to palliative care by job role/type of service provider. It is likely that these findings are linked, representing a degree of silo working and limited or restricted care pathways that are not experienced by mainstream health services.

Chapter 6 – Findings and discussion: Qualitative data

Three forms of qualitative data were collected. Focus group data with practitioners from our partner agencies, individual interviews with service managers, and in-depth case studies presenting the experiences of people with lived experience and their families, friends and carers. This chapter will present findings from the focus groups and interviews before chapter 7 presents the case study data.

6.1 - Practitioners focus groups *(Author: Dr Gary Witham with Dr Gemma Yarwood)*

Four focus groups were held with a mix of practitioners from our partner agencies. Table 3 below sets out the numbers and roles in each group. This served the purpose of mutual learning at the same time as sharing experiences and views.

Table 3 – Focus groups - sample number & characteristics

Focus Group	Participant numbers	Practitioner Role
Focus Group 1	7	Social worker (n=3) Hostel manager (n=3) Regional palliative care manager (n=1)
Focus Group 2	5	Social worker (n=2) Palliative care register (n=1) Hostel manager/worker (n=2)
Focus Group 3	8	Social worker (n=3) Hospice nurse (n=1) General Practitioner (GP) (n=1) Substance misuse worker (n=3)
Focus Group 4	4	Hostel manager/worker (n=2) Hospice nurse (n=2)
	Total	**24 people**

The following themes were generated from these data:

Professional boundaries and service development

The interdisciplinary nature of these focus groups meant there was a clear positioning from participants that linked with their professional backgrounds. There was a separation between “health” and “social care” with case study exemplars highlighting the gaps in service and different viewpoints about where the responsibilities lie in supporting people using substances at the end of life. Is this a health or social care problem? The universal acknowledgement by most participants was that this population often required complex care and trying to coordinate multiple services in a person-centred approach was challenging. This was often positioned in terms of personal care and medication management with participants who were social workers, hostel and temporary housing providers using this example to highlight the difference in health and social care. Personal, "hands on care" could not be provided by hostels and other temporary housing. As a hostel support worker comments on having clients using substances at the end of life:

> "it was quite difficult with the staff team, it was very confusing about what we could and couldn't do with the barriers of CQC and medication and things like that. It was quite frantic the first time that it happened, it was quite scary for us and the other residents" (FG 1).

For social care staff, trying to diagnose dying early and make timely referrals to other services when personal care was required, was challenging. A participant who manages palliative care services highlighted the extensive support offered to those people referred to her service. However, there had only been four referrals and although she positioned her team as non-judgemental and proactive, she did not suggest an effective way to open her services to this marginalised group.

A number of participants from a heath and palliative care background acknowledged the complexity of needs for this population and did not explore engagement beyond medical services, so a focus was on hospices, hospitals or community palliative care services. There was universal acknowledgement by participants that the lack of outreach to marginalised populations was a significant problem. Those health-related staff who had a "special interest" in homelessness and drug and alcohol use appeared to horizon scan more critically about the challenges of providing good palliative care to this population. Without this special interest it was perceived to be difficult to give person-centred end of life care to people using substances. For example, one social worker, commented on an interaction with a GP relating to a seriously ill couple using substances and hoarding in their flat. He said:

> "..the GP was sort of, like: "Well what can we do?" What I did was refer him to…the adult care line and got them a social worker to coordinate their care, not only in terms of health but everything, getting the flat cleared and everything. So it's a more holistic approach" (FG 3).

Maintaining moral adequacy in the face of traumatic death

The trauma of dying was also experienced and witnessed by other residents of hostels. One participant working within hostel and temporary housing presented the dilemma of clients having to leave for more suitable accommodation and although this was facilitated to support care and positioned by the participant as an ethical justification. The client, however:

> "…felt like he was being kicked out through no fault of his own, do you know what I mean? But we knew in the long run that that service was more beneficial for him, and he could get the care and support that he needed" (FG 1).

This raises the dilemma that social care staff working with clients using substances at the end of life have built up relationships that would be lost within a transfer to another service. Maintaining moral adequacy meant having conversations with service providers and advocating for clients. There was a lack of understanding surrounding addiction and this made supporting clients challenging. This led to “soul-searching”, that is, questioning whether outcomes could have been different, as one hostel manager commented:

> “I think a lot of time within our service, we feel like we’re forced into a position of questioning ourselves all the time, “Have we done enough?” I think the reason why that is, is because you’re forced between two services. So, what we’ve got is we’ve got our service which is trying to report somebody who may be at end of life and ensuring that they’ve got the appropriate accommodation without us having the appropriate accommodation.” (FG 2)

There was also general frustration about the impact on clients of poor interprofessional collaboration with one participant referring to one of her patient’s poor mental health:

> “She is really, really a lovely lady and she would, yes she had her issues, she’s not using now but her mental health just holds her back so much. She’s end stage COPD and she’s got lung cancer as well. We’re trying to encourage her to get up and mobilise but her mental health is stopping her, so it’s having a knock on to her medical health which, as you say, will lead to her death quicker than what it should be.” (FG 4).

Working with a client/patient group where a “good” death is not necessarily their priority

A hostel worker commented on how challenging he found a client using substances and dying. What he found challenging was the person’s self-neglect and that accessing alcohol and illicit substances was the overriding goal and focus for his client. This was compounded by symptoms relating to his medical condition that the participant had no experience of:

> “so when we were informed, he was on an end-of-life programme, until obviously the day come, it was very tragic really. I mean it was a lot of self-neglect and abuse in-between that time, and things I’ve never seen, the sort of medical condition that he was nil-by-mouth, so he had no oesophagus and stuff like that. It was really sad, the physical but also the mental health decline too, knowing his life was restricted heavily and stuff like that” (FG 1).

The priority of a lot of clients was on accessing alcohol or substances and not, therefore, focusing on self-care. So, for example, attending outpatient appointments was not a priority and this often led to a withdrawal of medical services based on perceived non-engagement. Health-related services were not responsive to the complex needs of this population and lacked understanding and training. For one respondent working in social care, trying to locate an appropriate smaller hostel was challenging when there was ongoing substance use by his client. He commented:

> “The best possible thing I would do in terms of intervention is try and get them into the correct environment for them. Typically, again I think of these three cases and these gentlemen were all told they had six months to live if

> they didn’t stop drinking and there was no willingness around abstinence” (FG 3).

Respondents commented that current substance use at the end of life makes access to palliative environments challenging and can cause significant problems managing symptoms. It was also a shock to hostel staff when someone, who they had built up a relationship with, subsequently died. There was an acknowledgement that homeless clients using substances often died young and had multiple co-morbidities. However, they often made poor choices as one hostel manager described:

> “One of ours, not at all well, got COPD and other issues, has chosen the last two nights to sleep out and you’d think, well in the current weather conditions that’s fairly insane isn’t it? But we will just continue to say, “Your door’s open, please return, is there anything that can keep you in, rather than you going out?” (FG 4).

Where’s an appropriate place to die?

There was an acknowledgement, particularly presented by social care practitioners, that stigma and discrimination was more explicit within health-led services including hospitals and hospices, and that this affected client engagement. A social worker commented:

> “they’re still people after all, and they’ve got the right to be able to choose how they wish to end their life, whether they want to be at home. A lot of people are afraid to go into hospice care, into hospital care, because they feel that they won’t be able to drink, so they often will put themselves at more harm really” (FG 1).

The dilemma arose when other social care providers could not provide the care required, not just in terms of staff scope of practice but also within the facilities and buildings in operation. They remained unsuitable for complex physical care without the space for hoists and often with shared bathroom facilities. This led some of the participants working in hostel and temporary housing to suggest specialist hostel accommodation with dedicated end-of-life beds. From a social care perspective, they also expressed the fear that client transfers were left too late and were contrary to the client’s wishes.

Hospitals were acknowledged by all participants as inappropriate places for people using substances at the end of life. This was for a number of reasons, with one senior hostel manager suggesting it was the challenges of getting to know the client since they often did not want to engage with health-initiated services:

> “And we send them into hospital and we just don’t know, we don’t know. And because they put so many barriers up to engagement with health professionals, you know, I wouldn’t be surprised if the health professionals would get, you know, you can’t do that work with that person, you can’t build that relationship up with that person” (FG 4).

However, there was also a positioning from some participants that hospices were reluctant to take people with complex social needs, as one participant (working in accommodation-based services) reflected:

> "… we haven't got any kind of accommodation. What we have had, the clients that we have got that are end of life, it's very, very difficult in terms of access to end-of-life services really. Also, around people with complex needs, the accommodation-based services such as hospice, there's a real reluctance for hospice services to take clients with complex issues" (FG 2).

Another participant (Palliative care consultant) also commented about hospices:

> "I think that can be quite difficult because I think the way the hospice is run, the environment, … the training of staff, it is often not adequate to support those people" (FG 2).

In particular, the respondent referred to a lack of freedom at hospices with doors often locked at night. Some participants presented the behaviour of some of their client group as a challenge for health-related services but also national charities that work with homelessness since a prominent charity will not take people using drugs or alcohol. This further reduces the end-of-life choices for this population. From a palliative care perspective, hospices were not a long-term place of care and if the person using substances improved, they would seek to discharge the person from a hospice.

To summarise, the key findings from the focus groups demonstrate how the complex needs of people using substances at end of life were not always helped by professional boundary concerns and the lack of cross agency working. There was also a lack of suitable training for staff with the lack of accommodation, particularly in relation to place of death, creating moral challenges for service providers. They were aware that the best care option for someone was not always what the person wanted because of the restrictions it placed on them and the separation from who and what is familiar to them.

6.2 - Managers ʼinterviews *(Author: Sarah Galvani)*

Template analysis of the managers ʼdata resulted in a preliminary template of 14 broad thematic codes. Subsequent ʻbottom up ʼor grounded coding identified more than 400 individual codes. The detailed codes were further categorised resulting in 14 broad thematic codes. Some of the original template codes were retained while others were amended to fit the more detailed analysis of the data. The final codes were:

1. Assessment and identification
2. Carer support – families and staff
3. Challenges – including stigma
4. Collaboration, partnership and multi-agency working
5. Commissioners and commissioning
6. Current response to people using substances approaching end of life
7. Demographics
8. Gaps in services or roles

9. Good quality end-of-life care
10. Prevalence and incidence
11. Potential improvements and developments
12. Recent changes in roles or services
13. Training needs
14. Miscellaneous

Demographic information was grouped into one code including job role and geographical remit. In total there were 13 participants from 12 interviews. Two clinical nurse specialists were interviewed together. As table 4 below shows, there were five palliative care specialists, five substance use specialists, three community specialists including two social care leaders and one GP. Three participants were from voluntary sector organisations, 10 from the statutory sector. Six participants were health care focussed, three were social care focussed, four combined social and health care. The geographical remit of their organisations was to serve the people of Liverpool primarily and some agencies covered the borough of Sefton (north or south).

Table 4 – Profile of participants: role, sector, geographical remit

Palliative care		
1. Consultant in Palliative Medicine	Statutory sector - HC	Liverpool and South Sefton and wider region hospital support
2. Consultant in Palliative Medicine; & Medical Director	Statutory and voluntary sectors - HC	Liverpool and Knowsley
3. Clinical nurse specialist in PC	Statutory sectors - HC	Liverpool and some out of area referred in.
4. Clinical nurse specialist in PC	Statutory sectors - HC	Liverpool and some out of area referred in.
5. Clinical nurse specialist in PC	Statutory sectors - HC	Liverpool and some out of area referred in.
Substance use		
6. GP & Medical Director	Voluntary sector - HCSC	Liverpool - substance use – not alcohol alone
7. Specialist Team Manager – Community Addiction Service	Statutory sector - SCHC	Liverpool - substance use, mh and physical health services
8. Team Manager – Community Drug and Alcohol Team	Statutory sector - SCHC	North Sefton – substance use
9. Community Manager	Statutory sector - SC	Liverpool – adult social care

10. Service manager	Vol sector – SCHC	Liverpool – substance use
Other community		
11. Director of Homeless Services	Voluntary sector - SC	Liverpool - vulnerable and homeless population; population with complex needs; community services including families
12. Advanced Practitioner in Public Health	Statutory sector – SC	Sefton – health protection including substance use, BBVs, sexual health
13. GP with special interest in AOD	Statutory sector- HC	Liverpool – special homelessness support and also student health. All ages.

6.2.1 Prevalence and incidence

None of the participants had specific data on incidence of people attending services with substance use and pc/eolc needs. And none of the participants asked routinely about either substance use or palliative care needs in their assessment processes. Anecdotally, numbers reported were generally small. There were differences, however, according to area of specialist practice. Those in palliative care reported an increase in numbers suggesting it was either ‘very frequent ’or ‘happening more frequently ’with one saying that ‘the general trend ’was definitely an increase. One participant suggested it may be because they were more aware of the possibility of substance use being ongoing as someone approaches end of life. However, across the palliative care specialists there was a clear sense of having people on their caseloads who use substances, plus ongoing concerns about additional substances, such as cannabis oil, as medicines:

> I think it’s happening more frequently. I think that’s probably partly being more aware of things. I think certainly with alcohol use, I think that’s more prevalent. I think there is also more use of other substances such as cannabis (Senior health professional 1)
>
> It’s very frequent. So I would say, at the moment, because of pandemic restrictions we have a few beds closed, so we actually have 16 inpatient beds at the moment. At any one time we will probably have at least one person with substance misuse issues in. I think it probably has increased slightly but I think also we’re probably better at finding out and asking the questions. So I think it has increased but I think we’re uncovering a bit more and having a bit more awareness of it. (Senior health professional 2)

By contrast, in substance use services, managers reported only smaller numbers of people in their services with ‘terminal ’illness, with one expressing that it would be a ‘rarity ’for someone new to treatment to be palliative or end of life, more that people who had been in the service for some time would become unwell. Another suggested that, while numbers were currently low, given our ageing population the picture was likely to change in years ahead:

> Going forward, obviously when we look at the numbers in service and the age of people, in the next few years that might change if a lot more people might become end of life of COPD within the same amount of time really. (Senior substance use professional 1)

The managers did, however, state that they would not know numbers and whether it was increasing or decreasing with one manager talking about the complexity of establishing that given the range of needs of their client group including physical and mental conditions that prevented them from attending the service.

Three managers spoke about care pathways (discussed further in s. 6.2.4) in some form with one stating the process of palliative care would be started if they became aware of someone with terminal illness, while one substance use manager stated they would usually withdraw when palliative care services became involved:

> We have a fair number of people who are terminally ill who are in service with us at the moment, and it’s within our service to be involved and understand more about end-of-life care. Even though there will be a point as I mentioned where we will withdraw. (Senior substance use professional 2)

For some professionals the specialist staff or team within their service made a reported difference to the numbers of people using substances and approaching end of life. One person said that their homelessness team saw more people “that unfortunately have a very short life expectancy because of the nature of their illness” but that, knowingly, they only saw possibly one person a year in the general substance use service. Similarly, the geographical location of services, for example, city centre versus urban location was a factor in the number of people seen, with city centre numbers being perceived as higher due to a greater homeless population. Another manager in social care also picked up on the shortened life expectancy and premature death preventing them from accessing any end-of-life care.:

> … it’s not just about the fact that there [are] inappropriate pathways into end-of-life care, it’s the fact that often death is so premature for them as well. So they don’t even get [to end-of-life care]. … you see health problems that are generally associated with 70 year olds, in 45, 50 year olds… (Senior social care professional 1)

The social care managers also reported difficulties in establishing the number of people in the service with both substance use and palliative care needs, although some of this reflected the uncertainty about ‘who counts ’as needing a palliative or end-of-life care pathway:

> I’d say the terminal illness, probably not very often, I can’t actually think of a case, but we do have a lot of people who have organ failure, cirrhosis of the liver, those sorts of scenarios where we would probably be looking at those

> people as complex health and perhaps that they needed that sort of pathway. (Senior housing professional 1)

One of the challenges for the managers appeared to be the lack of data collection and the lack of routine identification of people who may have dual needs. Clearly this would hamper any conclusions about prevalence and incidence. However, this is a new area of investigation, and participants acknowledged that they had more to learn and consider in relation to organisational responses.

6.2.2 Current service responses

Participants were asked about how their service currently responded to people using substances who were approaching the end of their lives. Unsurprisingly, these varied across specialist areas of practice but also within specialist areas depending on the remit and location of the service.

Palliative care

Palliative care consisted of hospital-based and community-based provision, the latter comprising statutory community teams and hospice provision often run by charities. Palliative care participants varied in their view depending on their own context. One statutory service provider said that current models of care were outdated because there were so many different organisations to liaise with:

> So we have a separate hospital for people with heart and chest complaints, a separate hospital for people with neurology and neurosurgical complaints, a separate hospital for people that have got cancer problems, a separate hospital for people with women's health and gynaecology problems and gynaecological oncology problems, a separate hospital for children. (Senior health professional 1)

An attempt at integration of palliative care services has been made in the City through a new team bringing together various palliative care services to offer 24/7 responses. The hope with this single point of contact service is that this would enable a more streamlined response for the 'patient 'and closer collaboration and understanding between agencies. Its evaluation is not yet published.

None of the respondents reported specific questions or routine questioning relating to substance use in their assessments, but most had developed links with at least some relevant specialists in other areas. Examples were, the liver team, COPD team and local GPs. The challenge was to bring them together. Several of the participants said that people using substances went through the same procedures as everyone else in terms of risk assessment and/or preliminary assessment, but that in the 'back of their minds 'were additional considerations, for example, thinking about the dosage of opioid medication for pain to make it effective but safe, or being mindful that, in some locations, particular medications cannot be prescribed by GPs so they needed to be careful not to start a medication regime that could not be continued. One participant said they would think earlier about 'up titrating 'someone with an opiate use history due to increased tolerance levels and not wanting to leave the person in pain. They would also consider whether or not they needed to liaise with substance use services to sustain community prescribing. One participant said they had a befriender service delivered by volunteers and would consider enhancing that service to support people with substance use issues.

Substance use

The substance use specialists had varying experience too. As with the palliative care specialists, there was no routine questioning relating to life limiting illness, rather there were general health questions with a further nurse-led health assessment if anything was raised as a concern in both statutory and voluntary sector providers. One participant reported an experience of conversations about a client's wishes at end of life and talking to him about his son helping him to start sorting out his collection of books. They also managed to talk to his son about naloxone administration.

Prescribing methadone spans substance use and palliative care and one participant stated that it was important to attempt to take the stigma out of continued use where the reason for the methadone prescription was moving from substitute medication for opiates to pain medication:

> I think in a way for some people, unless they have that really good relationship with the recovery worker, I think it's about us stepping back and actually saying, "You've done very well and we're not giving that medication for drug misuse," to try and help them with that. I've had one person that really wanted to be off his prescription before dying and that was one of his main goals. It's a really difficult situation of course because when you take away that script [it leads to] worsening breathlessness, worsening pain and it's about having those frank conversations about the fact that you're not going to feel better for coming off it, it's the psychology of it.

Another service, however, said they would pull out and not prescribe once the person became end of life but would continue to advise on medication withdrawal as the person's health deteriorated. They had also advised palliative care nurses who were nervous about supporting people using substances.

Given the recovery focus of most substance use services, this was a relatively new area of consideration for them. One participant said they were unlikely to look at recovery focussed interventions when someone had a terminal illness. However, one of the challenges they faced was determining when someone was end of life as people's health conditions fluctuated, as did their substance use. One service had instigated a monthly death review panel in-house, alongside the medical lead, keyworker and team leader. They also attended the quarterly multi-agency and multi-disciplinary death review panels held across two counties in the region.

In one location, there was no community palliative care team whereas there was in another part of the same borough. Thus, building relationships with the palliative care team had to be done with the hospital team as no community service existed. Usually, the service referred the person back to their GP or to particular medical specialist services. There were also challenges of getting adult social care involved unless there was a clear safeguarding issue or they were attached to a mental health team.

Social and community care

Again, responses were mixed. One manager reported the lack of a well-developed pathway for people using substances needing palliative or end of life care resulting in a response that was not very good. They said work was ongoing, particularly with local hospices but that they 'weren't there yet'. Another conducted risk assessment and care planning as standard and would consider assessing for rehabilitation funding if required.

One housing organisation had developed good partnership working with primary health care in order to establish what the person needed medically - alongside what the person wanted in terms of their accommodation and support. Some people decided they wanted to stay in an environment that allowed them to stay there even when they'd been using substances so work then was focussed on getting the right care in place. The service also had introduced an 'in-depth debrief 'and review when a client died to make sure they had not missed anything, but so far they found no particular weaknesses in care. They were reviewing people with multiple overdose histories, whose health was deteriorating and using those conditions as a trigger for advanced care planning and adult social care referral.

6.2.3 Identifying and assessing

There was no routine identification or questioning evident about substance use and palliative care needs across this group of participants. One health care practitioner stated that she tried to 'encourage everybody to ask the question about drugs'. However, two substance use managers felt there was no need for routine questioning:

> I don't think we need to have it as a routine question for us to pick up on it really. It might be that it's part of an assessment but I'm not aware of that. I think we just ask about general health problems. (Senior substance use professional 1)
>
> But obviously we wouldn't be asking necessarily everybody, it would only be those who were brought to our attention, … . (Senior substance use professional 3)

Several managers felt that it was information that would come through in the referral process or that people would tell them about during the course of their work with them.

> Often our patients will tell us as well, there's a lot in that. There's quite a lot of honesty about what's happening. (Senior health professional 3)

This was particularly the case with palliative care colleagues who stated that by the time people were end of life, the information would have been known, although this was qualified with where the person's use of substances was "very clear and obvious". Another stated they conducted 'holistic 'assessments in a relatively relaxed pace which enabled them to 'find these things out 'although they had no specific questions or tool to assess substance use. There was some recognition that not enough is asked about substance use and that this could be due to the sensitivity of the topic:

> I don't think we probably do enough checks and make it standard practice. I think there are a lot of things that are maybe still sensitive that although we talk about deep and heavy conversations in palliative care, we still shy away from… those with liver disease, for example. (Senior health professional 1)

One palliative care participant said it depended on the staff member as to whether or not they would find it difficult to ask about substance use. She believed the experienced staff would be more comfortable asking about substance use than newer members of staff.

The concern about sensitive questioning and identification was reflected in the responses of the substance use specialists. One participant felt it needed to be a conversation that was ‘service user led or…GP led ’if it went beyond asking general questions about health. Another felt it wasn’t appropriate for non-clinicians to have such conversations about end-of-life wishes without being in a position to do something about them. Several substance use managers said their experience was of people talking openly about their ‘terminal illness’:

> … you’ll get to the point and they’ll say, “I think we need home visits now”. And that’s kind of the notification that we know the health of these people are deteriorating. (Senior substance use professional 2)

One substance use manager pointed out the inappropriateness of some of the existing, required, quality of life measures, when working with people approaching the end of their lives, suggesting they need to be allowed sensitivity and flexibility in terms of whether to use them or not.

Two social care managers acknowledged that talking about end of life and substance use undoubtedly took many staff ‘out of their comfort zone ’and that training could help to a degree:

> I don't think we’re there yet, I don't think they are comfortable yet. … [we]…. had hoped to have all the staff trained and have some resources in place to help them have the difficult conversations that they need to have but with Covid and everything… . (Senior housing professional 1)
>
> And it’s no disrespect to the average recovery worker … but they’re probably extremely far out of their comfort zone when … we get to the critical end-of-life care, … I suspect that a lot of staff would be way out of their comfort zone having those discussions. (Senior social care professional 1)

A third social care manager stated that social and health care workers are unlikely to know the right questions to ask about substance use and was aware that assessment processes lack the specific questions required to sensitively access the information needed:

> I think sometimes people just focus on getting the information, and they're not getting the right information because they're not asking the right questions and they're not asked in the right manner and the right way that would enlighten and give you a fuller picture of what that person is like, what that person wants, how can you meet their need? And you're not just looking at a physical need, how can you meet their emotional needs in terms of what would make them feel this person is not judging me? I'm not a bad person if I take substances or I drink to excess. What's your background story, how did you get to be ...? … How are they managing? And how are we assisting them, I suppose, more to the point?! (Senior social care professional 2)

6.2.4 Collaboration, partnership and multi-agency working

There was an overwhelming agreement around the need for better integrated and inter-agency working. Participants described the inter-agency working as inadequate, uninformed, disjointed, untimely, and lacking a needs-led approach. Particular gaps were identified between mental and physical health teams and between community palliative care and community drug teams.

One participant from a larger organisation said multi-disciplinary working was needed within the organisation as well as across other agencies. There were several participants who commented on the need for earlier referrals and/or collaboration stating that referrals were often made at crisis point or at the point of hospital discharge. As one participant stated: "A better MDT approach would mean better outcomes '(Senior health professional e).

There was a clear sense of frustration from participants about the lack of integration or effective multi-disciplinary working. Several participants reflected on the need for a greater sense of collective working and how that could be achieved:

> How do you get that sense that we're all working collectively together as a team even though your badges are different? How do you move beyond the badge to get that sense of team and identity? … How do you get beyond old practices of working - to try and create that? And recognise safety and risk on a wider patch to help people so that you think, 'Well I'm all right Jack' but actually when that person moves on into being primarily under another service, or is actually under three or four people because of the problem that they have, how do you bring things together? (Senior health professional 1)

Participants spoke of working together for a common goal asking how that might be done and identifying the need for a community of practice to help each other understand how people are 'talking about 'people using substances approaching the end of their lives. One participant from a substance use service spoke about the need for people to have "stability and consistency" but this was difficult to achieve given the lack of stability and consistency in services. The context for this is a decade of cuts to substance use services and many rounds of retendering and changing service providers. Another spoke of the need to target people with COPD for joint care as this is a group that presents to all services.

Several participants identified improvements – these tended to be from organisations and individuals that were proactive in working with people using substances approaching the end of their lives. One reported greater collaboration while another spoke of a joint visit that was helpful and informative in terms of communication with the person who was experiencing mental ill health. One participant pointed to a relatively new integrated palliative and end-of-life care project – IMPaCT – happening in the City which provided 24 hour care (impactmersey.org.uk). Another social care provider spoke warmly about the relationship with a GP practice in the City that supported people using substances. They said it was an “absolutely amazing” example of how integrated working could work well although added “I don’t think we’re there yet with adult social care or mental health”. (Senior housing professional 1)

Care Pathways

Several participants spoke of the need for clearer care pathways between substance use, palliative and other health and social care services, with improved collaboration and joint working. However, the issue of capacity at the end of that pathway was also raised as a critical issue with participants suggesting that it is not just the process but the resources that are needed:

> … my impression is that in some instances the pathway’s a bit obsessed with getting people drug free before they can enter a hospice or an end-of-life service. But once you get there, if you get there, things are kind of okay. … But I think the complex and more problematic bit is how you get people to that, and is that deliberately complex, because people know that there isn't sufficient capacity at the other end of the pathway? (Senior social care professional 1)

One substance use service had developed and introduced their own end-of-life pathway bringing together the person, their keyworker and the GP for a shared care arrangement. This gave the person the choice about whether to have the GP manage their care or whether they would prefer it to be the substance use service. The better relationship between the key worker at the substance use service often resulted in them managing the person’s care until they died.

6.2.5 Challenges

The managers identified many challenges in supporting people using substances at, or near, the end of their lives. This is not surprising since this is a new area of practice focus and development. These have been summarised below into 5 groups, i) Policy, structures and processes, ii) Individual-related challenges, iii) Practitioner-related challenges, iv) Resource challenges, and v) Stigma.

Policy, structures and processes

The lack of coordination of services to adequately support the complex health and social care needs of someone using substances approaching end of life was repeatedly raised by participants. For example, participants said that the protocols were not always appropriate or sensitive to their needs and there need to be more flexible application of them. One example was the TOPS scale used by substance use staff that is a qualitative self-reported measure of health and well-being on a number of scales. One participant pointed out how inappropriate that was for someone who was approaching end of life.

As mentioned in s.6.2.4, late or delayed referrals between hospital and community services created real difficulties in, for example, trying to arrange appropriate accommodation and/or health and social care within their accommodation. This made it stressful for all concerned and placed the person's health and wellbeing at greater risk. A palliative care specialist pointed out that nobody was monitoring admissions for people using substances who were in hospital repeatedly, even where there was a clear trend developing in the deterioration of their health. They pointed out the person could have been referred to them earlier rather than seeing six different nurses and six different doctors on six different occasions.

In addition to the lack of knowledge about resources and where to refer individuals and families to, there was also a reported lack of communication across and between specialist providers. For example, where someone had a liver, renal, and lung specialist all involved in their care, all information was returned to the GP without any 'real MDT working'. One participant felt that national policy focus on recovery had resulted in a lack of clinical expertise in substance use services – a lost skillset when it comes to physical health and illness - that would be important for this group of people.

Another key challenge related to 'arguments 'about whether particular forms of support should be funded by health or social care. It was pointed out that these protracted arguments often left the person who was very ill in the middle of the argument, with delayed care. One example was given were there was a debate about whether the person's needs related to their brain injury, their substance use, or their homelessness - with health colleagues not prepared to see someone with 'difficult behaviour 'in the community. This sense of people who use substances having more difficulty accessing health and social care as a result of their substance use was not uncommon. One participant said the lack of understanding about their needs or how they might present to services extended to expecting this group of people 'to do all the things other people can do', whereas a more informed understanding would help to 'avoid premature mortality 'among this group of people.

One participant noted how the English national policy's framing of substance use treatment as having a 'successful outcome 'after three months was unhelpful. It measured only short-term involvement and not the longer-term support that many people required, particularly where there were multiple and complex needs.

Practitioner-related challenges

There was some overlap between challenges that were structural, or process driven, and those that related to individual practitioners. While they are not mutually exclusive, the practitioner-related challenges tended to refer more to knowledge about when to intervene, confidence to do so, and concerns over personal safety in the community.

> … just before the point where it’s very clear that they’re in the last days of their life, that’s often where the challenge is, as the needs increase, having something that’s responsive is a challenge. And being able to do our best to try and think ahead, and plan ahead, and have a group of professionals that are confident and comfortable and capable of helping people with this particular set of needs. (Senior health professional 1)

Many of the challenges raised at practitioner level related to this sense of having a ‘grey area ’in decision making, usually brought about by ignorance. This sense of knowing when to intervene or have the conversations was also a challenge particularly if the professional was aware that the person they were supporting was ‘in denial ’of, or fearful about, their prognosis. The lack of knowledge about supplementary drugs, such as cannabis and cannabis oil, was also a concern in managing someone’s care. Another practitioner stated that it was also difficult to determine when someone was seeking pain relief for genuine pain and when they were drug seeking:

> Even though I have got a special interest in the area, even I struggle with … knowing how far to go. Is this real or is this because they’ve had the trauma of a diagnosis and psychological pain? And how much pain is pain for them? I think that’s a challenge for us all. (Senior health professional 4)

Concerns were also raised about mental capacity and knowing when a person has capacity or doesn’t. One participant reported that capacity concerns had got in the way of delivering appropriate care. Importantly, another participant wondered whether a repeated history of drug overdoses counted as requiring end- of-life care.

Examples of other areas of ignorance offered by participants included managing the acute withdrawal process when the is person too ill to access the drugs and the need for specialist knowledge of opioids at that point. In substance use, an example was that staff may have to explain that the best course of treatment was to stay on methadone as a painkiller because other painkillers work differently and could result in increased pain or overdose.

One participant stated that they needed to take care not to ‘put professionals in challenging situations ’when providing care at home, while another said it was their job as care professionals to work with such behaviour:

> If somebody’s difficult and they’re vile and aggressive, and I know we have a non-tolerance of violence at work and I get all that and I do understand it, but then when you’re working with people with brain injuries and substance misuse and alcohol problems they don’t care, they’re not bothered about our policies. We just need to be a bit more savvy about how we deal with them and understand. (Senior social care professional 2)

The stereotypes about people who use substances were reported as making it difficult to provide care and carers for people at end of life using substances. Participants said that social care professions ‘shied away from it ’and didn’t see it as a priority for care. Similarly, substance use was reported as being blamed for the deterioration in someone’s health, when in fact it was their advancing lung cancer, for example. One substance use service manager empathised:

> That’s true even for us as professionals, sometimes trying to advocate for our patients, or when we’re advising patients’ GPs, … our concerns are not being picked up on either … So sometimes I think the biggest barrier is probably negative lived experience, perception of negativity from other professionals and fear of change… not feeling listened to when they’re going in with something (Senior substance use professional 3)

Finally, there was the frustration of not knowing what the answers were, only knowing what the problems were. As one manager put it, all organisations need to want to find solutions and while it might be a long-term plan, it was achievable to avoid people dying alone or without the necessary care.

Individual-related challenges

Participants noted some challenges that individuals faced. This included people not feeling they deserved palliative or end-of-life care and not wanting care. One participant suggested this was self-protection or people avoiding having to ‘bare their soul’. Individuals also faced challenges of being prescribed opiate-based medications for pain management when they had overcome opiate-based dependencies in the past. This raised their stress levels and fears of relapse. One participant stated that clients feared changing their medication as their illness progressed particularly if they had been using something for a long time. Family relationships were also complex, characterised by conflict, estrangement and ‘highly emotive ’encounters which were stressful for both the family member and the individual, particularly if they didn’t want family involvement.

Resource challenges

Resources, or lack thereof, also presented challenges. While s. 6.2.6 details reported gaps in service provision, some participants also identified areas that prevented good care including:

- Lack of political will to support this group of people
- Lack of support for families and friends
- Inaccessible location of hospices – often in leafy suburbs two bus rides from town
- Services not meeting the needs for a younger age group, particularly with non-cancer diagnoses, e.g. COPD, heart failure, liver disease among people in their 40s-60s
- Initiatives that clearly worked but are subsequently decommissioned e.g. outreach substance use services
- Lack of proactive planning in health and social care because of pressured environment and professionals’ ‘firefighting’ at work
- Lack of timely housing provision as health needs deteriorate faster than housing can respond to.

Stigma

A very clear message from participants was the presence of stigma and prejudice from professionals delivering care to people using substances who were approaching end of life:

> Hospital doctors unfortunately have a very negative skewed view of people [using] drugs and they often are seen as drug seeking behaviour for pain management, even when they're terminal. That is a big barrier. … some of the things that you hear that people have said to them in hospitals is just dreadful. (Senior health professional 4)

The sense that it was up to the individual to sort themselves out to fit into existing systems rather than systems being developed to meet their needs was raised by several participants:

> I think another barrier, another part of that, is also a bit of an assumption about how people live and if they don't live in the way that you live, that they're wrong and actually we need to meet people where they are and if people choose to live in a certain way of - are used, I should say, to living in a certain way and changing that is too much for them, how do we accommodate and meet in the middle? (Senior health professional 1)

In palliative care, some participants spoke about stigma resulting in late referrals to them as well as hospices being unwilling to take people who were currently using substances. Stigma also resulted in people self-selecting out of services either through self-discharge because of the way they were treated and/or their inability to get access to substances, or through avoidance of services in anticipation of discrimination. Hospices were also reported as being stigmatised in relation to their association with death and people with particular conditions:

> The building, I guess it's an unknown to them. There's the stigma around it being somewhere where, sadly, people do die. There's a link with cancer, and obviously some of these people with substance misuse issues will have cancer, but we do have people with end stage COPD from, for example, crack cocaine smoking. We've had some people dying from their alcohol-related liver disease. So, there is that association with cancer and with incurable illness. That might not be where they see themselves. (Senior health professional 2)

One participant also spoke about the layered negative narrative about substances (and people who use substances) as helping to maintain the status quo and the construction of the individual as the ‘problem ’through policy and practice. They spoke about the “constructed stigma” informing “so many people's understanding” of substance use with consequent harm:

> So, I think a lot of it is that somehow or other we have to deconstruct the drug problem, you know, the drug problem that is embedded within all the narrative, so it always is a problem. It's difficult to get beyond that idea of it being a problem because it situates difficulty within the individual because they are the problem, their drug use is the problem. Their existence is the problem. … And then we've got, I think once we've got that sorted to some extent, then we might see people who use drugs in a different way, and we

> might see them as actually being more entitled to a kind of equality of palliative care that I don’t think is there at the moment. (Senior social care professional 1)

6.2.6 Gaps in services

As this is a new area of research and practice consideration, it is not surprising that gaps were identified in terms of processes, resources and service provision. One palliative care respondent stated: “There are almost too many gaps to quantify.”

Specialist supported accommodation

Chief among these gaps, and with agreement across all participants ’specialist areas, was *the need for accommodation and/or bed space* that is suited to the needs of people using substances approaching the end of their lives. One participant described the provision of that bed space as “absolutely paramount” in order to offer care that meets their needs stating: “It’s that availability of being treated as humans as well, that’s the place of care, that’s definitely a barrier, we've struggled to get people into beds sometimes...” (Senior health professional 4).

Participants presented many reasons for the provision of specialist accommodation including:

- People not fitting into/feeling uncomfortable in a hospice or hospital setting – nowhere else for them to go
- People wanting to continue to drink alcohol or use illicit drugs at the end of their lives
- The need for a place where ‘success’ is not judged to be only abstention
- People don’t have to fear withdrawal of care if substance use is ongoing and/or disclosed
- The younger age group of people approaching end of life and using substances – an age group that isn’t well served by existing hospice provision
- Additional care needs and consideration given due to their substance use (past or present)
- Enabling better care through a workforce that has a better understanding and awareness of their needs and histories and is able to advocate for their needs
- Overcoming restrictions on how many people can enter their house in a day and overcoming barriers raised by risk assessments in people’s homes
- Identifying the unwillingness of some health and social care staff to go into a home where someone is using substances and allowing that refusal to be formally addressed.

One proposal was for allocated beds within hostels for homeless people with the relevant support in place:

> I guess an ultimate aim might well be to actually have supported beds in a hostel because some of the feedback we get from people working in this environment is that, for a lot of their clients, that counts as home for them.

> It’s the only place that they really feel they belong and they feel comfortable. I think it’s how can you take the support to the place where they feel comfortable? (Senior health professional 2)

Only one participant felt there were insufficient numbers of people to keep specialist service provision going. However, the lack of routine screening and the lack of formalised joint working means that accurate numbers are not known.

Specialist roles
There was a great deal of enthusiasm for a specialist role for supporting people across the range of services – a bridging role between services. As a substance use manager stated, it would be helpful “ … if there were specialist workers who were the ones who integrated all the services together who were that conduit, …” (Senior substance use professional 3). Specific suggestions included:

- A link nurse – a special interest palliative care nurse or similar professional to help overcome silo working.
- A link nurse – between GP practice and specialist services including, palliative care, mental health and substance use services. This would help to overcome the particular difficulties of engaging GPs in MDTs.
- Homelessness and palliative care joint posts – professionals “with a foot in both camps who understand both sides of it”. This would help overcome the “different languages” spoken in each of the sectors.
- Enhanced helper/befriender service to help with some of the practicalities when people return home from hospice or hospital care.
- Liaison roles between hospital and substance use services to facilitate faster and more effective communication.
- Practical support roles for assistance around financial, housing, and funeral affairs as people approach end of life.
- A specialist team – one participant suggested this should be located in palliative care with a senior nurse or consultant leading the team but with others with special interest working across the community teams and the specialist team. Another said it would be a service “that is happy to do that kind of advanced care plan, that end-of-life work and the palliative care support but with someone that might seem like they’re up and about the next day and choosing to go and score.” (Senior housing professional 1)

One participant felt the appointment of someone to a specialist role would be hard to achieve as they felt new medication costs were approved far more easily than new members of staff. They were also questioning whether it might lead to fragmentation of services and “yet another specialist” involved in someone’s care.

Improved processes
In addition to improved care pathways, participants spoke about the need to improve systemic processes to deliver better care. These included:

- Structural change to enable health promotion and preventative care within palliative care to “pre-empt the crisis of the future”. People using substances are at greater risk of premature death and there needs to be a response.
- An enhanced, structured approach to care – “everyone needs to know what the evidence is behind the prescribing and be aware of what support is available, and also, just in terms of whose role and responsibility it is to do certain things. That’s very difficult because someone does need to take ownership over the situation.” (Senior substance use professional 1)
- Greater integration of services – “it’s when provision is funded by different streams, you can never have a truly integrated service, because everything’s got its own priorities because of the money …”
- Allocated adult social care involvement and a pot of funding to help develop pathways between hostels and hospices.
- Improved TOPS form within substance use services – one participant questioned whether or not it was “humane” to ask someone to assess their health and well-being when they are terminally ill and approaching their end of life. Asking about their Quality of Life would be an alternative approach.

Palliative and substance use specialists wanted earlier notification and intervention when people arrive in hospital. One of the palliative care specialists said they could support people more if someone had referred them sooner, if they knew earlier they were in the hospital. Late referral had a knock-on effect, with another substance use manager saying:

> I know people have often felt there could have been better liaison with hospitals who are discharging somebody who is end-of-life. … It’s not a criticism of any person, it’s actually… it’s one of them frustrations, you think, “Why didn’t you ring us up a couple of weeks – a month earlier?” There’s probably a good reason why they didn’t, and I’m sure they have similar frustrations but with us. … it’s that liaising, it’s that joined-up work if you like, that often doesn’t take place as soon as it could have done to make things easier for the person who, at the end of the day, we’re all actually looking after, doing our bit. (Senior substance use professional 2)

Family support and practical support

As identified in earlier studies (Wright et al., 2018; Yarwood et al., 2018), there is a complete gap in support for family members who are caring for and/or living with a person using substances approaching the end of their lives. This includes, emotional support and practical support, during the palliative care of the friend or relative and after the person has died. One participant said that where family support exists, it is either generic support not focussing or understanding the complexities of substance use in the family, or it’s attached to a treatment service for the support of the person seeking support for their substance use. Families need support in their own right, particularly if their relative is not accessing any services. Examples given included support to families for end-of-life planning, such as links with funeral providers and accessing funeral grants.

6.2.7 Developing existing services

As a result of practice leadership in Liverpool, a number of service providers had already started to adapt their response to meet the needs of people using substances approaching end of life. However, in general, these were based on individual managers 'and practitioners 'good leadership and desire to improve care to this, and other, marginalised groups of people - rather than any formally commissioned service. These included:

- Hospice outreach to other services including homeless hostels – currently being developed by one hospice and led by a senior nurse including supporting staff.
- A specialist nurse appointed in a GP service to liaise across a range of different services.
- Upskilling hostel staff to know what to look out for and how to care for someone – including trauma-informed support - although acknowledging that such care is really the responsibility of health care professionals who are paid accordingly.
- Enhancing the skills and experience of the substance use workforce
- Offering flexibility in hospice for appointments with patients using substances, ie. not keeping to rigid appointments.
- Close working between i) a GP and a substance use service with a specialist drug worker working with the GP practice, ii) good relationships with a psychiatrist who will respond quickly with advice, iii) a nurse consultant who finds out about all relevant agencies and their referral procedures.
- Good partnerships with primary health who do in-reach into a homeless hostel, as well as drop-ins.
- Three ringfenced beds in homeless hostels were in the pipeline as 'out of hospital' beds which come with adult social care support, carers in place, multi-disciplinary team, integrated health, and primary health.
- Close working between a homeless hostel and substance use services.
- Regular meetings with the liver team at an acute care hospital unit and offering mutual support and resource for advice – thereby reducing the need for hospice clinic attendance.
- Integrated care model for palliative care across hospital and community sites.
- A palliative care staff online bulletin board used by people all over the world for peer support and advice.
- A hostel for homeless people providing therapeutic debriefing for staff after someone has died and establishing a memorial garden for residents, staff and family in the hostel.
- Brief guidance written in-house by a medical lead for a substance use service to identify what end of life might look like as opposed to people being 'generally unwell'.
- Monthly in-house palliative care multi-disciplinary team meetings in a substance use service and related home visits as needed.
- Joint working helping to develop good cross agency relationships.

One manager said they were rethinking how they documented some aspects of assessment, for example around next of kin:

> I think we are doing a bit of work to look at how we can write things differently, to keep asking those questions and to point out why they would be useful for us to share the details. It might not be someone we'd contact if they were arrested or taken into custody, but it could be someone we'd contact if their health situation changed. (Senior housing professional 1)

Potential improvements
A number of managers reported potential improvements to care for people using substances. In palliative care, a recent initiative was the Integrated Mersey Palliative Care Team or IMPaCT[6] initiative – a partnership between Marie Curie, Mersey Care NHS Foundation Trust, Liverpool University Hospitals NHS Foundation Trust and Woodlands Hospice. It is available to people living in Liverpool and South Sefton. One manager expressed 'hope 'that the IMPaCT model would provide a forum to help people using substances too while another felt a wider dissemination of the IMPaCT number may help improved joint working. The service evaluation is not yet available.

> I feel, as a start, we've just developed IMPaCT as a service and although it's still very early in the making, it's one number and one port of call and if you ring that number sat in that room is somebody from a hospice, somebody from the community and somebody from the hospital. So even if it is for the next 12 months, it was just getting that number out to different service providers for this group of people to say if you don't know, it's okay to just ring us and we will try and help, would be easy to do or easier than a multi-million pound model. (Senior health professional 3)

Other suggestions for improvement from palliative care colleagues included:

- Supporting substance use services to refer people to the Gold Standards Framework (GSF) register as a way of ensuring more joined up working.
- One palliative care charity had secured funding for a homeless and palliative care coordinator who they were hoping would be able to teach the team to become more trauma informed.
- Another agency was intending to start attending the quarterly drug-related death review panels in the region 'to see retrospectively is there a theme that we're missing and we're not capturing these patients for whatever reason and what can we do differently about it.' (Senior health professional 2)
- A new electronic notes system was also identified as a way of helping improve knowledge of someone's needs quickly.
- Improving outreach to the drugs team who may be involved in an inpatient's care to ask if there are any concerns.
- One GP was keen to 'demystify' prescribing with clear guidance on what to do if someone is already on methadone, for example.

In substance use services, one agency had developed a specific end-of-life pathway and was hoping to develop guidance for GPs in partnership with a hospice, as well as a learning package to help improve working together. Another had employed general nurses to help

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[6] The Integrated Mersey Palliative Care Team (IMPaCT) are healthcare providers and agencies working together to provide a continuous end of life care service. (merseycare.nhs.uk)

focus on physical health aspects of people's care and was hoping that their post-covid review of people using the service - as they returned to face-to-face contact – might quickly identify any significant changes for the worse, with the hope that their increased awareness of palliative and end-of-life conditions might help them have conversations with people about their care. A third was intending to recruit volunteers who may be able to support an improved palliative care response.

One of the social care managers was aware that the people using their residential service often wanted to stay there rather than enter hospital or a hospice at end of life. The manager said they needed to have the support to create an environment that was appropriate for them and that maintained the person's standard of living. Another had short term funding to do some work on integrating health and care services to minimise the inappropriate discharges from hospital. This is a key area where much could be achieved by hospitals taking responsibility for where patients are going to and who they will be cared for by.

6.2.8 Commissioning and commissioners

One of the areas discussed in the interviews was whether commissioners of services could help to fill any gaps identified in services for people using substances and approaching the end of their lives. The key message was primarily about the need for services that met the level of complexity people presented with, as well as support for their families and children. The second key message was about supporting integration across health and social care – improving what services knew about each other to facilitate earlier referrals. Once person felt commissioners had a role to play in shoring up integrated care delivery.

As with 'gaps in services' (above), the participants thought that commissioners needed to commission services for:

- Families and children – particularly supporting them with the emotional burden; and
- Wrap around care for people going in and out of hospital to stop the revolving door. Services and roles needed to be commissioned to provide that care.

One participant stated commissioners need to commission "really good end-of-life services for people that use drugs, and I don't think we have that at the moment, but we've got to get them there to enjoy those services, and far too often people are dying before they even get to that." (Senior social care professional 1)

One social care provider spoke about having supportive commissioners in Liverpool, while another felt they were not adequately qualified to commission clinical services for substances as they lacked any clinical expertise. The latter criticised commissioners ' judgemental approach to substance use service provision:

> That's a mentality that is shockingly apparent even in a lot of people who commission those very services, even amongst some people who work in those very services. It absolutely baffles me. … I think the more commissioners are aware and understand the service provision, that's great, but not all commissioners do, some commissioners are entirely driven by

> performance because their background is that, and they're thinking about the finance end, you know, the ability to provide this service for the lowest amount possible with the best amount deliverable. (Senior social care professional 1)

The challenge to commissioning services included organisations that undercut other services offering apparent value for money but then not delivering quality care and a lack of consistency of services commissioned. One example was provided whereby there were different services provided in the north of the borough compared with the south despite evidence of need. Also one agency doing innovative work said there was a need to build a business case for funding, demonstrating potential value of a new model of working and to then take it back to commissioners for funding.

6.2.9 Family support

Participants were asked about what good practice looked like in terms of family support. One participant said:

> I don't think there's a straightforward answer to that because I think it really depends on what the carer wants and what the carer wants, we should try and provide. It's obviously not always possible because we're tied by bureaucracy sometimes. But I think that's where we should aim to be, is actually finding out what they want and what they need and then trying as best to fulfil that. (Senior health professional 4)

There was agreement among participants about the need to support people around the person who is unwell. One person said this was particularly important if the person was newly back in the family's lives resulting in them re-establishing a relationship and simultaneously being a carer. Another said that practical, psychological and organisational support for families was needed including how to navigate systems of care and also post bereavement.

One of the challenges for family support, however, is that few services exist. One person spoke of month-long waiting lists for bereavement support. Two agencies were mentioned including a private therapeutic service based in Yorkshire, Being Better, and a bereavement service called Love Jasmine. However, neither were specifically for family members of people using substances. There was also an awareness that family support teams in hospices were not accessible to everyone and were often limited to certain levels of care. One substance use service manager spoke about a carer's group within their service and mused on whether that could be developed further to include end-of-life discussion. Another said they were not able to support families and carers properly and couldn't answer questions they often asked. Macmillan support was identified for families, but only for people who have cancer and not other conditions. One service mentioned an in-house chaplain who would offer support to families and friends and another mentioned having a carer's register in the GP surgery - with a nurse partner who ensured all carers were on it and attempted to provide the support they wanted. A palliative care service said it was part of their role to support family members and said there was a family support team within the local hospice. One participant said there was a good support network for carers in Liverpool, but no other participants mentioned it, suggesting it may be a matter of awareness or that it was not tailored enough to understand the needs of family members of people using substances at end of life.

Several participants stated that some family and friends would not be able to offer support and must not to be judged for that. This could be a result of their own substance use or from long term family estrangement. One stated that family members – siblings and parents – often carried guilt relating to their relative's substance use and ill health. Another said that family members did not often agree with the person's choice to use substances but wanted them to die safely with someone there with them. For staff, the challenge was balancing the wishes of the person who is dying and the family's wishes, which could be difficult if the person did not want to die at home 'to put that on the [family member's] memory'.

Finally, one hostel provider was conscious of trying to minimise the distress for family members:

> … we do try and do a little bit of that, when someone's passed away, for example, it's slightly different but we'll offer the family, if they do want to come and have a look at where they were living, it sometimes helps them, we'll offer them to come and look in the room. We'll tidy the room but not change it, we'll clean it and keep it how they would have had their things, but we'll make sure that [the family would] be happy with how they've been cared for. But I think that that's quite a big job for someone. (Senior housing professional 1)

6.2.10 Support for staff

As well as family members needing support, the managers were asked about what support services existed for staff due to concerns raised in the theory of change and model of care workshops about support for frontline staff. This was supplemented by comments from participants who spoke of a range of concerns, relating to: perceived risk to staff from working in the community with people using substances, emotional and mental impact of a client's death and dying, inadequate staffing adding stress to those in post, lack of resources to refer staff to, staff becoming "unboundaried" in their relationships with clients so they're more like family, staff understandably developing close working relationships with people they've worked with for years. A range of formal and informal supports were identified including:

- Partners, family and friends
- Self-care strategies
- Caring and compassionate colleagues in the workplace
- Formal peer support via debriefing sessions or regular MDTs
- Clinical supervision that encompasses staff support
- Employee assistance programme or in-house counselling/CBT support
- Wellbeing groups
- Regional resilience hub with online resources
- Monthly psychologist visits for reflective practice sessions

6.2.11 Training

Participants were asked whether they had previously received any training relating to working with people approaching end of life who use, or had previously used, substances. Most had not but were open to options for training in relevant areas or were currently exploring them. One stated they didn't know who to invite to deliver training on their particular needs. However, the need for better knowledge and upskilling of staff emerged from discussion throughout the interview process.

Most of the participants felt it was their responsibility to develop the relationship with other agencies and sort out the training between them and/or in house:

> I think we need to get the pathway sorted and look at developing the training with the palliative care team, as to how you manage somebody that's on methadone, how you manage somebody that's an alcohol dependent patient. That sort of stuff that you can muddle through individually with advice, but it would be really good to have a standardised approach. (Senior health professional 4)

Two stated they would add a palliative and end-of-life care component to their training in future. Another had organised training for their staff with two palliative care agencies after meeting them in the theory of change and model of care workshops stage of this research project. Subsequently they, and their staff, had completed some online training:

> I do think that makes you look at it rather than thinking "this is a difficult conversation", the session that I went on not long ago makes you think, "this is essential" - to know what they want and what their plans are and who they need around them, what their choices are and to get all that down. It makes you think about that rather than about it being a difficult conversation. (Senior housing professional 1)

Another had already developed a 'study day 'with a liver team to include role play and advanced care planning with people with end stage liver disease. They also reflected on their naivety in relation to substance use when an inpatient asked them for kitchen foil which they refused suspecting it was for drug use. The patient later asked for Dairylea triangles which somebody got for the patient, not realising it was the foil wrap the patient wanted:

> We all had a laugh about that, but I suppose it illustrates the difference between us and people working in a substance misuse environment - that they would immediately be onto that and that in many other ways I guess they just have a better understanding of how people with these issues operate. (Senior health professional 2)

Four participants felt it was difficult to train people when they've had little or no experience, particularly of death and dying. One stated it was a recruitment issue that stemmed from a social care workforce with limited life experience to bring to this particular group of people:

> We’ve got a lot younger social workers, social care assessors, coming into this profession. My concern – and this is just my concern – some of them don’t have the life experience to bring to this role. They’re very committed and they’re amazing, they do really well and it is lovely to see them come along. But I do question sometimes their life experience and their background, where do they come from? Are they basing their experience on TV programmes, on what they’ve seen or listened to in a lecture at college? Have they had any own experiences? I think it’s all valid, but it just makes me question sometimes are they clued up enough, and this is where I do think we need training. (Senior social care professional 2)

Another pointed out that the complexity of needs facing this group of people and those who care for them are transferable and “could equally apply to younger people who are facing certain illnesses for dementia and dementia care. How we deal with a society where … we have got increasing levels of complexity in all areas, how do we make ourselves skilled in that?” (Senior health professional 1).

One participant felt it was difficult to enhance skills across a whole group of people and that it would be difficult to keep on top of that as needs change and complexity increased. The other option they felt was to know more about the various care settings and what resources were available.

The structure of training the participants suggested involved:

- ongoing training – not just a one-off
- inclusive of people with lived experience
- based on case studies
- tailored towards different levels of experience and training needs
- joint training workshops with partner agencies – help to identify people to contact and build relationships

Ideas for content included:

- assessment processes and routine questioning, including tools to use to assess someone’s substance use or their level of ill health
- how to feel comfortable having conversations on difficult topics, e.g. end-of-life wishes, and the context for those conversations
- questions based on an understanding of the ACES and trauma that are the common among people using substances
- the conditions that would make people terminally ill or the potential to deteriorate and what signs to look out for, physically
- referral processes to partner agencies
- advanced care planning (ACP) and how that could be embedded into conversations with people who needed a less formal approach
- supporting people who want to carry on using substances at end of life and supporting their knowledge of the impact of their use on their safety and body.

Several participants said it was important to get the organisational structure right, including appointing a ‘champion ’to drive forward relevant changes at senior level - otherwise any change of practice would stop when the person left. There needed to be ownership of the issue at the top of the organisation otherwise it wouldn’t bed into organisational policy and practice.

> [we] need to change the structure before training will have any effect. Because if you don’t change the structure, if you don’t address the things that we’ve been talking about earlier, then people’s awareness will probably just become a huge frustration to them because they can’t actually effect change in a structure that it isn't set up to enable that change. …Training’s just, it’s seen as the solution and an easy fix, and it’s something that people can tick off, can’t they? (Senior social care professional 1)

6.2.12 Good quality end-of-life care

Participants were asked what they thought good end-of-life care looked like for individuals using substances approaching end of life and their families. Chief among the responses was the importance of someone dying with dignity, in a safe environment of their choosing. The concept of ‘dying well ’had a particular impact on one participant:

> Several years ago, I did do some work around end of life, not in a drug and alcohol context, just in general population, … and I was quite taken by some of the kind of discourse that had emerged at the time, and it was not just about living well, but also dying well, and I thought that was a really interesting concept. … And I remember … there was this theme about you only die once, and I think it’s kind of trying to put that, take that negativity away from the issue, and thinking about it in a much more positive and supportive way… . (Senior social care professional 1)

This need for a more ‘positive ’experience was reflected in many comments and suggestions for good practice. These ranged from principles to specifics. For example:

Principles

- Helping people to die with maximum dignity and minimal suffering
- Ensuring people have care based on human needs and rights and are free of unnecessary pain
- People being treated with respect and non-discriminatory practice and dignified care
- Having needs-led (not service led) care
- Same access to services and choices as anyone else has - in an environment that they want.

Specifics

- Care coordination to deliver what they need in terms of their healthcare and how it impacts on their substance use and ability to access services
- Having a budget to grant last wishes
- Ensuring advanced care plans are in place and all relevant agencies and out of hours services are informed

- Continuity of care by allocating small team of two to the person using substances – avoids person having to repeat things and would lead to ‘more timely advance care planning’.
- Improved family support:

> Being able to prepare families and carers that this is happening and what it may look like and making them feel safe that we’ve got a plan. We’ve got a plan for how to substitute drugs, we’ve got a plan for symptom management, we’ve got a plan for preferred place of care. So yes, I think that that would equate I guess good end of life care and good support for them. (Senior health professional 3)

- Tailoring the support offered to the needs of the person and tailoring who is giving that support.
- Developing specialist substance use team of three-four people to visit wards, attend ward team meetings, build relationships and disseminate understanding of substance use services to prompt greater collaborative working and earlier referrals and interventions. Currently wards are visited approximately once every nine months.
- For homeless people, retaining their support worker but having a better environment than a hostel to spend their final days in.

In summary, the managers ’interviews found points of disparity and points of agreement as might be expected from managers from a range of disciplinary backgrounds. There were mixed views according to professional discipline of the prevalence and incidence of people using substances at or near the end of their lives. This variation was set in context of a lack of routine questioning and training on this topic. They also reported a lack of care pathways between agencies too. There was also a variety of views relating to how they currently respond to people using substances at the end of their lives. In general, current responses were limited overall and hugely variable according to service and staff member’s experience. They also noted that commissioning affected what could be offered given some areas had more services than others. They agreed, however, that there was more to learn and to do.

There was no routine identification or questioning apparent in the services whose managers we spoke to. They had different views on whether or not routine questioning was necessary, particularly in substance use services where it was not seen as necessary given they were already asking about general health. Others felt more could be done in terms of identifying people early and asking the right question in the right way.

There was agreement that integrated and inter agency working was lacking and inadequate. The managers identified challenges in bringing teams together where someone has complex needs and where there are multiple people involved in the person’s care. Other challenges spanned policy, practice, resources, stigma and the person’s individual needs and wishes. There was a clear need for better knowledge set within a clear policy framework to facilitate clear pathways to better more appropriate resources that avoid people facing stigma at the end of their lives.

There were many gaps in services identified including the need for better specialist supported accommodation and specialist roles to support people and act as a bridge between services. There was a complete absence of family support with agreement across disciplines that more was needed and that there was an absence of services for family members outside broader carer and bereavement services. However, substance use stigma absorbed by family members and ignorance about substance use within those services can dissuade families from using them.

On a positive note, there was some development of existing services with initiative taken on an organisational level and often built on good interpersonal relationships with someone from another agency. Potential improvements for the future were also identified although these felt somewhat dependent on an individual driving change. The need for commissioners to fill gaps in service provision was shared with positive and negative views of current commissioners and their levels of experience to do so.

The need to support staff in this area of practice was recognised and there were a number of informal and formal supports in place. Training was part of that formal support and participants offered a range of content ideas from health conditions that are terminal to having conversations about end of life wishes to Advanced Care Planning and supporting people who want to continue using.

Finally, managers spoke about what makes good quality end of life care. There was clear agreement that the goal was to support people dying with dignity. Dying well involved respecting the person’s choices, offering needs-led care and minimising pain in an environment of the person’s choosing rather than inappropriate hospital settings.

Chapter 7 – Findings and discussion: Case studies *(Author: Amanda Clayson)*

A flexible and responsive approach to engagement enabled a group of individuals with lived experience to participate across the life of the project. These are communicated through a series of seven case studies. This includes four from people living with serious and advancing ill health and end-of-life care (three of whom have since died). The remaining three case studies include a partner, a parent, and a friend. The stories reflect a range of contexts, perspectives, and ways of sharing. These include shorter informal conversations (captured through field notes), recorded single interviews and more detailed, multiple interviews with the same individuals over a longer period. Engagement and participation was facilitated through VoiceBox Inc. This enabled a highly personalised and supported approach that recognised and was able to meet the specific needs of the individuals and situations. This included a proactive and protracted support process before, during and after any discussions around their experiences.

The information here provides a brief overview of the context and approach (tables 5 and 10 below) followed by the full case studies and key insights (tables 6-9 and 11-13 below)

7.1 - People with Lived Experience (PWLE)

Table 5 – Context and approach for people with lived experience

Name	Context	Approach
Jeff - 64 years old	Long standing 'Street Life' and heavy substance use (still active). Currently living in a hostel. Has chronic COPD and lung cancer. Is aware of diagnosis and palliative status. Chosen to die at the hostel.	6 meetings over an 8-month period (recorded). Additional visits where Jeff was not there or had to leave. Several interviews were with a Personal Care worker sharing reflections of conversations he had had with Jeff over several weeks. Recordings and transcripts.
Janet – 55 years old	2 years into 'recovery life' when diagnosed with a brain tumour which she lived with for five years. This included active treatment, several years remission and number of recurrences. She died at home.	Janet began sharing her experiences during the early stages of the research. It was important to her to continue with this process; the experiences towards the end stages of her life and after her death have been conveyed through her close friend Carol.

Sheila - 57 years old	Living with cancer for 8 years and receiving care through primary and palliative services. Historical use of substances (alcohol and marijuana). No involvement in substance use services. History of substance use in wider family. Died in hospice.	Informal conversations over a 12-month period (before and during final months of life). Participation in interview during final weeks of life (from hospice). Field notes as recording and visiting not possible.

Danny - 56 years old	Long term recovery (10 years) from multi substance use and addictions. Active in recovery networks (personal and work). Strong advocate for people marginalised and homeless. Developed close ties with family (after years of disconnect). Diagnosis of lung cancer 18 months ago. Palliative / end of life 6 months ago. Died in hospice.	Shared experiences through PEAT process and subsequent informal conversations during illness and end-of-life care. Further conversations with Recovery friends after Danny's death. Recorded through field notes.

Jeff - Age 64 - Person with Lived Experience

Jeff lives in a hostel (also referred to as the Centre). He has several health conditions including long term respiratory issues and lung cancer. He is receiving palliative care through his GP and staff at the hostel. He is actively using various substances. Jeff took part in ways that worked for him, meeting up at times that he arranged, sometimes changed without notice and managed the timings and focus. These happened over a six-month period. This is a brief picture of the things that he would like to share.

A little background

Jeff has hung out in or around 'the streets 'for over thirty years. This has involved periods of time in prison and dipping in and out of health and social care support; including short-term homeless services; outreach support and substance use services. During the last two years, Jeff has very gradually developed a sense of 'place 'within the Centre and considers it somewhere he can be himself and get on with his life the way he lives. This feels new for him. *'No one's on my case, I know the craic…there's no sniff of 'Your life doesn't have to be like this'...if there was, I'd be off'.* His support worker describes him as a *'low key kind of guy, who likes to be anonymous, a man of integrity and authentic*. 'He is an avid reader and likes music, playing the guitar for years. He leaves the poetry he writes dotted around the Centre for people to read, using humour to talk about the system and '*how it's fucked up'*.

Health, care, and treatment

Since being at the Centre, he has taken up some of the health checks and support for his chest issues and liver problems. Jeff speaks openly and respectfully about his GP, recounting a story of how he (Jeff) had to go and apologise after being rude; he felt heard. Every time he experiences something that's worthy of trust, it builds the relationship *'He knows my* *name'*. Jeff is also positive about his early experiences with his Consultant Oncologist; '*He was straight with me… gave me options. He said 'do you want treatment'… I said, of course of I fucking do…I'm not fucking stopping drinking though'*. Jeff thinks it can look like he's not bothered but he is. He wanted to know sooner what was going on; he was interested in options, treatment and taking advice even though he appears like he's not. He is angry about a missed appointment for treatment because the Centre hadn't let him know. *'They (*the hospital*) thought I hadn't gone because I was fucking about and just not turning up, wasted somewhere – I lay off a bit when I have to go there. It needs sorting!'*

He had to stop the chemotherapy he was taking because his body couldn't tolerate it. He is slowly getting support with his pain and working out how best to manage that. Jeff is benefitting from the honest and open set up they have developed together around his 'using' and his pain medication (him, his GP and his support worker). Jeff sees his using and pain medication as separate. 'Being seen' taking the pain medication helps with some of the pressures associated with the 'loyalty code' of sharing gear. Building this relationship with his GP has also helped Jeff share his fear of being addicted to morphine after seeing his sister struggle with pain medication and pain relief; effectively using slow-release morphine with options for breakthrough pain. He is starting to share a little more about what is really going on for him.

Substance Use

Jeff has noticed his using has changed over the last few months, particularly his alcohol use. This has moved from a typical use whilst he was on the streets of around three to four bottles of sherry a day, plus heroin and crack concoctions, to a bottle of sherry one or two days a week. He is still using heroin and crack. Jeff is a caring, giving and kind man, something which is evident in the way he manages his addiction. Although he doesn't speak much of this, Jeff knows his drug using may become more difficult to support as his health deteriorates. As he becomes less well, he won't be able to uphold his end of the bargain with his using friends (the acquisition of drugs). That brings a level of vulnerability for him.

Relationships

Jeff says he 'distances' himself and can be seen to give off an air of 'stay away'. Jeff speaks with a sense of trust and respect, particularly of his support worker who looks out for him. He has a sister who he cares about and respects. He visits her at her home occasionally, but she never visits him at the Centre; he keeps them separate. When he visits, he minimises his using to spend time with her and her family. She isn't involved in the main bulk of his life, and he does not see her being part of his end of life.

All of his friendships and associations are deeply embedded within the drug scene; this invites a (possibly) more complex dynamic and sense of loyalty. Is it a friendship or a drug using association? Jeff is very clear about the distinction (and overlap). He speaks of a deep bond with his friend Terry; his first 'using pal' and longstanding mate. *'We look out for each other…we've been mates for over thirty years…we're together about 10 hours a day, that's more than married'*. Jeff is happy that he has moved his room to the ground floor and that Terry has moved to the room next door. Jeff knows he will be pushing himself to bring in the gear as long as he is able to. He is open but does not talk about the details of what this means and how it is really impacting on him – this is a tricky road for him (and Terry) to navigate.

End of life and what Jeff wants people to know

Jeff knows what he's got and that it's terminal; he's slowly settling into it. He sees the end of his days at the Centre. He does not want to move to a hospice. The Palliative Care Team offered support, but he does not want this. He is clearly comfortable with his support worker and trusts his GP to help him manage his pain, He '*Won't be talking to anyone else*'. He wants '*his own space and when he needs to be heard, he's heard*'. This is a big deal for him to feel settled in the Centre. He would like people to know that '*he hates 'nagging' or chivvying, and that he is thinking about things all the time whether you think he is or not*'. He most values honesty; '*Being told straight*' and '*hates bullshit*'. On the streets he was '*in control of his own destiny…no pressure*'. He feels he can trust that the Centre staff get that and mean what they say. Jeff's growing sense of trust may seem tiny or unnoticeable but has a massive significance on his quality of life and his end-of-life experience. He has found this a positive thing to be part of and is very glad he gave it a go.

Table 6 – Jeff - Key messages and insights[7]

Information, Identification and Assessment	
Clear, honest, and open; 'No Bullshit'	- Appreciates straight talking and being given options (GP and Oncologist). Don't assume 'not bothered' or not thinking about things (even though may not seem so). - Not pushing but watching for spaces – gentle, 'low key' and taking time for things to unfold. - Work with the relationships that are meaningful – don't assume who these are or who they should be.
Non-judgemental Practice	
Find points of connection	- Be mindful of assumptions - how people present is not often what is going on 'behind the scenes' (may be used to saying what think they should to get professionals off his case and shut down conversation) - Pay attention and explore what someone's interested in - see the person - Don't overly intervene; it's about understanding and acceptance; all about pace. - Notice when someone might be avoiding or 'swerving'; might be a message that something's not quite right

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[7] Linked to themes – Information, identification and assessment, Good non-judgemental practice, Support for staff, Support for family and friends

What trust looks like and how it is experienced	- Learn what builds trust with each individual (it will be different) and is likely to seem much ‘lower key’ - Sow seeds of trust over time and learn how to support when trust isn’t or doesn’t seem to be there. - It’s about being heard (on his terms); live and die in place he’s settled; carefully noticing what not to do.
Understand and accept who is important in the person’s life	- Likely to be nuanced and complex, especially around ‘using’ connections. Don’t push but don’t ignore either. - Gentle exploration of relationships, what they might mean and if/how they may be impacted by end-of-life experiences.
Pain medication	- Creating space and opportunities to look at this – how to safeguard against potential vulnerabilities (e.g., loyalty code / sharing gear - Stay open to hearing reactions may not expect e.g., fear of addiction & reaction to morphine
Support for Staff	- Personal care staff often carry weight of care (emotional and physical) – how can they be supported? - Build in opportunities for support from within organisation and external (e.g., supervision, access to palliative care support)
Support for Family and Friends	- Some people are estranged but not everybody is. May be in contact but not closely involved in end-of-life care. - How to support friends – e.g. Terry during and after Jeff’s end of life. Moving Terry to room next door to Jeff in hostel allows them easier access to each other and privacy.

Janet – Age 55 - Person with Lived Experience

Janet embraced her life as a woman in recovery from substance use and a woman living with cancer. Her experiences of both shine a much-needed light on issues that are seldom spoken of. Her courage to speak out and her commitment to her own well-being and care are testament to the recovery she held dearly. Her experiences in life and in dying serve to help others as she always wished. Janet began sharing her experiences during the early stages of the research. It was important to her to continue with this process; the experiences towards the end stages of her life and after her death have been conveyed through her close friend Carol.

Janet was in her mid-50s when she died from a brain tumour which she lived with for five years. This included active treatment, several years of remission and a number of recurrences. Janet’s experiences with substance use led her down some ‘*dark and twisting paths*’ over many years. Although open to talking freely around her earlier life experiences, she felt the richer focus was on the challenges and positives of her more recent past, particularly her experiences as a woman in recovery and navigating life with a brain tumour through services that *'don't get it'*.

Janet's journey

Janet began her recovery life in her late 40s, moving through an initial 12-week residential rehab programme followed by longer term community-based support. She was part of a positive recovery network through the 12 Step Fellowship, attending regular meetings. She had started to build up a small group of friends. *'I'd started to get my life back…I had my own place (through supported housing) and was back in touch with my daughter and granddaughter…then BOOM!'* Janet had been 'clean '(from heroin and cocaine) for two years when she was first diagnosed with a glioma brain tumour. Janet first noticed feeling wobbly and speech slurring… *'I knew something wasn't right, something was 'off' and I got a vibe that other people did too'*. Her friend Carol remembers having conversations with people in fellowship meetings about whether Janet was using again ' *–it does cross everyone's mind, it's easier to think that than a brain tumour'*. Although Janet said she understood this, she spoke with emotion about her sense of '*not being believed'* by family and people in meetings. *'It runs deep that feeling, especially when you don't know what's going on yourself'*.

Initial surgery was followed by a 12-month period of remission. Janet took an active role in her treatment and well-being following diagnosis. Carol recalls how she embraced her cancer treatment as she had her recovery' *…She did everything she could during this period to look after her own well-being, including exploring complimentary therapies, nutrition and meditation'*. A year later, she underwent a second surgical operation which she described as *brutal,* resulting in a very difficult and prolonged physical recovery as the surgery impacted on her speech, walking, and reading. *'This is where we really got closer and I leaned more into my recovery Buds* [buddies] *to get me about and help me with appointments, just living really.'*

Palliative care and support

Five years after the initial diagnosis, Janet had a seizure after which she was informed that she could no longer be actively treated and was, from then on receiving palliative care. During the final 12 months of her life, Janet lent increasingly upon her recovery friends for support. *'We became known as Janet's Posse'*; Carol remembers how clear Janet was about wanting to be at home rather than be in a hospice, '*She was very vocal about this and tried her best to get what we could for her, but it wasn't easy'…* 'She trusted us much more than the formal care support services she was provided'. Carol describes the experience as '*disorganised and insensitive'*, in particular around some of Janet's dealings with the multi-disciplinary team meetings.

Through her care and treatment planning, Janet expressed that she did not want to take prescribed opiate medications as she felt this impacted on her view of being "clean". A key issue for her was that she struggled to get her view accepted and acknowledged and felt it was merely dismissed as irrational rather than something to be acknowledged and worked through. No alternative analgesics were offered and this led her to believe that staff felt she was being awkward and 'non- compliant'. Janet did not feel understood or emotionally safe or able to work through some of these experiences. She was not connected with substance use services. Her recovery friends found this whole issue difficult too and struggled to identify with the position of the services and their lack of empathy and understanding. Some friends found this negative attitude quite triggering for their own traumatic experiences and found it difficult to work through their own issues too. For Janet, she felt she was not being heard and felt marginalised from her care and was angry. This had a real impact on her levels of trust and relationships with many of the care practitioners. This became more pronounced as her communication difficulties progressed.

Advocacy and control

Janet found the support of a voluntary agency particularly helpful in helping her express and record her wishes around her death and afterwards via the process of what she called her 'Living Will'. Although Janet spoke openly and often about her wishes, the reality of the situation highlighted the 'Advanced Directive 'as more of a box ticking exercise that seemed worthless when it was most needed. As Janet's sister was her Next of Kin, the default response of services was to communicate solely with her, with no formal recognition of the primary role the friends had. This caused significant distress and, Carol believes, a failure to carry out Janet's personal desires including the scattering of her ashes. *'We had been through so much together, and at the very end, I couldn't do this for her'.*

Table 7 – Janet - Key messages and insights [8]

Information, Identification and Assessment	
Train, support, and monitor the use of advanced directives	- Enhance the value and trust required between professionals and individual beyond a perceived bureaucratic process. - Provide clarity around who can be involved and how potential relational complexities may present (and be worked through) - Establish protocols across all potential services involved (including family and friends)
Non-judgemental Practice	
Recognise areas of particular sensitivity and 'charge'	- Understand personal experiences of being 'clean' and how this may impact for different individuals. - Understand the fear that you won't be believed and not actually being believed in relation to other health issues that may raise questions about whether or not you are using again. - Sensitive and open support and facilitation to connect with issues

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[8] Linked to themes – Information, identification and assessment, Good non-judgemental practice, Support for staff, Support for family and friends

Avoid or question potential myths and stereotypes	- Feeling by some that people with a substance use history don’t look after themselves - Services can be quick to go to a place of rationalising poor communication and fragmented care by displacing these failings upon the person with a substance use history as not being reliable as a user of their services. The fault then lies with the patient rather than the service, especially if they are angry about the poor quality of care they are receiving
Support for Staff	
Build greater participation in the development and review of the range of support services which could be involved	- Provide awareness, information and forums to share what works from people with lived experiences and users of services - Invest in real, robust and longer-term engagement and connection using approaches that are meaningful to the people involved
Support for Family and Friends	
Enhance support for friends	- There is a sense of powerless in helping a friend (when it really mattered). Was a key part of friend’s support circle over the years and person of trust / confidante. Understood concerns friend had around pain medication and the associations it brought up around ‘relapse’ and addiction (insights that did not appear to be understood or taken seriously by medical and care teams and friend’s relatives (a fractured and difficult relationship) - Understand the role that friends can play in the circle of support - Recognise and respond to the potential needs of friends in maintaining their own health and wellbeing (during and after the individual has died.

Sheila - Age 57 - Person with Lived Experience

Sheila lived with breast cancer for eight years, receiving care and treatment during this time from a wide range of services. A significant period of this time was during the metastatic, palliative phase, bringing her into contact with a wide range of services and care providers. Sheila experienced the impact of substance use within her own family growing up (that still remains). Although she had her own historical use of alcohol and marijuana that she described as ‘eventually problematic’, she was not involved with substance use services. *‘I found other things, other ways.*’

Sheila’s professional career had been in human services at a senior level. She was a strong advocate and activist for innovative development, quality and the central role of the experiences of people receiving them. As a result, she brought her insights with her when experiencing care and support from cancer services and was spurred on by the opportunity to share these. '*I didn't really know what it felt like to be dying when we first started talking… what people go through (referring to herself and the practitioners around her) – now I've got even more to say!'*

From Sheila's initial diagnosis she experienced a range of cancers and their treatments. Her journey was both long and difficult, some of the treatments were very punishing for her. As a result, Sheila had a protracted experience of being around health care services although it never defined her. Her life was rich and adventurous, creative and courageous. Sheila was ideally suited to the professional role she had as she was a great connector with people and had a strategic eye; this helped her during her cancer journey. Her final experiences and insights of services were drawn from across her experience, ending with her six-month relationship with the hospice where she finally died.

End of life and what Sheila wants people to know

Sheila spoke of '*having to take her GP to task'* to access the care and support she needed in the earlier days of her cancer and as her health changed. She found this extremely difficult despite knowing the system, how it operates and its problems. *'We're on good terms now and understand each other but it took time…it's different when you're doing it for you and not someone else – so much harder!"* She expressed huge concern for people who didn't know how things worked, how to navigate it or who were not able to advocate for themselves. '*People shouldn't have to fight or feel like they do – many of the people I know have been doing this their whole lives and are used to getting what they're given (or not, usually!)'*

For Sheila, this was not just about the patient themselves but it was vital to understand and meet the needs of their family and friends; to help them to best support their loved ones. As a result, she felt that people did not easily receive the holistic care and support they needed, '*They carry the brunt of things…my partner does, it's so tough. I feel I have to be strong to look out for them – we get by because that's who we are, but it could be easier…should be easier (and then I get angry!!)'.*

In the last six months of her life, as Sheila spent more time with the staff at the hospice, she realised that the formal carers also had to work too hard to be able to get the support they needed for themselves. She observed that these staff were not cared for or nurtured and this took its toll eventually had on their own well-being. '*There's just a culture that this is ok, everyone's under pressure and often don't have basic things like cosy places to relax and take a break. I know this isn't unique to here, but it's just so stark – they were running on empty and needed some comfort.'* This became a primary motivator to Sheila and her partner, '*to do what we do, be who we are…it has to be action, change, things we can directly impact'.* And so, they did!

Table 8 – Sheila - Key messages and insights [9]

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[9] Linked to themes – Information, identification and assessment, Good non-judgemental practice, Support for staff, Support for family and friends

Information, Identification and Assessment	
Support people to connect with and express what they need	- Share responsibility and awareness of how difficult this can be for people, especially when they are vulnerable and fearful. More community support and breaking down barriers that exist, creative and participative action to build skills and sense of worth. - Signpost to advocacy support and share examples of how this can work and help (skilled peer support).
Non-judgemental Practice	
Recognise the roots of defensive practice	- Create safe spaces to be open and honest around what creates and sustains defensive practice. Build cultures that allow challenge of colleagues with courage and compassion.
Support for Staff	
Look after staff!	- Invest in the care and consideration of all staff, especially those who work in more isolated environments (e.g. personal care workers, home based carers). - Better training, learning and support – many people miss out if they are part time or on sessional contracts.
Support for Family and Friends	
Work with individual needs and family dynamics	- Substance use may not be immediately obvious or linked to the individual themselves – often a long held 'secret' or area of denial. - Be open to opportunities to support the wider family to deal with their own issues (not about pushing but noticing and being responsive). - Access to trained and skilled support that understands the complexities of the family dynamics that play out – this helps the individual themselves not get caught up.

Danny - Age 56 - Person with Lived Experience

Danny's ability to lean on and into the strengths and assets gained through his journey with addiction and recovery were a great source of personal support for him, both emotionally and spiritually. He initially shared his experiences through his father's death, his bereavement process and then, unexpectedly, through his own diagnosis of cancer, treatment and care. His understated style and surprise that he might have anything worthwhile to share is honoured by the impact he had on those around him and his blessing for them to pick up the baton of his story.

What made him tick

Danny was a 56-year-old man with over a decade of recovery behind him. His long -term addictions to multiple substances had disconnected him from his family and “mainstream society” for many years. Unsurprisingly, Danny had a strong connection and empathy for people who had travelled a similar path to himself and a deep sense of the importance of, and challenges in developing a sense of belonging and trust. He found great peace when in nature, especially during the latter period of his life. Danny held a strong belief that people should be helped to develop a personal sense of agency and not simply fit into boxes that society and services expected of them; something he had been denied when he was at his most vulnerable in the past.

Danny’s lived experience as part of a recovery community, and a ‘seeker out ’of people who were most often overlooked were key drivers underpinning his time as a recovery community worker. Over time, he observed changes within the community as statutory and non-statutory agencies became more fragmented and reduced. Sharing his deepening concern for the impacts upon other people, who would not be able to draw upon the support he had received in his early and later recovery. Consequently, he moved away from working in the recovery community. *‘It’s all smoke and mirrors now – there’s so much shit around targets and saying things are happening that aren’t really, it makes me sad and angry coz some of these poor bastards don’t stand a chance’.*

During his recovery Danny was able to reconnect with his family and, in particular, his father. Consequently, when his father died, he was able to be with him at the end and was able to connect with his own grief by drawing upon his personal recovery experience. He felt he “*had the tools*” to be able to do this because they had been developed during his own recovery. *‘I could just hand it over and be where I am needed to be…that’s a miracle and I’m so grateful”.*

Diagnosis, treatment, and care

During the period of his father dying and Danny grieving himself, he started to become unwell. Initially he *“put off doing anything about it”. ‘I was wrapped up in the stuff with me old fella and, to be honest, I fucking hate going to the doctors, so I just ignored things, and then covid and you couldn’t go anywhere – I shut it down until I couldn’t fucking breathe an ’ had to go. I couldn’t believe we were talking about all of this and then I get cancer – I had to tell you!* ’His active treatment went on for a year before he learned he was entering palliative care. During this time, he spoke positively about getting well and how he felt he was luckier than some people who hadn’t been to the hell places he’d already experienced. *‘I can pray, I can tell people I’m shitting it’.* He planned his care and support jointly with services and was very happy about his experiences of this. Danny was actively involved in things such as his pain relief and where he wanted to die. *‘I think I’ve changed me mind – they’re not all bad (laughing) – I’m towing the line!* He was particularly proud of his relationship with his son. *‘He’s decorated me flat and takes me places – he’s a good lad coz he’s been through a lot with me.’* Danny died peacefully in a hospice, with his son and very close friends with him.

Band of brothers

‘We just wrapped him up and loved him… tried to give him the best time we could in his last months – the Band of Brothers on Tour!

His funeral was poignant and affirming; attended by family and many recovery friends who spoke warmly and openly about his life, the challenges he’d overcome and the dignity with which he conducted himself. He had a ‘*quiet, under the radar, but ever-present approach that made people feel relaxed and ok to be themselves*’. There was a huge sense of comfort and pride that he “died clean” [not using substances], acknowledging the skill, compassion and sensitivities of the staff who cared for Danny.

Table 9 – Danny - Key messages and insights [10]

Information, Identification and Assessment	
Raise profile of issues around Serious and Advancing Ill Health across people who may be less forthcoming	- *‘Be visible but don’t ram it down people’s throats – it makes ‘em run’* - See the bigger picture - build long-term support that helps people live, love, and learn.
Non-judgemental Practice	
Judging by who? Accept that judging goes on – by everyone	- Meet people where they are at – make it less formal or ‘medical’ - Work through people who ‘know the score’ and can just have a word in the right way at the right times’
Support for Staff	
Break down the ‘them and us’	- Tell them what it’s like (or can be like) for people who’ve lived ‘on the edges’ for many years. It’s not personal (even if it might seem like it is). - Shout outs when things have gone well…helps break down old experiences and know that things can change (but keep it real and don’t over sell it)
Support for Family and Friends	
Support families to help other families (but in their own way)	- Tricky and sensitive but can help with healing – that’s part of recovery. - Don’t make it all about talking and counselling– more laid back spaces where things just come out naturally.

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[10] Linked to themes – Information, identification and assessment, Good non-judgemental practice, Support for staff, Support for family and friends

7.2 - Family Friends and Carers (FFC)

Table 10 – Context and approach for family, friends and carers

Name	Context	Approach
Cath - 48 years (Partner)	Cath cared for her partner of 25 years. Both her and her partner had long term substance use histories and had been 'clean' for last 10 years. Cath shares her experiences of caring for John and the impacts it had on her own physical and mental well being	Informal conversations over a 3-month period. Partner had died 3 years ago. Cath had never spoken of this before.
Katie - 56 years (Friend)	Relationship developed through recovery/peer networks. Had a central role in friend's care. Shares around the 'gifts and costs' of this. Significant challenges around status of 'friend' during final stages of life. No formal support offered. Impact still felt (almost 4 years after death).	Shared experiences through several informal conversations over a 4-month period (not comfortable taking part in formal interviews). Recorded through field notes
Mary - 63 years (Mother)	Son lived with long term mental health (schizophrenia) and historical substance use (alcohol and other drugs). Was involved in mental health services (via Clozaril clinic) but not with an active Care Coordinator or Substance Use Services. Had loving relationship that respected son's boundaries and desire for privacy. Recognised significant gaps in his care in the last month before he died – health and care services not picking up on his acute needs (severe ascites) and end stage liver cancer.	Mother wanted her experiences to be heard – conversations towards the late stages of son's death and in few weeks afterwards.

Each case study includes a range of key messages and insights; these have been organised around the key themes emerging from project. Although these are specific to each individual, a number of common themes were evident across the collection and highlights a high degree of synergy with the experiences gathered through other channels. These include:

- A sense of having to 'fight' or being 'invisible/dismissed' in dealings with (some) practitioners and contexts. This includes the nuances and complexities of situations activating past experiences.
- Sensitivities and complexities around the handling of pain medication and its interplay with ongoing or past substance use.
- Moving beyond over generalised and less helpful positions – for example 'difficulty trusting' progressed to 'finding points of connection'.

Katie - Age 46 - Friend and Carer

Katie and her friend Helen met in the early days of their substance use recovery journey. They were part of a group of women who were all going through similar things. At the beginning they were not particularly close friends, but their friendship grew over time and developed significantly when Helen became more seriously unwell (with chronic respiratory conditions, heart problems and later cancer). Katie welcomed an opportunity to take time to reflect on her experiences of ‘*walking with my friend through some of the most painful and powerful times*’ she has had. ‘*There was an openness and honesty, a lack of judgement… we were able to go there and share things others couldn’t because we’d seen each other in our shit”.* Taking time to do this over a few months helped Katie hugely. ‘*I didn’t think I could do this or wanted to do it, something I’d just shut off…well, no one ever asked me about it*’.

Katie’s role in Helen’s care

Initially their contact increased through Katie providing practical support such as lifts to appointments, helping with shopping and so forth. Helen valued this support a lot. Although she had some contact with her immediate family, it remained at a distance and ‘guarded’. Katie knew that Helen carried a lot of ‘stuff’ around what her family really thought about her being sick and whether they thought she’d brought it on herself ‘ –*it was something she really struggled with*’. A deep sense of trust, grounded in their shared experiences and recovery experiences, meant that nothing was off limits; they could share both things from the past and also the present as Helen’s illness progressed. They had a safe emotional space to share their feelings about recovery, life, and many other things with each other but importantly for Helen it was also a safe space for her to share her feelings about dying. Whilst Katie describes this as a ‘*precious privilege*’ that she would not have changed, she also speaks of a weight of carrying this sometimes with no awareness of any support that she could lean on.

In Helen’s final year, Katie was very hands on. Helen trusted Katie with her care because of their relationship and also because many years before Katie had been a nurse. Katie was regarded by Helen as her “chosen family”. In the last six months they went through a period of what they called “making memories”. They went away on holidays, places were Helen felt safe, they went through a “bucket list”. They had fun and laughed together. ‘*It was life changing for me, something so beautiful and heart breaking*’. As Helen became more unwell and started to receive active palliative care Katie continued to be an integral part of that support. Katie worked hard to maintain a relationship with Helen’s mother but also felt there were ‘vibes’ between them that she couldn’t really figure out and made communication difficult at times. Helen died in hospital; Katie was able to visit her but was not with her at the end; something that she still finds difficult.

Following Helen’s Death

After Helen’s death, Katie had no real contact with Helen’s mother or other family members beyond the day of the funeral. Katie describes the deep hurt she felt and sense of aloneness. ‘*I struggled for a long time with the gaping hole – I still do… I just got on with things as best I could*’.

Table 11 – Katie - Key messages and insights [11]

Information, Identification and Assessment	
Develop and proactively share support available to friends	- Friends are not seen as a formal validated asset to be supported. The formal system responds to relatives whereas the status of friends does not formally get the response it often requires. - This is often regarded as ‘the way it is’ and not expected or requested – this does not indicate it is not needed or desired.
Non-judgemental Practice	
Take time to explore the experiences of people involved – create time and space for people to be heard.	- Services do not connect with friends unless it is functional, often practical things, and are not offered things in their own right in order to fulfil this function. Can be very upsetting and isolating. Katie merely wanted to speak about it and share her experiences.
Support for Staff	
Be more aware of what might be going on and don’t take everything on face value	- Relationships between families and friends can be complex, especially if there remains unresolved and (often) unspoken hurts, fears and resentments from the past. Whilst this is not unique to the context of substance use and end-of-life care, it may be outside the experiences of many health and care practitioners.
Support for Family and Friends	
Recognise friends as ‘Chosen Family’	- Not all “recovery friends” have a deep bond like the one described here but where it does exist, this can be very powerful for the friends involved. It is often linked to a shared sense of reciprocity and looking out for each other. - The closeness of this bond can carry a particular weight of responsibility that needs to be supported. - The sense of loss and grief can be underestimated by people outside of this, especially if it is something the person cannot articulate to others. Others may not see where the friend’s grief is in the same way they might do with the family.

Cath - Age 52 – Partner and Primary Carer

Cath and her partner John had been together for over 25 years when John died. *‘We’d seen it all, the highs (literally), the lows and the ‘can’t get lower than this’ times…or so I thought!’* Cath’s partner had a range of health care issues including COPD and lung cancer. Cath also

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[11] Linked to themes – Information, identification and assessment, Good non-judgemental practice, Support for staff, Support for family and friends

has her own health issues too (respiratory disease and PTSD) and has struggled with her own health while caring for John. *‘I promised him I would keep him at home and not let him die in hospital - he was petrified… he hated everything about them (me too). It nearly killed me, but I did it.’*. Cath took time with her decision to take part in this research, speaking over the phone in small chunks of time, a gradual unfolding. ‘*I’ve never spoken about this before, to anyone – I’m scared of talking about it now in case I can’t cope with what comes up – thank you for taking such care, I can feel it - I want people to know (not for me but so other poor bastards don’t have to go through what we have).*’ Cath chose the areas she most wanted to share.

Support and Care - How it was for her

Cath felt a deep sense of isolation and a great weight of caring responsibility, particularly during the palliative period of her partner’s end of life. She realised she was a crucial part of his care and support but felt inadequate, minimally held and supported in this role. Cath recognised that to a large degree she withheld her true feelings about this, and it brought up complex emotions as a result. *‘All the feelings came rushing back… I didn’t know what they were, I didn’t know what to do…I still don’t really, and it’s been nearly three years since he died’.*

She had limited knowledge of how to respond to the increasing needs of her partner and felt she had to learn for herself, for example how to respond to extreme pain he experienced. ‘*We’d been clean for over 10 years… it reminded me of the dark days when we were both using, getting clean and relapsing…the rattle and screams of coming off gear*’ Cath spoke of her distress and distrust of people who were supposed to be helping. In particular, she recalls her begging for someone to help John with his pain and his breathing. *‘I think I got paranoid in the end that they thought I was taking stuff, his painkillers…nobody ever said it, but I felt it…. especially from some of them’*. She describes their ‘*using past*’ *as* ‘*the elephant in the room*’, never knowing if it was something to talk about, if it was ok or how it would be used.

When things got really bad, she finally told her GP that she wasn’t coping; she was angry that his first response was to suggest anti-depressants. ‘*I wasn’t fucking depressed, I needed help. I was drowning and nobody seemed to notice or care.’* On reflection Cath now believes she needed her own therapeutic support. She doesn’t remember if it was offered or, if it was, whether she was up for taking it. ‘*We were in that “us against the world”’*. This insularity increased her sense of feeling alone. She and John were loners, not part of the substance use recovery scene. *‘There’s a lot of crap talked; people want to say things to help but it just makes it worse’*. She recalls how triggering it was when a couple of people she knew from recovery networks came and were talking about how we were going to beat it (the cancer). ‘*I just wanted to scream – he’s fucking dying!*’

Table 12 – Cath - Key messages and insights [12]

Information, Identification and Assessment

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[12] Linked to themes – Information, identification and assessment, Good non-judgemental practice, Support for staff, Support for family and friends

Practical resources - made with 'people like us' in mind	- Ways to share experiences and information on what to do. *'All the stuff I looked at on the internet showed shiny pictures of families, not people like us who were carrying years of crap. I needed to trust that someone got it, got me'.*
Non-judgemental Practice	
Get to know people – spend time being around people who've gone through what we've gone through.	- Let people know we're human…fragile and sensitive. *'We're not a different species'* - Bring together people who work in health and care with people who have experienced substance use, how it feels and how it leaves scars.
Support for Staff	
Better understanding and guidance of when and how to talk about substance use	- Understand what it can feel like to be asked or not – - Is it safe? - Is it relevant? - How will it be used?
Support for Family and Friends	
Take time to follow up and check in on people after the person has died.	- Go beyond the 'survival' stages of just getting through it. *'I've shut that box tight again now – I can't go there again…but it might have been something I would have tried if it was done right.'* - Specialist bereavement workers who know how to support people who've got histories of trauma, stigma and trust issues.

Mary - Age 63 - Mother

Mary's experience brings to life the complexities of meeting the holistic needs of individuals and family members in an integrated and co-ordinated way. A lack of overall responsibility, effective communication or compassionate care left her son in an extremely vulnerable position that led to unnecessary suffering, especially in the final weeks of his life. This has caused frustration, anger and distress across the wider family. Here, she highlights the lack of advocacy and skilled, sensitive support that should have recognised the situation and responded appropriately both for her son, herself and the rest of her family.

Mary and Josh

Mary had a loving relationship with her son Josh, grounded in a deep respect for his desire for privacy and how he lived his life. This was not an easy path for either of them to have trod. Josh was 40 years old when he died; a gentle and sensitive soul who lived with schizophrenia from his late teens and had worked through dependence issues with alcohol. He no longer drank or smoked. Josh lived alone and preferred to spend his time in the workshop he had created working on various creative projects. His regular contact with services was through the Clozaril Clinic where he had monthly blood tests as part of the monitoring protocol for his medication. Josh attended regularly and managed his medication himself.

Mary retired from a long-term career across many areas of health and social care. A nurse by profession, she had worked extensively in service development and was well attuned to how care systems operated. On a personal level, Mary's own long-term recovery (from alcoholism) deepened her insights and she had worked through significant issues around her relationships and the maintenance of boundaries.

'Nobody joining any dots…"

Josh had shared his diagnosis of liver cancer with Mary a few months earlier. Mary knew that this was a significant thing for him to share with her (with anyone) and she knew to walk lightly alongside him, being there if and when he invited her in. As Josh's health deteriorated, her concerns for his wellbeing increased as she recognised there was no one really looking out for his overall care. With Josh's consent, she was able to advocate on his behalf. It was Mary, not any of the services that helped Josh get what he needed. This finally resulted in Josh moving into a hospice in the last few days of his life where he could find some sense of relief.

Mary felt that if the system had owned his care holistically, he may have been able to experience a better death than he did. Although she is reluctant to share too much about her own distress, it is clearly evident as she speaks. She was very frustrated by the lack of services picking up on issues he was facing such as his liver cancer with everything identified and dealt with separately rather than as a whole. She hopes her inputs shine just a little light on some of the practical ways she believes her, and Josh's experiences might help move forward.

Table 13 – Mary - Key messages and insights [13]

Information, Identification and Assessment	
Information and flexible ways to respond to health and social care needs	- Josh was reluctant and uncomfortable around people – options of how to access support that was sensitive to this were not explored.
Non-judgemental Practice	
Recognise and address the need for advocacy and support (where people are particularly vulnerable)	- Sensitive and proactive communication that goes beyond the physical aspects of care - Josh was turning up for appointments and doing what was asked but was left vulnerable and unsupported to advocate for himself or work out what his options might be.

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[13] Linked to themes – Information, identification and assessment, Good non-judgemental practice, Support for staff, Support for family and friends

Support for Staff	
Awareness raising and support to understand the complexities faced by individuals and the people around them	- See beyond the presenting issues (e.g. the symptoms of Josh's cancer) - Notice when things may need following up – Josh was attending the Clozaril appointments with a growing ascites (a visual symptom of liver disease) – it was not picked up or addressed.
Support for Family and Friends	
Be proactive in following up support	- Provide resources and opportunities for families to independently access support – work through ethical and consent issues.

What is particularly stark through the experiences here, is the (potentially) more central role that friends play in the bigger picture. This 'plays out 'in various ways throughout each of the scenarios highlighting, unsurprisingly, a need for greater understanding and exploration of the strengths and challenges around this area.

To summarise, this chapter has presented seven case studies powerfully highlighting the needs of people with lived experience and those of family and friends supporting people at end of life and with a current or previous history of substance use. Their stories have illustrated the ways in which people with experience, be they individuals or family and friends, can lack support and care. The negative toll this takes on their physical, mental and emotional wellbeing could be minimised at worst and avoided at best. A key theme running throughout the case studies is the need for greater understanding and sensitivity by professionals. There is a need to take time to listen, hear, empathise and support, and to understand that not every individual or family member will present their needs in the same way.

Chapter 8 - Training and dissemination

The implementation of the new approach to caring for people using substances near the end of their lives involved a training component. Prior to the training participants were asked to complete an online survey questionnaire to determine their responses in a range of dimensions. This was sent to their managers for dissemination to them via email and/or the link was placed in the ‘chat ’facility within MS Teams software at the start of each online presentation.

8.1 - Training and dissemination: survey results from T1 evaluation *(Author: Lucy Webb)*

The evaluation of training used a bespoke 25-item questionnaire (see appendix 7), to be performed before receiving training (T1) and within six weeks of training (T2). T2 aimed to capture application of training as well as acquired knowledge and skills. As Covid reduced the opportunity to conduct a follow-up survey at T2, only T1 data were analysed.

The bespoke 25-item questionnaire was developed to measure five domains of training from five items for each domain:

A. Expectations/attitudes to people using substances/end-of-life needs
B. Knowledge and skills
C. Confidence managing people using substances and end-of-life care needs
D. Role acceptance (legitimacy, adequacy, support, engagement)
E. Practice change

A Thurstone unidimensional scale (agree/disagree) was adopted. Items were reviewed by the research team and consensus agreed on wording and relevance to domains. Analysis was conducted using a straightforward sum/percentage and z-test for one proportion.

There were 42 trainee responses of which 33 provided complete questionnaire responses. In total, 33% (14) were social care/housing staff, 28.6% (12) mental health staff, 12% (5) addictions, 14% (6) palliative care, 9.5% (4) healthcare, with one unknown.

Domains

Mean calculations of each domain, where low scores/means represent positive findings, show that role acceptance and practice change were rated as most problematic by respondents, while expectations and attitudes to managing patients/clients with comorbid substance use and end-of-life needs were high. Table 14 reports positive scores for knowledge and skills, confidence in managing cases, and expectations and attitudes towards these clients among trainees generally, but there were higher (more negative) scores overall for role acceptance and practice change.

Table 14: mean scores for training needs domains

Domain (N=33)	**Sum domain score (from 5 items) (%)**	**Mean domain score (out of 5)**	**Std deviation**
Expectations/attitudes	70 (35%)	2.12	1.08275
Knowledge and skills	85 (42.5%)	2.58	1.41488

Confidence in managing cases	74 (37%)	2.24	1.78589
Role acceptance	126 (63%)	3.82	0.80834
Practice change	103 (51.5%)	3.12	1.53618

Care role

Mean comparisons between care role suggest that role acceptance is rated somewhat negatively by all professional carers (mean range = 3.60-3.90) (Table 15), and all except those in addictions services (mean range 1.60- 2.75 vs. mean = 3.20), impose high expectations on their practice and service to manage people with dual needs. This is supported by staff members ’confidence rating in managing comorbid patients, again with the exception of addictions service staff (mean=3.00). Staff members from addictions services and palliative care appear to have more confidence or belief in making practice changes (mean = 2.20) than those in mental health (mean =3.50), social care (mean = 3.44) or general health services (mean = 3.75). However, low numbers across the care role cells makes these comparisons suggestive of potential trends only.

Table 15: Mean comparisons by domain and care role

Care role (n)	**Expectations/ Attitude Mean (0-5) (95%CI)**	**Knowledge and skills Mean (0-5) (95%CI)**	**Confidence in managing cases Mean (0-5) (95%CI)**	**Role acceptance Mean (0-5) (95%CI)**	**Practice change Mean (0-5) (95%CI)**
Mental health (10)	1.90 (1.19-2.61)	2.60 (1.63-3.57)	2.10 (1.18-3.02)	3.90 (3.37-4.43)	3.50 (2.59-4.40)
Addictions (5)	3.20 (1.84-4.56)	2.40 (0.52-4.28)	3.00 (0.37-5.63)	3.80 (3.24-4.36)	2.20 (0.58-3.82)
Palliative (5)	1.60 (0.49-2.71)	2.40 (1.29-3.51)	1.80 (0.18-3.42)	3.60 (2.49-4.71)	2.20 (0.58-3.82)
Social care (9)	1.78 (0.94-2.62)	2.56 (1.40-3.72)	2.00 (0.37-3.63)	3.89 (3.63-4.14)	3.44 (2.11-4.78)
Health general (4)	2.75 (1.95-3.54)	3.00 (0.67-6.67)	2.75 (-1.43-6.93)	3.75 (0.74-6.76)	3.75 (0.74-6.76)

Discussion

The low numbers of respondents make analysis unreliable but may give indication of where there may be issues for some services. A strength of these data, however, is that staff members represent a range of service providers within each care role (with the exception of primary care), and therefore findings may not simply represent specific issues within individual services.

The negative ratings of role acceptability and confidence in managing people with co-existing needs support the notion that staff are experiencing difficulty in managing complex clients and yet have an expectation that they should be able to deliver care to this client group, which is rated as positive. It is also interesting that addictions service staff do not place expectations on themselves to manage end-of-life clients, in comparison with other services. This may reflect the current policy emphasis in substance use services that focusses on prevention, treatment and recovery from substance use rather than management and harm reduction (Black, 2021).

Practice change beliefs may differ between statutory and 3rd sector services, as these data indicate a split between addictions/palliative care staff and social care and health staff, whereby the latter have more positive scores. Addictions and palliative care staff in this cohort where mostly from 3rd sector providers, while health staff were from NHS services. This difference therefore could be indicative less of the role per se but of the organisations in which staff work.

This element of the project was intended to capture change in performance following training in end-of-life care for people with histories of substance use. Without a follow-up survey post training, there is currently no comparison between pre training and post training. The findings do, however, give some insight into different care roles and staff preparedness to manage people with comorbid health needs at end of life.

Overall, these findings should be interpreted with caution due to low numbers and lack of power in the analysis. However, the findings present further questions about the different policies and organizational cultures within services that should be further explored.

8.2 – Training and dissemination sessions

The training presentations provided a brief overview of the issues raised throughout the research with some powerful testimonies from participants. It introduced practitioners to the new model, how it had been developed and the resources in place to support it.

As with all aspects of this project, the training programme was negatively impacted by the ongoing pressures of Covid-19 on staffing levels and pressures of workload in the social and health care agencies working with us. One example was arriving to a morning face-to-face training session to be told they had to pull staff from the training to cover other staff who had phoned in sick with Covid. Given the staff were dealing with people approaching end of life, people needed to be seen and therefore, understandably, they took priority over the training.

Even with the challenges facing social and health care, and the research team, 164 people were trained from across 11 social and health care providers in Liverpool and Sefton. Table 16 (below) sets out the organisation, mode of delivery and numbers attending each training.

Table 16 – profile of training offer

Organisation	Mode of delivery	Number attending
Specialist GP service	Online	14
Housing service A	In person	16
Housing service B	In person	8 (max no.)
Hospice A	In person	10
Hospice B, session 1	In person	9
Hospice B, session 2	In person	8
Adult social care service A	Online	16
Adult social care service B, session 1	Online	13
Adult social care service B, session 2	Online	22
Substance use service A	Online	10
Substance use service B	In person	17
Community palliative care, session 1	In person	7
Community palliative care, session 2	In person	0 – cancelled due to sickness and staff cover
NHS team A	Online	12
NHS team B	Online	4
NHS team C	Online	6
	Total to date	164

The training focussed on demonstrating and disseminating the resources available. Sessions were 1 or 2 hrs long depending on how much time the agency could spare and while the core information was the same, they were also tailored slightly for audiences in different specialist areas of practice. (See appendix 6 for example of training presentation.) Hard copies of the resources were also requested as well as online access and these were handed out at training sessions or posted to people following online sessions.

8.3 - Feedback on training and resources

While T2 data collection was not possible, the feedback in the ʻchat ʼfunction on MS Teams and the unsolicited emails received from participants suggest that many people had highly valued the training. Examples included:

Community Assessor – Adult Social Care

“Thanks for the training session today, thought it was great. Very informative and interesting. I’ll be accessing the website for some reading.”

Team leader – Social care charity
“Thank you so much for all your work on this area, it was a real pleasure to listen to you today – I found it interesting, thought provoking and inspiring … . It really was enlightening to listen to some of the research, I have no doubt you will make great strides in this area and wish you the best of success. … What a great team of experts! … Good luck with your research, your work is greatly needed and your contribution invaluable. It was a pleasure to hear what’s going on.”

Service manager – Housing
“ Thank you from us…I’ve had some very positive feedback…I look forward to seeing where we can go with this work.”

Service manager – Substance Use
“It's been a great project … . I am committed to improving services for those who are at the end of life so the work that you have undertaken has been extremely valuable and will have changed processes for many.”

Safeguarding social worker – Adult Social Care
“Really interesting and useful.”

Learning and development officer – Adult Social Care
“Really good session… so impressed with the work that has been done and the resources developed”.

Duty social worker – Adult Social Care
“Thank you for today, the training course was really helpful and informative.”

Consultant – Palliative Medicine
“Everyone found it incredibly valuable and it has already been shared with colleagues across the hospice.”

Nurse – General practice
“Currently the service from your vision would be a massive asset and something I am passionate about … Keep up your amazing work!!”

8.4 - Community dissemination process *(Author: Amanda Clayson)*

Establishing a core group of ‘Connectors ’extended the commonly adopted training event to a more dynamic process, designed to both ‘share ’and generate ongoing engagement and ‘life ’to the work of the project. Six individuals (three male and three female) formed the team, each bringing a particular contribution to the process. All six were people with extensive lived experience of their own substance use and recovery. All were actively embedded across a range of peer communities and networks. Although most were also involved within substance-related work across a wide range of contexts (supported housing, recovery and rehab, social support), there was a clear distinction made that their involvement was grounded within a peer, lived experience context. The approach involved:

- Engagement with the project themes, outcomes, and focus
- Immersion in the materials and resources
- Activities to share this across their own personal networks and contexts
- Serve as a point of reference and ‘spread the word’ after the official project team had ended.

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Individual sessions between Connectors and the VoiceBox Inc were built upon via an in person gathering at a familiar Recovery Friendly Social Space (The Brink) in Liverpool City Centre. The ability to ‘gather ’in an informal space, over food and refreshments proved extremely positive contributor to the participative process. Many Connectors invited others and shared openly and actively.

Each Connector received a Resource Pack including:

- Tailored presentations which could be used in a range of contexts
- A supply of hard copy resources (Pocket Guides, Posters etc)
- Background supporting materials to extend their own awareness and understanding of the project area.
- Posters developed to help them connect and communicate.

Flexibility and clarity around their role, and a lack of direction on how they needed to carry this out has proved powerful in sowing seeds and rippling the messages of the project. Positive feedback on the evening of the gathering has been built on further through ongoing contact, requests to know more and a raised awareness and profile of the issue. Examples include:

- Personal comments of how the themes have ‘touched’ people, sparked wider conversations and identification of people experiencing some of the issues raised by the work.
- Informal (and more formal) ways of sharing; for example, having a coffee after a 12-step meeting with a couple of people, talking with a friend, to raising it at workplaces and requests for speakers and more information.

Ongoing support has also been built into the approach, with a member of the PEAT acting as a point of contact. This will retain a connection with the project team (MMU and VoiceBox Inc) after the project has ended. This is particularly valued. It also has the potential to build ‘lived experience ’capacity for ongoing participation in any continued development of local practice and/or research activity.

8.5 - Resource dissemination – next steps

Since the start of the original project in 2016 we have had interest regionally, nationally and internationally. The next steps for dissemination is therefore to capitalise on this interest and develop far wider dissemination through research and practice networks.

We have also had interest in developing and delivering training. We have built on the project training sessions and are currently piloting an online training package in partnership with Alcohol Change UK. We intend to develop this and offer it out more widely to people from all areas of social and health care. This would need funding from delegates or through further grant money.

We will also be setting up an international network of practitioners and researchers working in this field. Initially this network will be established using an email group but further consultation may lead to an online resource or forum through media such as Facebook.

Plans are already in place to publish findings within the trade press. Our team comprises people from health and social care and therefore our reach across those professional magazines and journals is considerable. We currently have dates/deadlines booked to disseminate our work through Drink and Drug News (DDN) and Community Care Inform.
We are also writing for peer reviewed journals. We have been invited to submit to a number of high profile journals and writing is underway.

We also plan to expand our resources to minority ethnic groups/migrant communities. This will involve a process of consultation to determine whether our existing resources are culturally appropriate and, if not, to determine how best to develop new resources. This may include translating them into other languages.

Finally, part of our dissemination effort during the project timeline was running online practice forums and family forums in response to the model of care participatory workshops. These should be continued and we will work with partner agencies to see if they will take a lead role in taking them forward.

Chapter 9 – Discussion and conclusion: taking the research forward

In this final chapter, we will reflect on what we know, what we found and learned through this project, and the work that is still to be done at research, policy and practice levels.

9.1 - What we know

The evidence shows that palliative and end-of-life care for people using substances is a new area of research and practice development. It brings together two core facts:

i) most people in the western world are living longer and, as a result, are taking more social and health care needs into older age (World Health Organisation 2022)
ii) alcohol and other drug use trends show we have an ageing population using substances and, consequently, experiencing the harm associated with long-term substance use (Crome and Crome, 2018).

The hypothesis underpinning this research is that this combination of facts, together with the limited evidence base, suggest our social and health care services will increasingly see people requiring palliative and end-of-life care where substance use is a feature of their life, either past or present. They, and the systems within which they operate, need to be ready.

The core principle underpinning this research is that everyone deserves a ‘good death’ and that people using substances deserve the same choices, respect and care as anyone else. What our research shows is that this is generally not the case (Galvani, 2018; Witham et al., 2019). With some exceptions, people who use substances are often seen as difficult and non-compliant at best, and undeserving, abusive and violent at worst.

We know that people who use substances are one of the groups of people who face health inequalities. Their needs are often overlooked due to a lack of understanding and empathy from service providers who are uneducated about substance use and ill-equipped to respond other than within the systemic boundaries within which they work. This ignorance extends to policy development that prioritises numbers and targets as measures of success at the expense of services that provide a depth and quality of care that embraces the needs of marginalised groups of people.

Even in the literature that highlights marginalised groups of people falling through gaps in palliative and end of life care, people who use substances are not included (Care Quality Commission, 2016, 2017). In the substance use field, policy and practice are still dominated by a recovery discourse (Black, 2021) that, at best, is insensitive to the needs of people reaching the end of their lives or, at worst, does not even recognise this population at all. In addition, there is no research that identifies the role and support needs of family members of people using substances approaching the end of their lives; even though family (or friends) are often the primary carers for people with ill health (Morris et al., 2015) and for people using substances and experience stigmatised bereavement (Yarwood et al., 2018).

What the evidence also shows is that alcohol and drug deaths are at an all-time high in the UK (Office for National Statistics, 2021, 2022). While there are likely to be several contributing factors, including a decade of cuts to Government funding for substance use services, increased alcohol use during the Covid-19 pandemic, and the ageing population of people using substances, this situation is not going to change overnight and is unlikely to change in the near future.

What this project, and its predecessor (Galvani, 2018) set out to achieve, was to raise the profile of this group of people within health and social care services, identify good practice where it exists, and develop a new approach to care built on the evidence base and the lived experience of individuals and families who have participated in our research. It sought to determine whether a new approach would improve access to palliative and end-of-life care for people using substances and their families. It also sought to ensure professional care givers felt better supported to work with people with substance use histories and life-limiting and terminal illness.

9.2 – The Covid-19 challenge

Unfortunately, this was a research project taking place during the Covid-19 pandemic, relying on social and health care providers from our 10 partner agencies to participate and, in some cases, to act as gatekeepers to people with lived experience, be they individuals or family, friends and carers (FFCs). At a time of a global pandemic, these agencies were either prevented from working in the ways the project needed to access participants or they were at their busiest, and had zero capacity, physically or emotionally, to take part. This meant that the involvement of one of our key partners, Mersey Care, was extremely limited as research was put on hold. Even where the partner agencies had adapted their working, it meant that face-to-face contact with individuals and FFCs was not possible. While the result of this was that two of our original aims were met only minimally, we were able to collect some baseline survey data from professionals, conduct the participatory workshops to develop the theory of change and model of care, continue online interviews and focus groups with some participants, and spend additional time developing the website and a large amount of resources. Face-to-face and online training and dissemination sessions were held in 2022 based on the preference of the participating agencies.

9.3 - What we achieved

- In keeping with the co-productive methodology, the PWLE research members organised into what was known as the PEAT (People with experience advisory team). This core group drew from their own specific lived experiences and, where possible, linked in with wider lived experiences from the people around them.
- Specific focus and participation of the PEAT team included the development of research tools, the theory of change and model, collection of case study data. All research outputs were co-produced. This included final report writing, resources and tools. The PEAT planned and facilitated a community facing dissemination process, building a wider team of connectors to take forward the research across formal and informal lived experience networks. Participation in carrying out interviews and questionnaires (as originally planned) did not happen due to the consequences COVID pandemic.
- Four participatory workshops were held online to develop the theory of change and model of care, supplemented by email contact with participants. The theory of change reflected the need for much improved service provision that is both compassionate and

non-stigmatising. This requires system change, additional funding and resources, as well as individual training and strong leadership.

- The Model of Care developed in the workshops was discussed, drafted, redrafted and agreed. The challenge was taking the large amount of ideas and identified need and consolidating it into a model. The content of the final agreed model ranged from practical to aspirational. In the context of short, medium and long-term outcomes, the focus of a time limited project was necessarily the short-term outcomes. These became the focus for the project and involved supporting people to have the conversations about end of life (terminology changed to serious and advancing ill health – see s. 4.1), substance use and advanced care planning, to have consistent advocacy for people using substances approaching end of life, to promote non-judgemental and empathetic practice, and for practitioners and family members to feel better supported. Our task was then to combine this with the qualitative and quantitative data collection and provide the resources to address the short-term outcomes of the model of care.
- The survey data from social and health care professionals found differences between disciplinary groups as to the level of interdisciplinarity. Palliative care staff rated the lack of interdisciplinary working as most problematic for their clients. Access to palliative care was rated as most problematic by social care staff. Social care staff also rated psycho-social-spiritual problems as most significant for their clients than colleagues from other disciplines.
- The differences identified in the quantitative data were confirmed by the qualitative data. Many gaps were identified between health and social care particularly in relation to the complex care required for people using substances approaching end of life and the coordination of multiple services, e.g. hands-on personal care could not be provided by housing workers. The differences highlighted the focus of care was often on medical needs rather than more holistic wrap-around care.
- The focus group data demonstrated how professional boundary concerns and a lack of training negatively impacted the care of people with complex needs. The lack of appropriate accommodation for people approaching end of life and still wishing to use substances was problematic in providing quality care.
- The managers also agreed that integrated and inter-agency working was inadequate. There were mixed views about the number of people approaching end of life using substances, however given the lack of routine questioning, lack of training and lack of monitoring, any perceived number was likely to be underestimated.
- Managers reported that current service responses were limited and variable, however, they agreed there was more to learn and to do particularly in relation to improved knowledge and a clear policy framework to support clear pathways to care and overcome stigmatising responses.
- The need for specialist supported accommodation and specialist roles to act as a bridge between services were identified by all managers, as was the need for family support as this was completely missing from current service provision.
- There was some development of existing services reported by the managers with initiative taken by strong innovative leadership at an organisational level. Commissioners were identified as having a role to fill gaps in service provision.
- The need for staff support was recognised through formal means, e.g. training and supervision, and informal means, e.g. peer support. Examples of training requested included understanding more about health conditions that are terminal, how to have

conversations about end of life wishes and Advanced Care Planning and how to support people who want to continue using as they approach end of life.

- The managers all agreed that the goal of care was to support people dying with dignity, respecting the person's choices, offering needs-led care and minimising pain in an environment of the person's choosing.
- The need for information, knowledge, training, and good practice examples was a shared message from the participatory workshops and the participants from the qualitative and quantitative data. This did not just apply to professionals but also to people with lived experience, be they individual living with substance use and end of life care needs or family members.
- The seven in-depth case studies powerfully portrayed the ways in which people with lived experience lack support and care and the detriment this caused to their physical, mental and emotional wellbeing. The need for greater empathy and thoughtfulness by professionals was a clear message as was understanding that people present for care in very different ways and require flexible and considered responses.
- The case studies also reflected the lack of resources for people with lived experience. They also pointed out that the current approach to care was trying to fit people into existing services rather than being flexible and needs-led service provision.
- We developed a comprehensive online and face-to-face training and dissemination programme, reaching 164 people across 11 agencies. This programme was restricted to our partners and close associates but is being developed and piloted for a wider audience.
- The pre-training survey gave some insight into different care roles and staff preparedness to manage people with comorbid health needs at end of life. It noted variation between substance use and palliative care staff and other health and social care staff when it came to views of practice change. However, given the number of responses were low, these data need to be treated with caution.
- A project website was added to the resources planned for the project. It was developed to host a large selection of resources for professionals, family members and people with lived experience (see sections 4.3 and 4.4 above). Currently there are more than 40 podcasts, and more than 17 different publications aimed at the three groups of people who are the focus of this research. It also hosts reports from the first, exploratory project, the good practice guidelines and the policy standards that predated the current project.
- In addition, six support forums were held, three for practitioners and three for family members. The family members forums did not work. We conclude these need to be run by family focussed organisations who carry more credibility than academic hosts. The practitioner forums ran very well and there is an appetite for these to continue. Discussions are ongoing with partner agencies about co-hosting both forums.

9.4 - What work still needs to be done

This research project, along with its predecessor (Galvani, 2018; Witham et al. 2019), has highlighted the dearth of research on this topic. Far more evidence is needed, both qualitative and quantitative, to document the extent of the issue and to determine the appropriate service response. Beyond this there needs to be evaluation of the pockets of good practice and innovation that currently exist, putting the voices of people with lived experience, including family, friends and carers, at the core of those projects.

Much of the negativity relating to current service provision relates to the stigmatising and judgemental attitudes people using substances experience when in touch with care services (Black, 2021). This serves to keep them away or to leave services earlier than medically advised. It also relates to the lack of joined up and interdisciplinary working and the inflexible and boundaried roles within which staff operate. The danger is to interpret this lack of joint work and resistance to step over boundaries as the responsibility of individual practitioners. This would be an error. While each member of staff has responsibility for their own manner and attitude, they are often working within services and in environments that are over stretched and under rewarded. There needs to be change at a systems and structural level. This change is enacted through policy development, innovative commissioning and strong leadership. There needs to be policy engagement in this work (Galvani and Wright, 2019) and that policy work needs to be ‘joined up’ in order to drive (and model) practice change.

Chief among these changes at system and structural levels is the need for specialist accommodation and specialist services and roles to provide an empathetic service. Just adding extra training and demands on the time of existing staff is not going to work. For training to be beneficial, the organisation has to support the changes needed and to do so requires commissioners to allow for innovation, challenge and change without fear of services being decommissioned.

Our conclusion is that while small scale changes can be made on individual and organisational levels, there is a need for a separate service to focus on caring for this group of people, who understand their lifestyles and needs and are able to work well across disciplinary boundaries. This would also serve the purpose of reaching the medium and longer-term goals identified in the model of care (see s. 4.3).

Galvani et al. (2022) propose the development of a ComCAS model, Complex Case Management and Assertive Outreach model (see Figure 4 below). The model proposes a co-located team of experienced professionals from different disciplinary backgrounds who offer a case management, training and outreach service. This would not only ease the pressure on existing services but would allow truly interdisciplinary working and mutual understanding. This could then be shared with the wider professionals from each discipline by the ComCAS team member that shares their particular discipline giving credibility to the model and spreading a wider understanding of the pressures, priorities and roles of other disciplines that may be preventing routine interagency and interdisciplinary working.

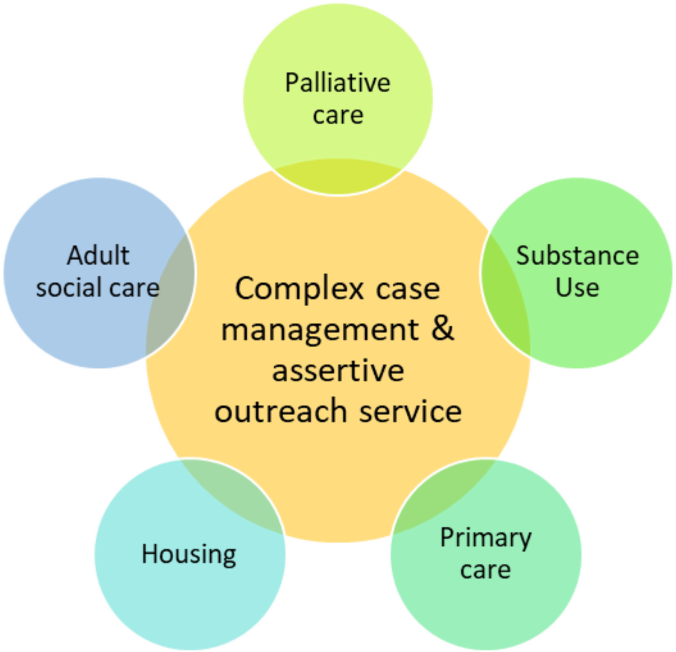

Figure 4 – Complex Case Management and Assertive Outreach model (Galvani et al., 2022)

Galvani et al. (2022: 185-186) suggest the ComCAS service would comprise:

- experienced professionals with expertise in multi-agency working and collaboration as well as expertise in two or more complex needs
- a case management approach to ensure consistent and coordinated care for people with multiple needs that works alongside each of the partner agencies
- an assertive outreach component to reach people facing health inequality, and who are currently excluded from services due to a range of barriers
- co-location for ease of communication and shared knowledge
- commitment to information sharing, transparency, developing shared tools and coordinated intervention
- an agreed leadership and management structure
- a commitment to joint training and education within single service teams.

Such a model will maximise the care for people approaching end of life using substances; a service that is responsive to their needs and the changes in their behaviour and lifestyle as their illness progresses. It will also maximise the care for people for whom a ‘good death’ is neither a priority nor focus.

What this model does not do is provide specialist accommodation where people can feel safe, welcome and cared for to whatever degree they wish towards the end of their lives; a place that allows people to die with dignity while continuing to use substances. This is an urgent and outstanding gap in services.

9.5 - Conclusion

This research set out to determine what a new, co-produced, model of care should look like for people using substances needing palliative and end-of-life care. It aimed to determine whether the model would improve people's access to, and experience of, end-of-life care. It also sought to determine whether the professionals supporting people using substances and with serious and advancing ill health felt better supported by the new model.

We knew from the outset that this was an ambitious project. Working alongside 11 partner agencies spanning social and health care and the statutory and voluntary sectors was going to be messy and complex. However, this is the system faced by people navigating their care needs and these are the agencies faced with the reality of working with people using substances approaching the end of life.

While the bulk of the project timeline was during the Covid-19 years of 2020 -2021, severely limiting the data collection, we were able to meet our aim of developing the new model of care (s. 4.3). In addition, we were able to collect the experiences of managers and practitioners through surveys and interviews (chapters 5 and 6) and move to quality not quantity for the experiences of people with lived experience in the form of in-depth case studies. We had plenty of data to provide clear direction for the development of resources to meet the short-term outcomes for the model of care.

What the data and subsequent training and dissemination highlighted was that we were overly ambitious about achieving change. First, the participatory workshops and model of care set medium and long-term goals beyond the reach and timeline for a research project, for example, Information sharing pathway between fora, local MDTs and commissioners. Second, it was clear from the training events with front line staff that people were further back in their knowledge and thinking than we anticipated. The feedback was overwhelmingly positive (s. 8.3) but it centred around helping people to think about the issues and engage with this topic, as if for the first time, rather than drive practice change. It is possible that this will follow outside of the timeline of this research. Third, it was also not an easy subject to address or hear about and was an emotive topic for everyone, particularly on the back of a global pandemic resulting in so many deaths among families and clients. Some practitioners had to leave the training sessions as a result, and some of the research team needed time out. Fourth, we had little buy-in from professionals in lead policy roles for a range of reasons (s. 3.8). This is vital to effecting change and taking work forward beyond individual and organisational levels. Reengaging with policy makers is a priority.

Despite the challenges, it is clear this research has found traction and had impact. In meeting the short-term outcomes of the model of care and in hearing the experiences of people with lived experience and professionals caring for them, there was commitment, reflection, and the beginnings of change. We are working with partner agencies to continue developments in practice and to disseminate widely through a range of forums. The national and international interest in this project suggests this wider dissemination work has only just begun.

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