End of life care for people with substance problems: exploring policy and practice

MMU research team: Dr Jo Ashby, Ms Amanda Clayson, Dr Cherilyn Dance, Prof Sarah Galvani, Prof Carol Haigh, Dr Marian Peacock, Dr Lucy Webb, Mr Gary Witham, Dr Sam Wright, Ms Lorna Templeton, Prof Josie Tetley, Dr Gemma Yarwood.

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Background

- Research focus on end of life care for people with substance problems (alcohol and other drugs)
- Stemmed from practice concerns about adequacy of service provision
- Purpose: To improve and/or support service responses and reduce inequalities for people with substance use problems, their families and carers, receiving, or in need of, end of life care.
- Exploratory study alongside 3 hospices, 3 substance use agencies, and a community organisation facilitating access to people outside services

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Methodology

Research question	Methods *(☑ = complete; A = analysis; O = ongoing)*	Progress
1. What does the existing international research and wider literature tell us about current responses to end of life care for people with substance problems?	• Rapid Evidence Assessment (literature review) • Key Informant Semi-Structured Interviews (Template Analysis)	☑ A
2. How many people with substance related chronic or terminal illness are receiving, or in need of, end of life care in the UK?	• Secondary analysis of existing datasets in substance use and palliative care	☑
3. How do people with substance problems, past or present, experience end of life care?	• Individual unstructured interviews (Thematic Analysis – Braun and Clarke 2006) • Digital stories	A O
4. What is experience of family members, friends and carers supporting a relative with both issues?	• Secondary analysis of qualitative data (SAQD – ESRC dataset; Template Analysis) • Individual unstructured interviews	☑ A
5. What are the challenges and opportunities professionals face supporting people with substance problems and chronic or terminal illness?	• Online or paper-based survey • Focus groups (Template Analysis) • Individual semi-structured interviews	A A O

Knowing what we don't know:

what the data do and don't tell us about end of life care for people with substance problems.

Dr Lucy Webb

Dr Sam Wright

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Aims and approach

- to establish the prevalence and incidence of people with problematic substance use receiving or in need of end of life and palliative care in the UK

- A strategic search for available databases, datasets and reports based on datasets, consultation with key informants for further sources of data

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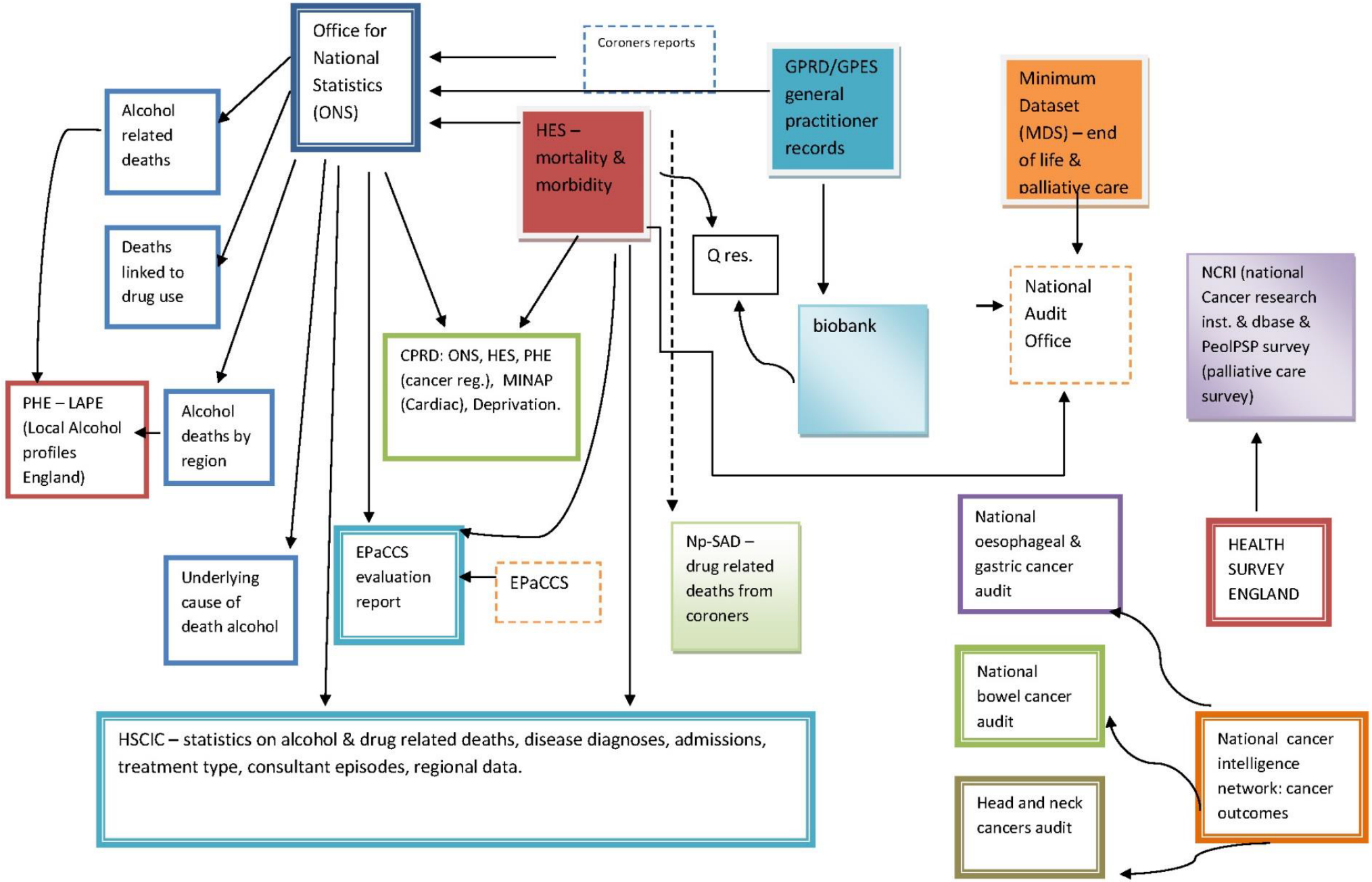
Office for National Statistics (ONS)
Coroners reports
GPRD/GPES general practitioner records
Minimum Dataset (MDS) – end of life & palliative care
Alcohol related deaths
HES – mortality & morbidity
Deaths linked to drug use
Q res.
National Audit Office
NCRI (national Cancer research inst. & dbase & PeolPSP survey (palliative care survey)
biobank
CPRD: ONS, HES, PHE (cancer reg.), MINAP (Cardiac), Deprivation.
PHE – LAPE (Local Alcohol profiles England)
Alcohol deaths by region
Np-SAD – drug related deaths from coroners
National oesophageal & gastric cancer audit
HEALTH SURVEY ENGLAND
EPaCCS evaluation report
EPaCCS
Underlying cause of death alcohol
National bowel cancer audit
National cancer intelligence network: cancer outcomes
Head and neck cancers audit
HSCIC – statistics on alcohol & drug related deaths, disease diagnoses, admissions, treatment type, consultant episodes, regional data.

Issues found….

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

cancer is over-represented in hospice referrals. Over 80% of hospice inpatient cases in 2016 were cancer referrals, (Hospice UK, 2016)

Link between multiple morbidities, high deprivation and likelihood of death in hospital than at home or in a specialist end of life care service (Higginson et al. 2017).

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So, needed to examine data for estimates – proxy variables

Proxy variables such as:

- disease type (ICD10)
- cause of death
- place of death

Other direct sources

- Disease-specific audits
- Substance treatment monitoring data
  - Not recording detailed comorbidities
- end of life care records
  - currently poorly reported and cannot facilitate accurate surveillance or monitoring.

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Proxy variables findings

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

- There is no ‘typical’ disease profile for chronic drug user deaths - it is not possible to extract these cases from others in which there is no illicit drug use (decreased specificity).

- Alcohol related deaths easier to identify – 4 character ICD10 codes.

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Deaths with alcohol as contributory factor, England and Wales 2014 (ONS, 2016b)

Underlying cause of death	No. deaths from underlying cause	deaths mentioning an alcohol-related condition (%)	% of deaths with alcohol as a contributory factor
Ischaemic heart disease	60,509	1.0	38.5
Pneumonia	25,386	0.6	9.0
Ischaemic stroke	19,094	0.5	5.3
Cancer of Oesophagus	6,754	0.4	1.6
Liver cancer	4,452	9.9	26.9
Cancer of the lip, oral cavity, mouth or throat	2,345	2.2	3.1
Transport accident	1,792	5.2	5.8

Key results – proxy variables

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

- ONS & PHE currently use partly attributable cause of death. Includes more cases.

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Drug-related mortality data

- only acute and directly attributable deaths are recorded by ONS as drug-related deaths. As these are largely deaths by overdose, sepsis or accident related to drug-taking

- A more reliable prevalence estimate by the National Treatment Agency (PHE, 2013) –
  - approximately 293,879 people aged 15-64 using opiates or crack cocaine in England (8.4/1,000),
  - 2.5/1,000 injecting drugs between these age ranges.

These figures may be a more useful basis for estimating potential chronic disease incidence

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Research evidence Beynon and McVeigh 2007

- traced cause of death of 102 individuals in contact with drug treatment services in the North West of England.
- 70.6% were classified as non-drug related deaths : cellulitis, infection (seven from pneumonia), alcohol-related liver disorders and suicides.
- Those who died from non-drug-related conditions were a significantly older cohort than those who died of a drug-related condition ($p = 0.004$).
- This work led the researchers to conclude that a considerable proportion of deaths classified as non-drug-related are likely to result from substance use - particularly through infection.

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Beynon et al. (2010)

- indicate that people with a history of problematic drug use die at an earlier age than the general population

- among drug users over 40, 15% died of liver disease, 13% from cancers, 8% respiratory disease, 6% viral hepatitis.

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Tridimas et al (2013)

- 71% of surveyed drug treatment clients smoke cigarettes

- a large majority (figure unreported) had symptoms of respiratory disease.
- Respiratory diseases may be an overlooked cause of morbidity and mortality among older drug users –
  - Smoking heroin, cannabis and crack cocaine are all associated with chronic obstructive pulmonary disease (COPD), emphysema, and respiratory diseases at a younger age

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Stenbacka et al. (2010) Swedish drug user cohort study

- 40% also had problematic alcohol use.
- The biggest cause of death was cardiovascular disease
- Tumour was given as the cause of death for 12.5% of the deaths
- liver cirrhosis and suicides each accounted for 10.5% of deaths.

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What do we know…

- approximately 10% of alcohol-related deaths are associated with ischaemic heart disease as an underlying cause, as recorded by the ONS

- approximately 15% of (chronic) deaths among drug users is likely to be due to cardiovascular disease

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What would be interesting to explore…

- some evidence is emerging that older drug-using populations carry a burden of liver cirrhosis, cancers and respiratory disease, often with an earlier age of onset

- Respiratory disease may be a ‘hidden’ COD for older drug users

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Top tip: what data would be of most use

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

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The impact of using the new definition of alcohol-specific deaths – ONS

- Will be recording only wholly attributable alcohol deaths
- Excludes
  - Chronic hepatitis, and Fibrosis and cirrhosis of liver.

- This skews the age ranges by lowering proportions of older age deaths by partly attributable causes
- This simply shows that older ages may have more complex needs at end of life.

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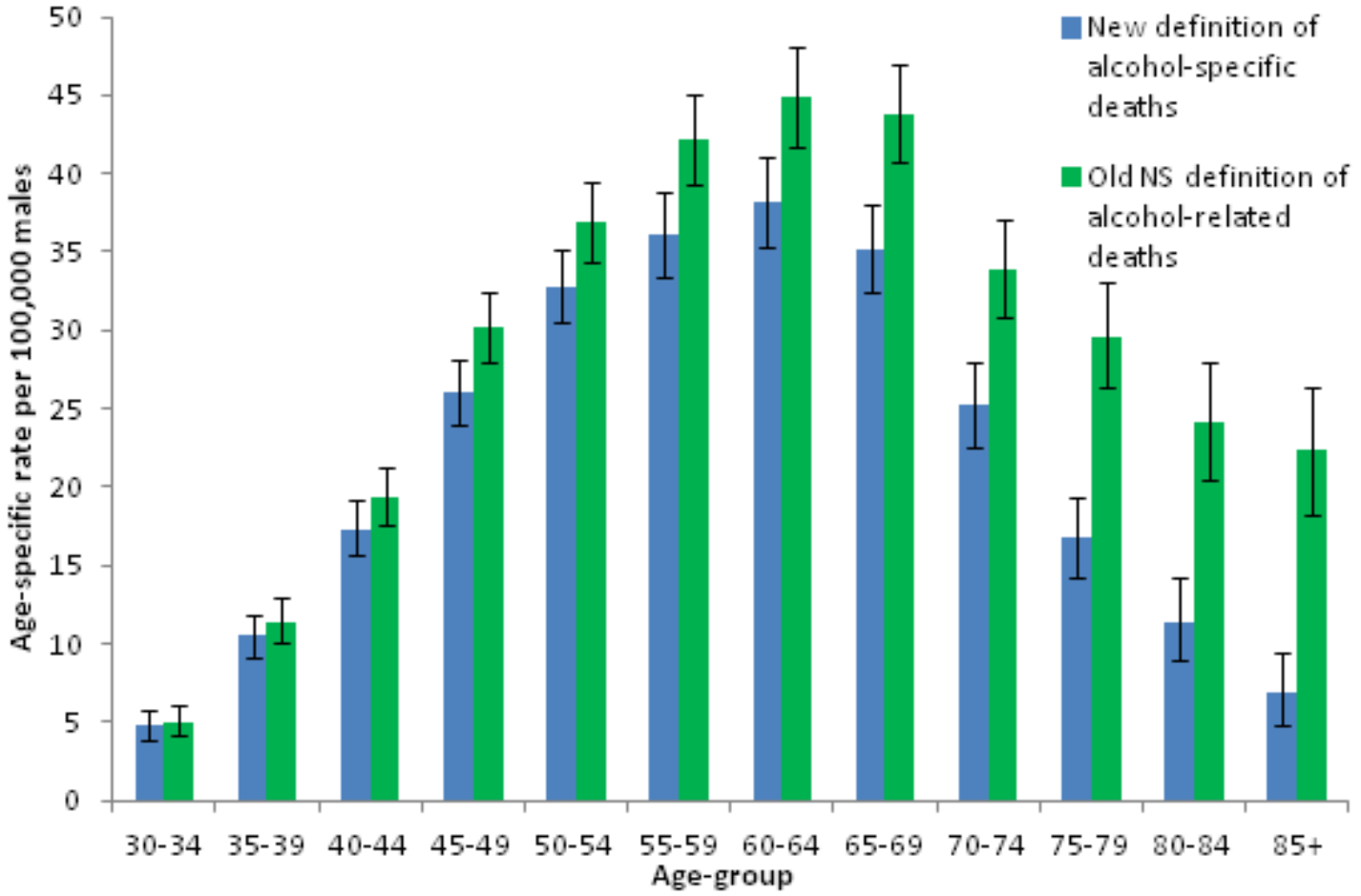
ONS (2017) comparison - males



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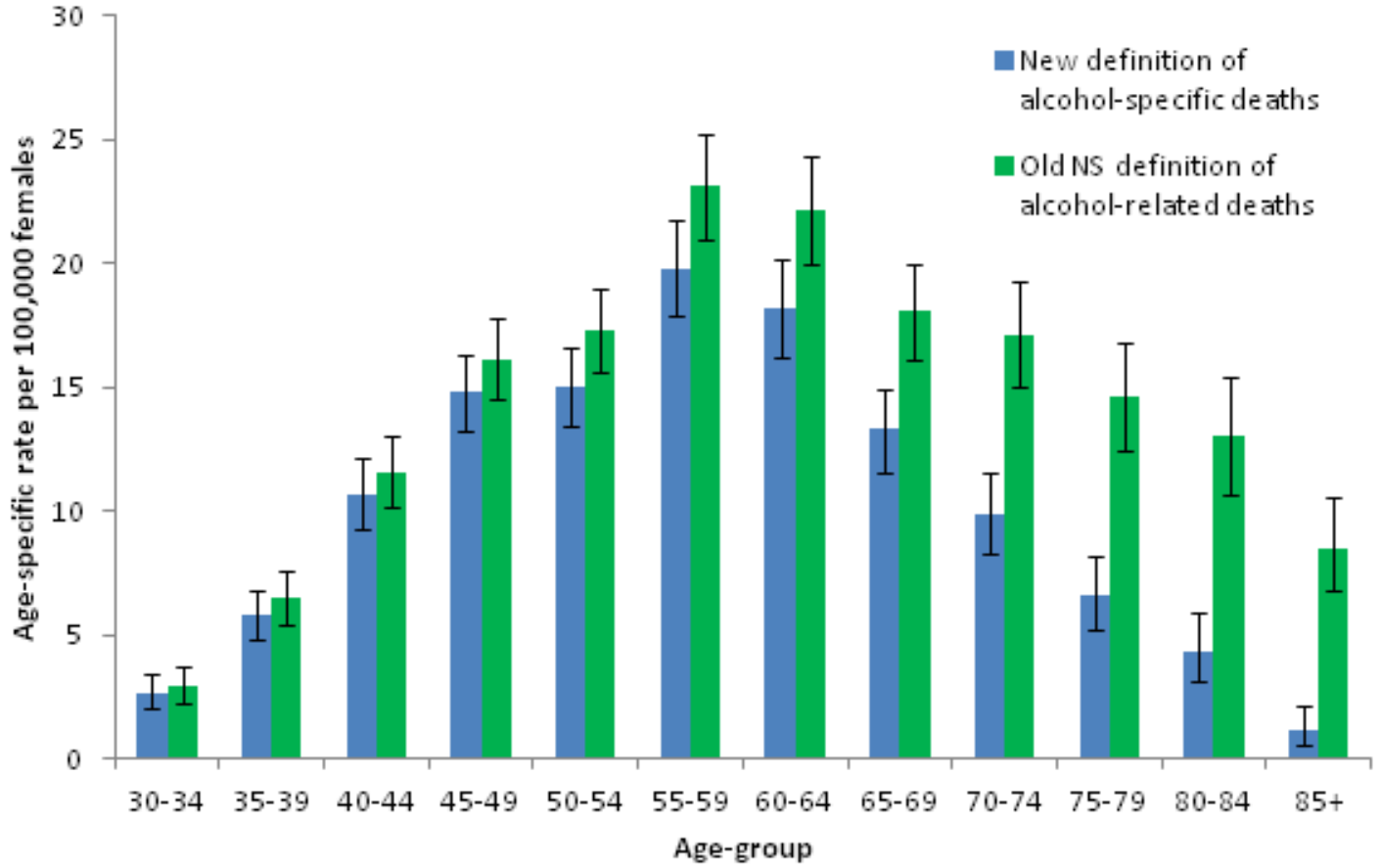
ONS (2017) comparison - females



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Questions?

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Supporting substance users at the end of their lives: professionals' perspectives on challenges and solutions

Prof Sarah Galvani

Dr Cherilyn Dance

Dr Sam Wright

Prof Josie Tetley

(with Dr Marian Peacock and Ms Lorna Templeton)

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Strand 5 – The Professionals

Research question

What are the challenges and opportunities professionals face supporting people with substance problems and end of life care needs?

Methods

Three forms of data collection:

1. Survey data
2. Focus groups
3. Individual interviews

Last of five strands!

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Practitioners' perspectives: survey data

- 5 section survey:
  - professional role (and demographics)
  - recognition/encounters with combined issues
  - working with PWE
  - working with 'the other' service
  - knowledge/attitudes and training
- Completed by 41 SU staff and 72 hospice staff
- In both types of service over 90% of respondents had good or moderate opportunities to build relationships

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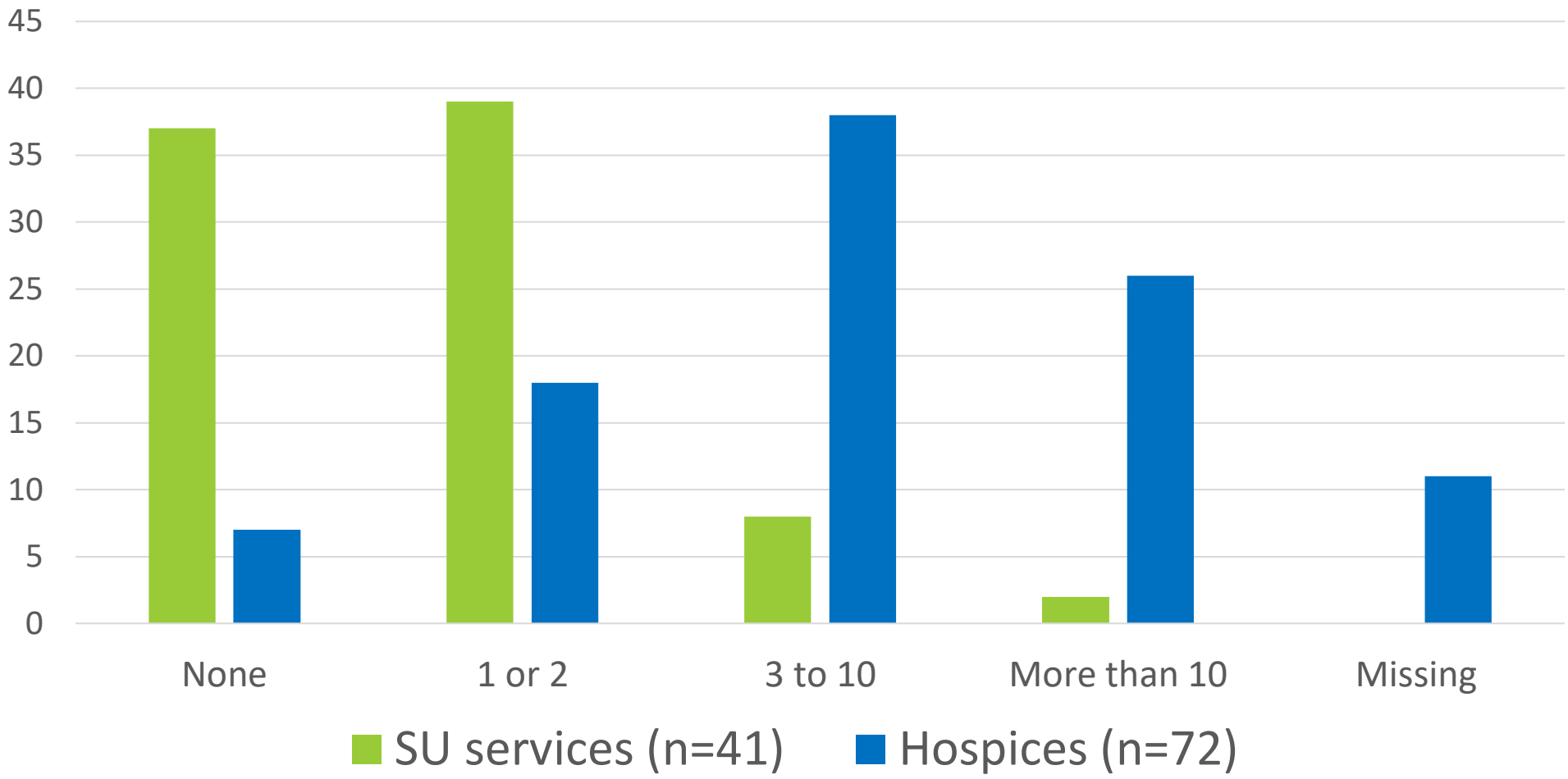
Number of patients/clients worked with who have both EOLC and SU needs in current role



Joint working – SU services and Hospice/EOLC

Substance use respondents (n=41)

JW Experience:

- 15% (6) yes, 17% (7) would have liked to
- Mostly for clients & family member

Ease of access – mixed

Hospice respondents (n=72)

JW Experience:

- 20%(14) Yes, 18% (13) would have liked to
- Mainly to support patient, but also family member sometimes

Ease of access – mixed

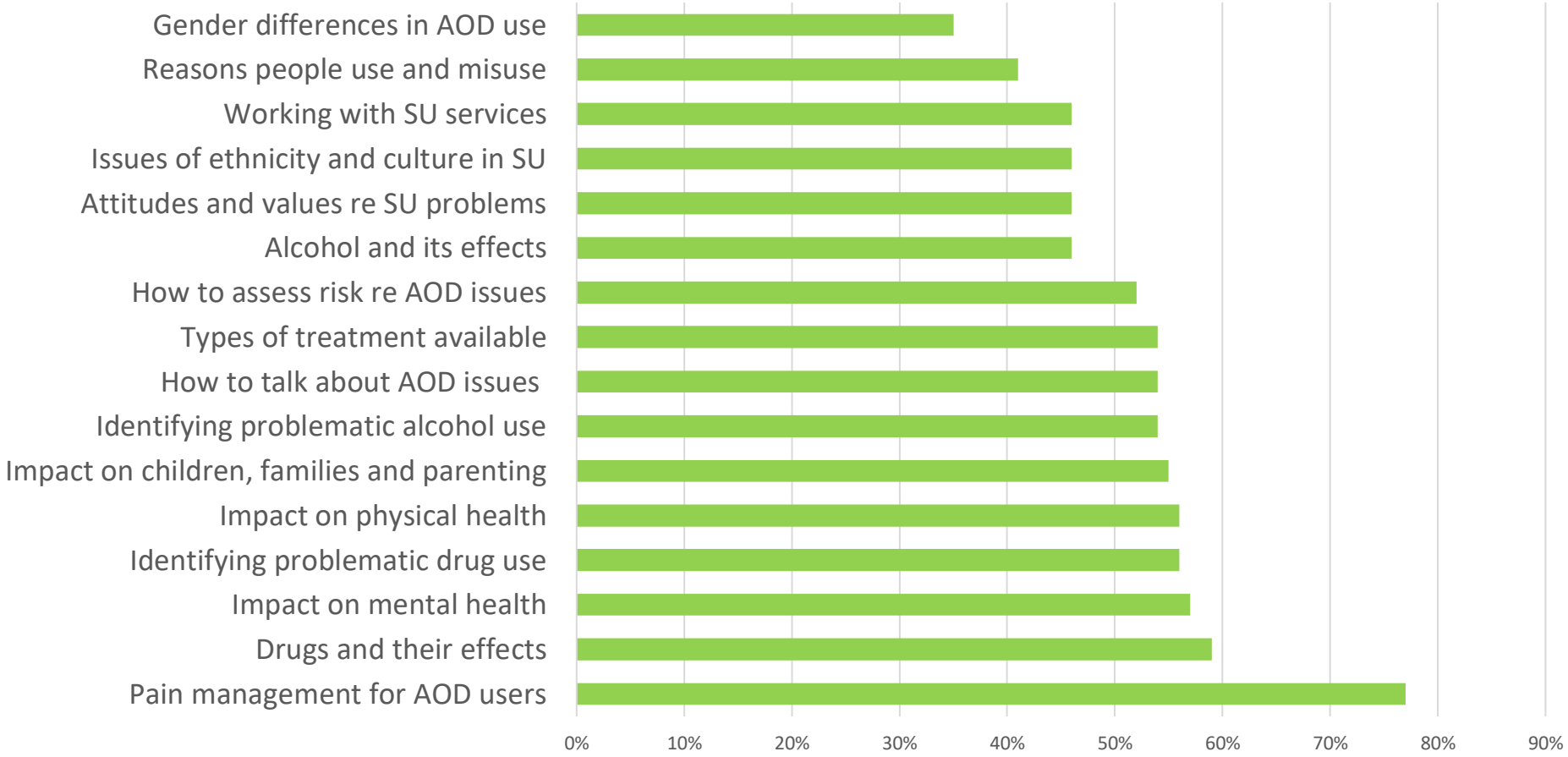
Mean scores knowledge and attitude domains

Mean domain scores (SAAPPQ/equiv)	**Hospice respondents *(sd=)***	**SU respondents *(sd=)***
Role adequacy	3.74 *(1.4)*	3.79 *(1.4)*
Role satisfaction	4.44 *(0.8)*	4.38 *(1.3)*
Task specific self-esteem (negative)	5.11 *(1.1)*	4.71 *(1.1)*
Role motivation	4.78 *(.92)*	4.60 *(1.0)*
Role legitimacy	4.60 *(1.2)*	5.09 *(1.0)*
Support	4.94 *(1.3)*	5.46 *(1.4)*
Task specific self-esteem (positive)	5.00 *(1.1)*	4.40 *(1.2)*
Role Satisfaction	**4.40(0.9)**	**4.43 (1.0)**
Therapeutic Commitment	**4.80 (0.7)**	**4.79 (0.8)**

OVERALL, BOTH GROUPS NEUTRAL TO LOW POSITIVE ATTITUDES, ADEQUACY BELOW MIDWAY FOR BOTH

Training needs: Hospice services

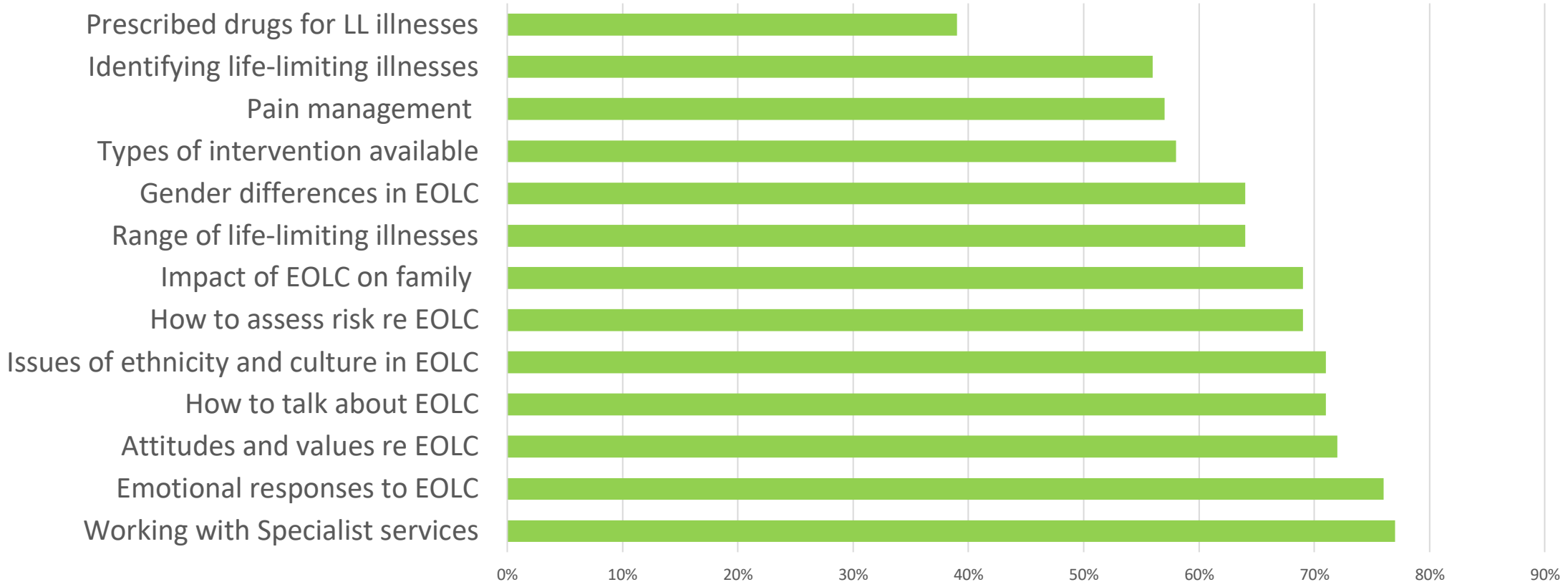
% indicating training very important in this area



Importance of training 6.7/10

Training needs: Substance Use services

% indicating training very important in this area



Importance of training 7.4/10

Practitioners' perspectives: focus groups

- **Seven focus groups** to date – 3 in hospices and 4 in SU services
- Total of **41 people** so far – ranging from social workers to senior managers, nurses and recovery workers

- Template analysis to date:

  7 broad themes (across both groups)

  - Challenges, Talking or asking about the 'other', Family Involvement, Good Practice, Bad Practice, Resource and Training Needs

  5 themes: 2 specific to SU staff responses; 3 to Hospice staff

  - Emotional toll on staff; Sub Use diverting health responses (SU)
  - Symptom management; referral practice; class differences (Hospice)

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Challenges

- 5 sub themes: systemic – external; systemic – own agency; practice of other professional groups; for individual staff; individual client factors

Systemic – own agency	**For individual staff**
Switch from 'recovery' orientation to managing long term conditions (SU)	Uncertainty about when people are end of life (SU)
Lack of resources to do follow up outreach care for people with complex dependencies (SU)	Lots of complex health problems could contribute to life limiting status (SU)
Struggle to work with people who don't want to change sub use – gap in service provision (SU)	Sorting medication – people not taking correctly (SU)
Prescribing and pain management (H)	Going against nurse training – giving alcohol (H)
Relying on others'/consultants' knowledge they might not have (H)	Risks to self in community/home visiting, e.g. prescriber in unsafe area; needle stick (H)
Lack of alcohol or drug link in hospice as there is in community work (H)	Knowing enough about SU to attribute behaviour correctly, i.e. sub use or illness/meds

Talking or asking about the 'other'

- 4 sub themes: not asking, how to ask, when to ask, result of asking.

Not asking	Not had training/frightened to ask; not role – specialist area; not asking routinely; can't ask if do nothing with info
How to ask	Language to use; not using 'dead' word; need to transfer skills around dealing with uncertainty to death and dying (SU); using the 'if' question; point out health risks
When to ask	Establish relationship; not asking initially – don't want to scare off (SU); contribution of SU to cancer (hospice)
Result of asking	SU – opening pandora's box; don't want to be 'left with the problem' if they refuse EoL treatment; could prompt more drug use – "not a resilient group" Hospice - Asked and got honest response; about getting care right not being judgemental; important to meds management/understanding tolerance levels;

Substance use professionals

"… if nobody else is going to bring it up, then I suppose we need to bring it up. But it's a bit like Pandora's Box, if you start it, and then you don't know how to address it, … or direct it then you can't open that box, because you're going to create so many more problems for that person… "

"… I never bring up the word, I think, "What do you think will happen if this carries on? You've lost one lung," and kind of highlight, then tease it out and once they say, "Probably bye." "There you go," and then we'll have the conversation. … I don't like saying the dead word or whatever, I'll let them say it on their own. Jump all over it, but yeah."

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Emotional toll

- Two sub themes: personal response, process/professional response

- Personal – shock; “nasty death”; sadness/tears; anger; loss

  “…you're a step away from being family or really close, that is hard and as much as we work and obviously you're working at keeping that person alive, but their mental state at times can be, “I want to let go”. … so I find that quite difficult, it doesn't matter how close they are to you, you don't know.

- Process/professional – questioning own practice; putting own feelings aside for family and/or paperwork; dealing with complex health needs/providers - “ten rounds with Tyson”; referrals to others- “please take them”; understanding context of people’s lives; professional frustration.

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Resource and training needs

- Two sub themes: knowledge; expertise and guidance.

Knowledge	**Expertise and guidance**
Info on other e.g. range of EoL conditions/how drugs can be misused	Multi-agency or joint working
Care pathways – advice and referrals	Expert in 'other' they can ask
How to have the conversation and how the 'other' can be addressed in own care context	Prescribing advice for people with addiction problems
Managing pain for people with addiction problems (hospice staff only)	Views of PWE – know what patients want in last days, e.g. nicotine patches (hospice staff only)

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Thank you!

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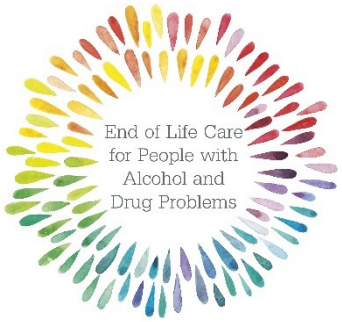

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“I’ve never been a problem patient”: service users’ experiences of end of life care.

Dr Jo Ashby

Dr Sam Wright

Ms Amanda Clayson (Voicebox Inc)

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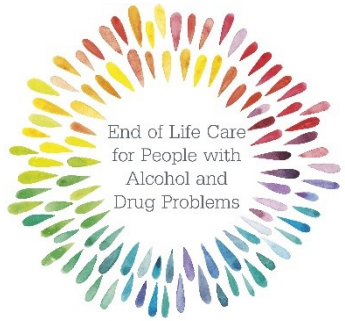
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