Marginalised and Missing? Palliative and end of life care for people using substances

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Ageing cohort of people using substances

- Increase in “harmful or mildly dependent” drinking in 55-64 age group (Drummond et al. 2016)
- Alcohol-specific deaths at highest rate since 2008 (ONS, 2018)
- 60-64 yrs age group now highest rate of alcohol-specific deaths (previously was 55-59 yr olds

- Increase in numbers of older drug users (EMCDDA, 2019)
- High risk drug users are 3-20 times more likely to die than peers of the same age and gender (EMCDDA, 2019)
- Illicit drug use research counts ‘older’ drug users as >40 yrs
- Older drug users living long enough to die from unrelated health conditions, ie. most people using drugs die from same conditions as everyone else

Health and social care needs

- People using substances excessively will often die younger from conditions seen most among older people
- Social care needs too: defined by NICE (2015) as including "dependence on alcohol or drugs"

- Context: Massive service cuts in substance use field
- Background: Conversation with CEO of alcohol charity, Palliative Care Social Worker and wider conversations with number of alcohol/drug agencies and hospices
- Concerns about improving response and solutions to challenges

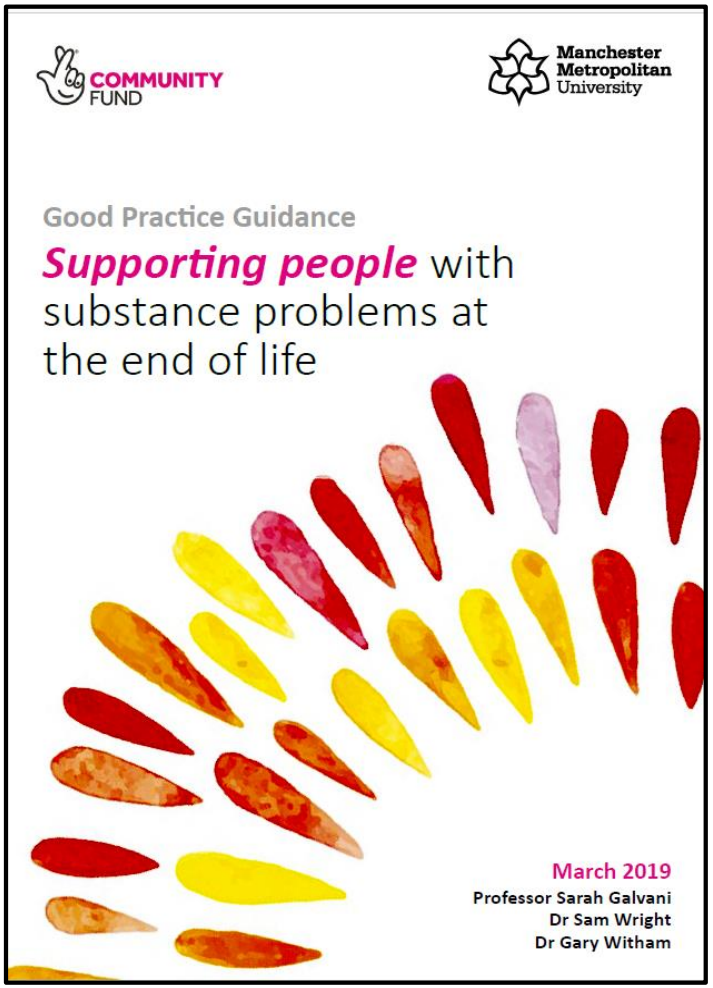
Body of work

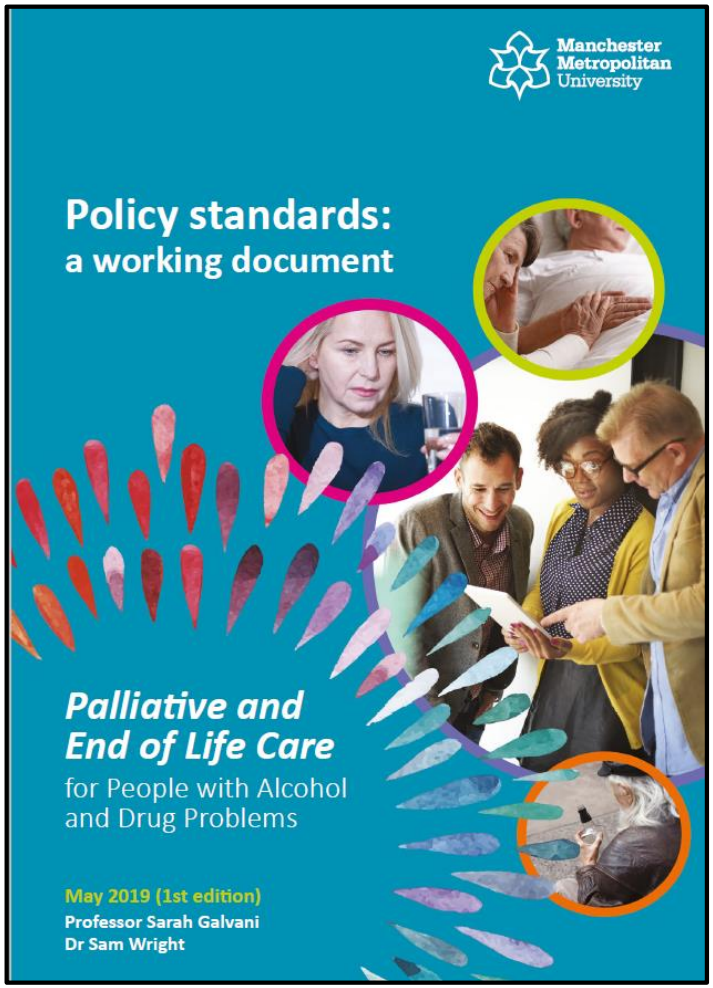
6 strand exploratory project	• Funder: National Lottery Community Fund, 2016-2018
Good practice guidance	• Funder: NLCF, 2019
Policy Standards: a working document	• Funder: Metropolis, Manchester Met, 2019
Development of new model of care	• Participatory action research and mixed methods evaluation • Funder: NIHR, 2019-2022

Six strands of work

- Rapid evidence assessment (REA) of existing literature
- Explore scale and prevalence of overlap
- Listen to people with experience (PWE)
- Listen to the families, friends, carers
- Listen to the professionals
- Listen to key informants working in this area
- https://endoflifecaresubstanceuse.com/reports-and-resources-2/

Good Practice Guidance & Policy Standards





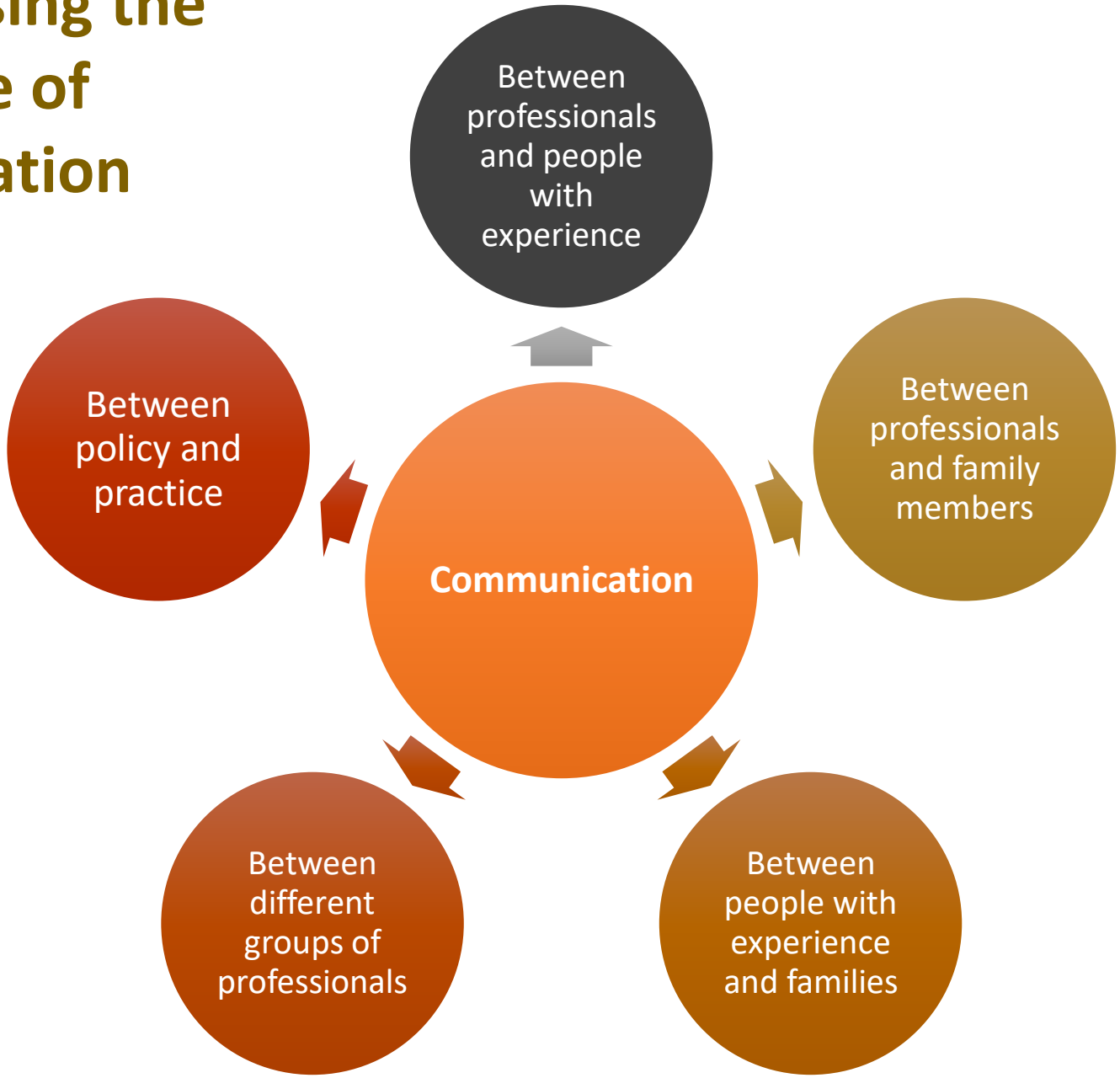
Missing data

- Currently people with PSU and EoL care needs in the UK cannot be directly identified in any single health or population database or dataset.
- Cancer is over-represented in hospice referrals.
- Link between multiple morbidities, high deprivation and increased likelihood of death in hospital…rather than at home or in a specialist end of life care service (Higginson et al. 2017).
- Improved monitoring and surveillance of service accessibility for disadvantaged patient groups will require more detailed and specific data collection at service delivery level.

Common themes

- Recognising the importance of communication
- Understanding the complexity and multiplicity of needs
- Countering stigma and stereotyping
- Addressing symptom and pain management
- Delivering compassionate and non-judgemental care

1. Recognising the importance of communication



Rob (42)

Six months later they told me about this place (hospice) and said “how do you feel about going there?” … I was scratching my head thinking, “why do I need to go to a hospice?” … the nurse explained, she said you know you’re very ill?” and I’ve flippantly remarked, “no shit” … my heart is working at 14%, I know I’m ill”, she went, “no you’re really ill”, she went, “you could have as little as a year to three years to live.”

And later…

I had this conversation with possibly half a dozen people at the hospital and at no time did anybody ever say, “The likelihood of you actually being here in ten years is next to zero”.’ ‘It came across as almost flippantly mentioned but I think it was more a case of I think she presumed that I already knew.

Key informants and professionals

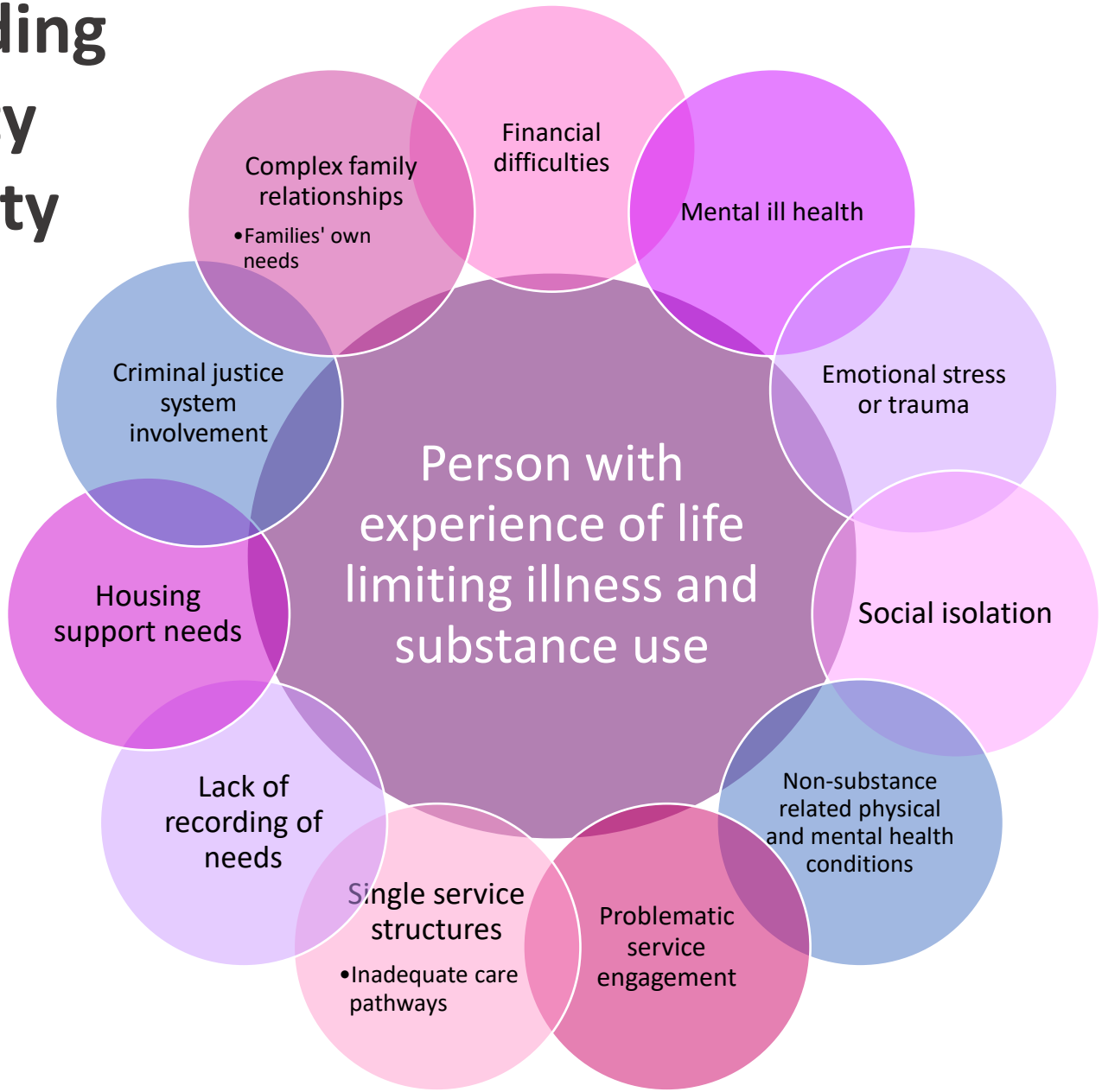
So there is something about the end of life care prospect that is invisible to this group of people...the talk never gets to the fact that people die, so the talk is always about prevention, self-care, best management and I keep having to say but they will die at some point so when are we going to deal with this?

(Group 3 - Policy & Commissioning Professionals)

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

(Group 4 – Other Professionals)

2. Understanding the complexity and multiplicity of needs



3. Countering stigma and stereotyping

- Entrenched stigma and stereotypes around people with problematic substance use.
- Fear of disclosing SU at EoL or to social care or health practitioners.
- Health problems not addressed and attributed to substance use or drug seeking behaviour.

Female ex-partner, former partner died at home

It’s not like they were walking to a house with needles all over the floor, or we were threatening them or smashed out of our faces, I wasn’t using anymore, even when I was using, I wasn’t like that, I still had a really clean house, lived in a completely normal life but you know what society’s like, we’re like green slimy monsters that live behind a dirty, filthy couch. ...We were being treated [by HSCP] as if we were diseased creatures.

4. Addressing symptom & pain management

- Very common concern among health practitioners - how to alleviate pain safely with people using substances
- ‘Chemical coping’ – substance topping up their medication due to inadequate pain relief
- Drug diversion by family members or friends
- People with historic substance use refusing medication based on opioids

5. Delivering compassionate and non-judgemental care

- Anecdotes of caring and supportive individuals/services
- Heard examples of staff being innovative, creative, advocating*
- Holistic models well received – care starting with their priorities
- Examples of very poor care – from disrespectful treatment, to uncomfortable and undignified deaths
- Better education and training for health and social care professionals required, preferably in context of better public health messages that address stigma.

Good practice: Hospice professional
(Focus Group)

I saw a patient in a nursing home who had dementia caused by alcohol and he was very agitated and I was sat talking to him and he kept saying to me, “Jack Daniels, Jack Daniels” and I said, “Why don’t we just get this gentleman a Jack Daniels rather than go to the cupboard and get him a shot of [medication] to calm him down?”. So he got a mix of Jack Daniels and lemonade and he calmed down.

… Again, it’s about he’s abused alcohol so now why are we stopping him when [he’s] in the last few days of his life, actually just having a sip and a taste of it and nobody had addressed that….This sort of thought process and advice goes against everything, when you go and do your nurse training, … if you wrote that in your nursing exam, you'd fail wouldn't you?! Talking about how to address psychological needs and things, “give them some alcohol”, you'd fail wouldn’t you?

Where is this taking us?

- How can we make health and social care more accessible for highly stigmatised people/families?
- How do we provide support to marginalised and isolated people?
- How can we properly respond to the emotional burden of caring for people with substance problems at end of life?

A new 'Model of Care' for people using substances at, or near, the end of life

A new study to work with people with experience in co-producing and assessing the impact of a new model of EoLC for people using substances, their families, friends and carers.

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Thank you

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Policy Standards

1. Develop public health policy which assertively **counters stigma and stereotyping** relating to substance use and serious ill health

2. Develop **national, local and organisational policy** that supports co-existing substance use and end of life care needs in practice.

3. Create policy that promotes **accessible care environments** and offers the required support to people with substance problems at the end of life.

Policy Standards (cont.)

4 Ensure policy directives **bring people together to work jointly** across substance use, palliative/end of life and primary care

5 Ensure policies informing **education and training** equip health and care professionals to work with people who use substances at end of life.

6 Ensure policy identifies and responds to the needs of **people who are important to the person** with substance problems at the end of life.

Each standard contains:

Standards for national, local and organisational levels of policy.

Standards map across the three levels as well as stand alone within their own policy context.

Small amount of text to offer clarity or emphasis when needed.

Standard 2 – large and broad. Offered in stages: Foundation, Enhanced, Developed

There are case studies on 'what good looks like'.

Appendix for policy and practice resources