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

Policy standards: a working document

May 2019 (1st Edition)

Manchester Metropolitan University

COMMUNITY FUND

NHS Mersey Care NHS Foundation Trust Community and Mental Health Services

Marie Curie Care and support through terminal illness

How it all started

2016-18 Scoping study

Manchester Metropolitan University

LOTTERY FUNDED

What did we discover?

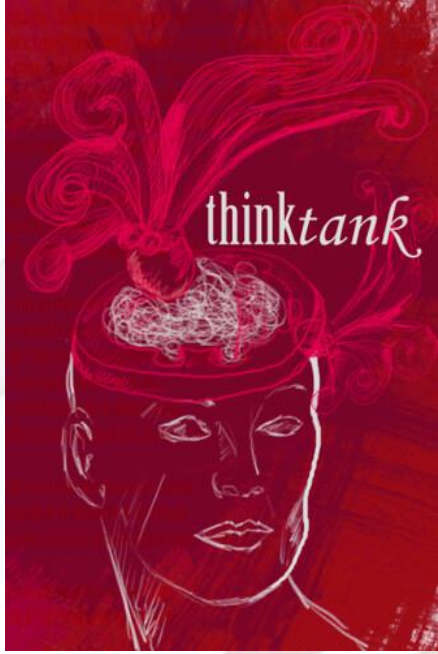
- Unmet chronic health and social care needs
- Barriers to service access
- Isolation and late presentation to healthcare
- Families devastated by traumatic bereavement
- Many services and staff insufficiently equipped to respond

What did we then want to do?

- To create greater understanding for a group of people who are as entitled as any citizen to sympathetic and expert care, particularly when they are dying.

- To help all those people of good will in the NHS, social and other health care services who want to answer the call of every patient who is in need.

How did we go about doing it?



1. Discussions with key people working in Liverpool
2. Consultation with national organisations
3. Evidence base from previous project
4. Collation and analysis of key findings
5. Draft circulated, feedback event 28th Feb 2019
6. Policy Standards launch May 2019

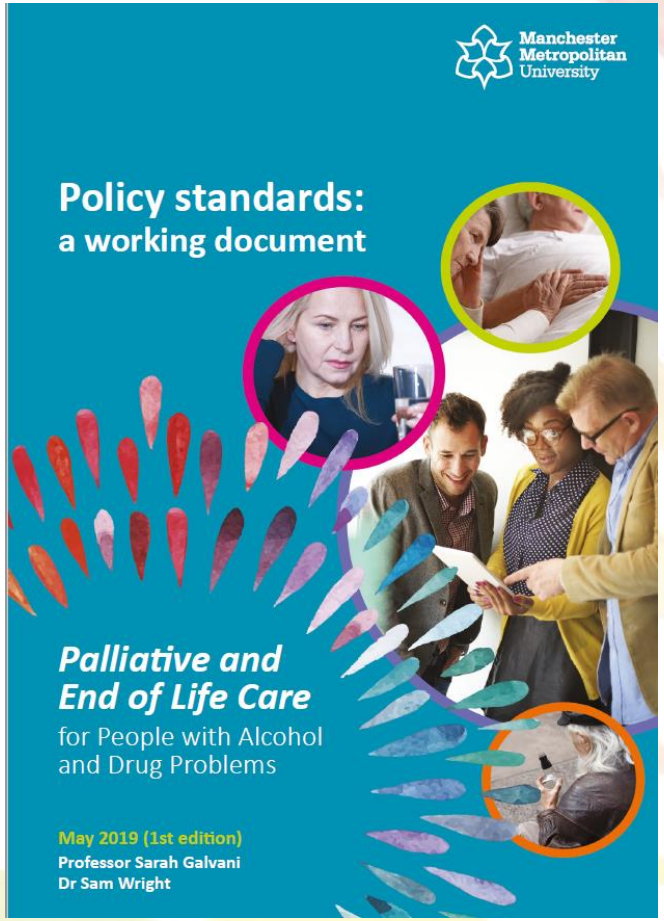
NHS
Mersey Care
NHS Foundation Trust

Community and Mental Health Services

Let’s be aspirational!

- Speak to policy makers at national, local and organisational levels.
- 1st edition WORKING document: open to rethinking and continuous learning.
- Acknowledge challenges (unpredictable deaths, identifying needs).
- Offer an infrastructure for good practice borne of research.
- Intend to be both practical and aspirational.

The Policy Standards:



- National, local and organisational policy levels
- Case studies of ‘what good looks like’.
- Tips on overcoming barriers to policy devp
- Appendix for policy and practice resources

The six standards

1. Counter stigma and stereotyping
2. Support collaborative substance use and EoLC practice and strategies
3. Promote accessible care environments
4. Bring people together to work jointly
5. Train health and social care professionals
6. Support the people important to the person who is dying

1 Countering stigma at national, local and organisational levels

National

1. National public health campaign to counter stigma around PSU including print and visual media, and social media.
2. Ensure P/EoLC policy includes people with PSU as among those suffering health inequalities.
3. National public health campaign about dying and how to have conversations about planning for death.

Local

1. Local public health campaign to counter stigma around PSU including print and visual media, and social media.
2. Local initiatives to address health inequalities in P/EoLC include people with PSU.
3. Commission specific services for people near the end of their lives, with PUS as part of the target group.

Organisational

1. Raise practitioner awareness of people with PSU; promote understanding of the complex needs / histories of this group.
2. Increase knowledge of P/EoLC within substance use, housing and social care agencies, focusing on early intervention and ACP.
3. Ensure explicit organisational commitment to equality of service provision for people with PSU and end of life care needs.

Collaborative EoLC/SU strategies (organisational level)

1 Develop policy guidance for substance use and end of life care.

2. Enable staff to facilitate early identification and access to primary, acute, palliative and end of life care for PUS.

3. Appoint an organisational lead to take this work forward.

4. Develop local care pathways to support work with PUS who need end of life care.

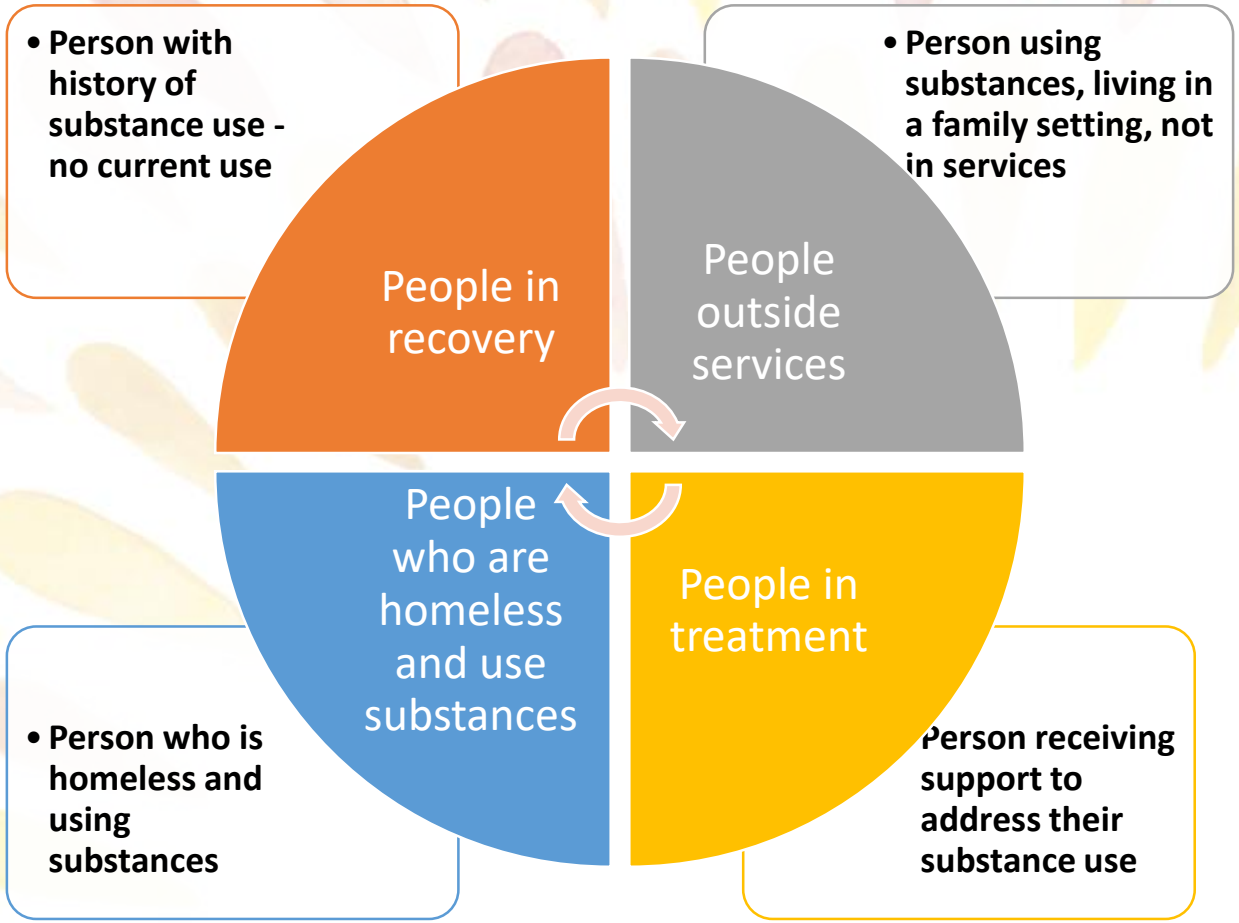
5. Develop appropriate service standards, quality outcomes and measures of success including cost effectiveness.

7. Routine identification and recording of multiple and complex needs.

8. Commit to supporting/joint staffing any new service or resources for PUS at the end of their lives.

9. Respond to the implications for the new strategy at organisational level - in particular joint working requirements.

Who are we thinking about?



Case study 1:

- A woman who was sleeping rough was discovered to have had tests at the local hospital but had self-discharged without knowing what the results were. No attempt had been made by the hospital to contact either her last registered GP or local homelessness services. She had ovarian cancer. Fortunately, she was treated by a GP practice that specialises in supporting people who are homeless and who were very proactive in assessing and dealing with her healthcare needs.
- A policy to make explicit the need for liaison between hospital services and specialist community services would help to ensure that vulnerable adults are supported irrespective of their self-discharge from inpatient services.

Applying the standards: where next?

- Create an audit tool for organisations to prioritise action
- Use as a framework to bring people together and identify priorities
- As a ‘straw horse’ for policy makers to tear apart and revise

Health inequalities and access to good end of life care

Care Quality Commission (2016) focus on people:

- with conditions other than cancer
- with dementia
- from black and minority ethnic groups
- with mental ill health
- with learning disabilities
- who are homeless

"...it seems completely alien to us why somebody would drink themselves to death but when you understand the context of somebody's life and the things they've been through, it makes sense..."

Substance use professional

A new Model of Care for People with Problematic Substance Use and End of Life Care Needs

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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The six standards

5 Staff training (Organisational level)

1. Training for SU and EoL care staff to have sensitive conversations with people in their care and better deal with SU/PC or EoL care needs.

2. Care homes to develop/refine policies and practice around working with people with substance problems.

3. Ensure staff have easy access to resources and information about supporting people with PSU, and their families, at EoL.

4. Specialist information and communication skills training around palliative care for SU staff and talking and asking about SU for EoL/PC staff.