End of Life Care for People with Severe Mental Illness: an Evidence Synthesis
(the MENLOC study)

Project Team and Stakeholder Advisory Group Meeting

Meeting notes

Record of attendance

Project team	Position	Present
Prof Ben Hannigan (chief investigator)	Professor of Mental Health Nursing	Yes
Deborah Edwards (project manager)	Research Fellow	Yes
Dr Sally Anstey (co-investigator)	Senior Lecturer	Yes
Dr Paul Gill (co-investigator)	Senior Lecturer	Yes
Mala Mann (co-investigator)	Information Specialist	Yes
Prof Michael Coffey (co-investigator)	Professor of Mental Health Care	Yes
Alan Meudell (co-investigator)	Public and Patient Project Member	Yes
Roger Pratt (co-investigator)	Public and Patient Project Member	Yes
Stakeholder advisory group		
	Position	**Present**
Dr Nikki Pease (independent chair)	Consultant in Palliative Medicine, Velindre NHS Trust	Yes
Dr Idris Baker	Lead Palliative Care Clinician for Wales and Consultant in Palliative Care, Abertawe Bro Morgannwg University Health Board	Apologies given
Dr Liz Davies	Head of Mental Health and Vulnerable Groups Division, Health and Social Services Group, Welsh Government	Yes
Hazel Powell	Nurse Director Mental Health and Learning Disability, Abertawe Bro Morgannwg Health Board and Chair of the All Wales Senior Nurse Advisory Group for Mental Health	Apologies given
Pam Penman	Practice Development Facilitator, Marie Curie Hospice, Cardiff and the Vale	Yes
Dr Helen Noble	Lecturer, Queen's University Belfast and expert in end of life care for people	Yes (via videoconference)
Prof Ian Jones	Director of the National Centre for Mental Health and Professor of Psychiatry, Cardiff University	Yes
Kathleen Caper	Head of Policy and Advocacy, Hospice UK	Yes

Niamh Brophy	Palliative Care Coordinator at St Mungo's	Apologies given
Dr Stephanie Perrett	Lead Nurse for Health and Justice, Public Health Wales	Yes
Sian Jones	Public and patient representative	Yes
Huw Davies	Public and patient representative	Yes

1. Welcome, introductions and apologies
Stakeholder advisory group (SAG) and project team members were welcomed by the chair, Nikki Pease, and the chief investigator Ben Hannigan.

2. MENLOC project team and project advisory group: terms of reference
Proposed terms of reference for the SAG were tabled and discussed, and it was agreed to amend these to include an estimation of the time commitment for SAG members.
[document: *MENLOC project team and SAG - terms of reference v2*]

3. Introducing the MENLOC project
Ben Hannigan introduced the MENLOC project, noting that this is funded through an award from the NIHR HS&DR Programme. As a preamble to a more detailed discussion of search terms SAG members commented on the aims of the study, though the meeting also noted that any change to these would require the approval of the funder. It was agreed to confine suggestions and advice to the inclusion and exclusion criteria for the selection of outputs, and to specific search strategies and terms.

Early discussions included the project's exclusion of outputs relating to end of life care for people living with dementia. It was identified that in the case of outputs focusing on end of life care for people with both severe mental illness *and* dementia that these would be included, but that outputs relating to people with *only* dementia would be excluded.

Discussions also centred on the identification of specific types of organ failure, and suggestions were received to also include genetic conditions, irreversible progressive conditions, permanent vegetative states and the potential of adding the word 'chronic' in front of the different types of organ failure described and included.

4. Defining the project's parameters: 'severe mental illness' *and* 'end of life' (and related)
Search strategies and terms developed by the project team were distributed for discussion, and for welcome suggestions from SAG members. Specifically:

Severe mental illness
The imprecise nature of 'severe mental illness' was noted, though the everyday currency of the term was also recognised along with the recognition that MENLOC is broadly focusing on end of life care for people who have used secondary, specialist, inpatient and/or community mental health services.

SAG members proposed, and meeting participants discussed, the inclusion of additional diagnoses (e.g., anorexia and PTSD) not listed in the MENLOC protocol. It was noted that diagnostic manuals are extensive and that listing new individual diagnoses at this point opened the door to including *all* diagnoses, making for unmanageable searches. It was decided therefore not to include such terms.

A particular discussion was held around the diagnosis of depression, in the context of large numbers of outputs reporting depression as a *consequence* of receiving an end of life diagnosis, as opposed to *preceding* this. The continuum of depression was also noted, and meeting participants agreed that outputs concentrating on people with mild, commonly

experienced, depression (and by extension, anxiety) should not be included. A consensus was to remove 'depression' as a search term or MeSH heading (particularly given that Deborah Edwards' screening of hundreds of papers identified in this way produced no outputs meeting MENLOC's inclusion criteria), but to instead to use 'depression' in conjunction with other terms such as 'psychosis' or 'pre-existing' or 'severe'.

Mala Mann confirmed that older terms such as 'melancholia' do not need to be searched for because database indexing groups together outputs using these phrases with outputs using more contemporary terminology.

Project members reported that not all end of life care outputs retrieved make clear whether or not the mental health problems experienced *preceded* end of life diagnosis.

Some discussion was also had on whether a fourth arm should be added to the search strategy, capturing use of secondary services in recognition of the fact that people with severe mental illness are overwhelmingly people using secondary mental health services. It was noted that using a four-arm search would be too narrow, and that citations containing such terms will already be identified using the existing three-arm search.

Neurological and neurodegenerative conditions
SAG members identified a group of conditions not previously considered by the project team, covering (for example) 'brain failure'. It was noted that 'brain failure' outputs would be captured under the term 'organ failure', and that a separate funding proposal is being prepared to synthesise the evidence in the area of end of life care for people with neurodegenerative conditions.

End of life care
Suggestions from SAG members for end of live related search terms were noted, including: 'thanatology' (the study of the theory, philosophy, and doctrine of death); 'best supportive care'/'enhanced supportive care' (these being new terms currently in use); 'end-stage' as a term to represent dying with chronic conditions; and 'conservative management' or 'conservative treatment'. A consensus was to exclude 'self-poisoning' or 'self-inflicted injuries' where the goal of treatment likely to be reported in outputs is to sustain life. A consensus was also *not* to add into search strategies terms attempting to establish the reasons for end of life care, but to *include* terms reflecting the closing down of active treatments: 'withdrawing active treatment'; 'withdrawing' or 'refusing' treatments such as dialysis; and 'moribund'. It was noted that the expected last six months of life is a term used in the US, and should be included.

It was agreed not to search for 'suicide', 'assisted death', 'assisted suicide' and 'euthanasia' (noting that euthanasia may be seen by some people using services as the only possible option when all else fails) as papers in these areas should be found through existing search strategies.

5. Finding grey literature, including non-research material
Websites to search which have already been identified by the project team were circulated, and SAG members were invited to identify more in the meeting or to forward these to Deborah Edwards via email after the close of the meeting. Suggestions made in the meeting included: a Hospice UK report (Kathleen Caper); deaths in custody (Steph Perrett); palliative care in prisons (Nikki Pease); searches on institutional repositories.

SAG members encouraged the project team to consider including outputs focusing on caregiver perspectives, and indeed the MENLOC protocol includes this as part of the project plan.

6. Summary of meeting

Discussions were recapped, and SAG members were thanked for their time and valued contributions.

7. Future meetings

The MENLOC timeline suggests a meeting in March 2019, to be scheduled via online poll.

8. Close

Ben Hannigan
Deborah Edwards