

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

Project Team and Stakeholder Advisory Group Meeting

Friday 08 March 2019

12:00 – 14:00

Room 704/705 Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB

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	Yes
Dr Liz Davies	Head of Mental Health and Vulnerable Groups Division, Health and Social Services Group, Welsh Government	Apologies given
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	Apologies given
Dr Helen Noble	Senior 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	Apologies given

Kathleen Caper	Head of Policy and Advocacy, Hospice UK	Apologies given
Jane Cook	National Health Advisor for Ministry of Housing, Communities and Local Government's Rough Sleeper Initiative	Apologies given
Dr Stephanie Perrett	Lead Nurse for Health and Justice, Public Health Wales	Yes
Sian Jones	Public and patient representative	Apologies given
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 v2

Revised terms of reference for the SAG were tabled, which now include an estimation of the expected length of time SAG members can expect to spend reading papers ahead of meetings.

[document: *MENLOC project team and SAG - terms of reference v2*]

3. Minutes of the meeting held on the 04 December 2018, and recap of decisions made

Notes from the last meeting were reviewed, and key decisions (particularly on search parameters and search terms) were recapped. It was noted that Dr Helen Noble is a *Senior Lecturer* at QUB.

4. MENLOC progress update: searching, screening and finalising included citations

Deborah Edwards presented an update on project progress since the December 2018 SAG meeting. It was noted that the project team had reviewed 7,830 citations having searched multiple databases, websites, tables of contents and other sources. Citations had been screened by two team members, with differences in the review of full-text items being referred to a third member. It was noted that team members had also convened during the morning before this SAG meeting to discuss citations for which there was still uncertainty, and to identify outstanding issues for tabling with stakeholders to agree a definitive judgment. Key areas discussed, and decisions made, were:

Case studies

Forty percent of the citations found addressing end of life care for people with pre-existing severe mental illness are single case studies. Mala Mann advised that including these in an evidence synthesis would be unusual, and following a suggestion from Michael Coffey it was agreed by participants that case studies could be subjected to a separate thematic synthesis to be included in the final report submitted to the to the HS&DR Journal.

Advance care planning and advance decision-making

Sally Anstey reminded participants that there is a difference between advance care planning and advanced decision-making, although some papers appear to use these terms interchangeably. A number of papers located explore end of life treatment preferences for those living with severe mental illness (SMI), but who are not currently at the end of life (EoL) (e.g. Foti et al 2005a), or advance care planning for those living with SMI but not currently at the EoL (Foti et al 2005b). These papers address hypothetical, rather than actual, end of life scenarios. It was agreed that even though they do not meet the review's inclusion criteria they should be referred to and used in a non-systematic section of the final report and be written up separately.

Eating disorders

Reflecting decisions made at the December 2018 SAG meeting, 'eating disorders' was not used as a specific search term. However, using other search strategies it was noted that one relevant paper in this area was retrieved (Lopez et al 2010) with another identified through back chaining (O'Neill et al 1994). Deborah Edwards reported on the project team's uncertainty as to whether a separate search in this field should be conducted, with the literature showing this to be a highly controversial area (including whether or not people with eating disorders should be considered as receiving 'palliative' care). Idris Baker agreed with this from his experience, and meeting participants were invited to guide the project team via further discussion. It was noted that all of the papers located falling into the eating disorders field were case studies, and reflecting the agreement noted above would therefore not be included in the main evidence synthesis but can be included in a separate thematic synthesis. Idris Baker also pointed out there is a difference between the physical sequelae (e.g. organ failure) of mental health problems such as eating disorders, and additional diagnoses (e.g. cancer) otherwise unrelated to mental illness. This distinction relates to a number of other (non-eating disorder) papers that the team have also been unsure of, and which can therefore be ruled out of the review as they do not focus on *additional* diagnoses.

Refusing treatment/non-compliance

Participants discussed whether an end-stage renal patient with pre-existing SMI refusing to have more dialysis was an example of EoL care in the context of this project. Paul Gill informed the meeting that a person in this position would only live for two weeks or so after stopping dialysis, and that therefore these are indeed people at the end of life. Discussion at the SAG meeting confirmed this, and Idris Baker observed that many people making the decision to refuse treatment do so because they have already learned that their treatment has ceased to be effective. The meeting also noted that all of the papers exploring these issues are case studies, and would therefore not be included in the main evidence synthesis as per decisions recorded above.

Suicide

It was decided that to be included a paper had to be about a person with severe mental illness who also had an additional end of life diagnosis. Papers about people with SMI who had attempted suicide, and who were then at EoL because of their injuries, would therefore not be included.

Severe mental illness

It was noted that the project team may need to revisit the inclusion of papers to make sure they relate to people with pre-existing severe mental illness. It was also 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.

5. Policy documents and grey literature: progress update and finalising documents for inclusion ***Policy documents from other countries***

At the project team's pre-stakeholder meeting Deborah Edwards reported that a number of policy documents had been retrieved via online searching for NSW Australia that covered both mental illness and EoL care. Sally Anstey reported that Australian EoL care is highly regarded in the global context, and if it is ranked as the world's best then an option would be to refer to this as a context-setter in the final project report.

Policy, guidance and grey literature for chronic conditions

Prior to the SAG meeting Paul Gill and Helen Noble had provided the project team with a list of documents relating to renal/kidney disease at EoL. However, there were no references to mental illness within any of these documents. Mala Mann and Deborah Edwards expressed confidence that the search techniques employed across each of the charitable and organisational websites, covering specific chronic conditions using EoL and mental illness, would have retrieved any documents that covered both these subject areas. Using renal disease as an example to test this out the team has decided that they will not search any further.

Generic policy documents

Deborah Edwards asked the SAG whether searching should include national generic healthcare policy documents such as England's Five Year Forward. The SAG felt that this would be a worthwhile exercise but Steph Perrett reminded the team to be mindful that they should not always expect to find references to mental illness and/or EoL care specifically as these documents relate to high-level strategy.

Prison and Probation Ombudsman reports

Deborah Edwards introduced these, which report on deaths in prison, where the team has reviewed one year's worth of reports. At the SAG meeting it was suggested that the team include them as a type of output in the non-systematic part of the project along with the case studies. Nikki Pease informed the meeting that she knew of a Master's student who has looked at palliative care in prisons, and will forward contact details.

Context of care

Sally Anstey proposed a section in the final report called 'context of care', to include papers that explore caring for people with SMI at EoL in hospices, palliative care units or psychiatric wards along with those papers that explore issues for homeless people with SMI at EoL. The SAG agreed with this decision, with Idris Baker pointing out that in the UK the term 'hospice' has changed over the years. Where it used to refer to a building it now refers more to care the community setting, In the US the term 'hospice' tends to mean community.

Charities and organisations

SAG members were asked to review lists of charities and organisations whose websites have been searched. Additional sites to search were suggested:

Samaritans: <https://www.samaritans.org/>

Llanmau: <https://www.llanmau.org.uk/>

SSAFA: <https://www.ssafa.org.uk/>

Community Housing Cymru: <https://chcymru.org.uk/>

National Housing Federation: <https://www.housing.org.uk/>

Shelter Cymru: <https://sheltercymru.org.uk/>

Shelter: <https://www.shelter.org.uk/>

Gofal: <http://www.gofal.org.uk/>

Compassionate communities: <https://www.compassionate-communitiesuk.co.uk/>

Byw Nawr: <https://www.dyingmatters.org/wales>

Combat Stress: <https://www.combatstress.org.uk/>

Royal British Legion: <https://www.britishlegion.org.uk/>

[all websites last accessed 08th March 2019]

Team members also noted an additional Welsh Assembly report into inequalities in palliative care, and a Welsh Government response to this, which should be reviewed in the policy section of the final report.

6. Summary of meeting

Main points addressed, and decisions made, were reviewed and thanks were expressed to SAG and project team members for their valued contributions.

7. Future meeting

The next combined project team/SAG meeting will be on 18 December 2019, 12.00 to 14.00, in Eastgate House (room to be confirmed). The agenda will include updates on further progress, dissemination and impact.

8. Close

Deborah Edwards
Ben Hannigan