

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

Project Team and Stakeholder Advisory Group Meeting

Wednesday 18 December 2019

12:00 – 14:00

Room 506/507 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
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	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	Yes
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	Apologies given
Roger Pratt	Public and Patient Project Member	Yes
Sian Jones	Public and patient representative	Yes
Huw Davies	Public and patient representative	Yes
Dr Julia Terry	Senior Lecturer, Swansea University (observer)	Yes

1. Welcome, introductions and apologies

Stakeholder advisory group (SAG) and project team members were welcomed by the chair, Nikki Pease.

2. Recap of study aims and objectives

Ben Hannigan presented a brief recap of the aims and objectives of the MENLOC study.

3. Recap of decisions made by group in previous meetings (BH)

With reference to the minutes from the last SAG meeting held on March 8th 2019, Ben Hannigan summarised the discussion and decisions made.

4. Summary of findings

Deborah Edwards presented details of the search strategy, Michael Coffey presented a summary of findings from the case study thematic synthesis and Ben Hannigan presented a summary of themes from the synthesis of policy, guidance and research. It was noted that case studies appear in the literature before research.

5. Observations on 'last year of life' (LYoL)

Sally Anstey led a discussion on how care in the LYoL varies, and/or how the content of care in the LYoL is unspecified, in material retrieved for the synthesis, and on how material retrieved for this evidence synthesis has revealed (for example) differences in the meanings attached to the word 'hospice' ('hospice' as a place, or 'hospice' as care provided at home). Project team and SAG members discussed how the final report for the NIHR might usefully include a commentary on this.

6. CerQual and GRADE

Deborah Edwards provided an overview of plans to use CerQual and GRADE, as a key task for the new year.

7. Clarification of terminology for final report

Following a discussion It was agreed to use the term 'patients with severe mental illness' but to add a note in the final report that the project team recognise that differences in terms used are found across the literature.

8. Dissemination/Accessible summary/Impact/Publications

Ben Hannigan opened a discussion on strategies to share findings from the MENLOC study. Members of the SAG agreed to receive and comment on the accessible summary (or equivalent) when it is produced, and to provide details of people and organisations who might be sent a copy. There was agreement to 'aim high' with journal papers, with *BMJ Supportive and Palliative Care* as a possible target. With the MENLOC grant award including support for open access papers the meeting noted the value of developing a publication strategy, potentially including the preparation of a research/policy paper and the preparation of a case study paper. Idris Baker informed the meeting of the high level of policymaking interest in Wales in end of life care, and project team and SAG members noted that the SAG includes people with access to government and cross-party AM groups. Idris is a member of the End of Life Board, which is a key group to which findings should be brought. Potential conferences for dissemination were discussed, including the Palliative Care Congress, the European Association of Palliative Care, the International Congress of the Royal College of Psychiatrists, the Wales Palliative Care Conference and the International Mental Health Nursing Research Conference. Ian Jones suggested a blog piece for the NCMH and Cardiff University mental health site.

9. End of project event

Ben Hannigan reminded people present that the MENLOC award includes a sum for a report launch event, to be organised once the NIHR Journal Library publication is published. Ideas discussed included an evening event sponsored by the Welsh Government

10. Future work/ideas

Ongoing plans to initiate new research building on the MENLOC study were shared and discussed.

11. Close

SAG members were thanks for their time and contributions at this and earlier meetings, and Nikki Pease was thanked by Ben Hannigan for serving as independent chair. The meeting closed with all present reminded that they will be welcomed to the launch event in the future.

Deborah Edwards

Ben Hannigan