

End of Life Care Guideline Committee meeting 1

Date: 04/03/2016

Location: National Clinical Guideline Centre, 180 Great Portland Street,
London, W1W 5QZ

Minutes: Draft

Committee members present:		
Adam Firth (AFi)		(Present for notes 1 – 4)
Annette Furley (AF)		(Present for notes 1 – 4)
Elizabeth Webb (EW)		(Present for notes 1 – 4)
Jan Ablett (JA)		(Present for notes 1 – 4)
Jan Bolton (JB)		(Present for notes 1 – 4)
Mark Thomas (MT) (Chair)		(Present for notes 1 – 4)
Sam Ahmedzai (SA)		(Present for notes 1 – 4)
Sarah Fisher (SF)		(Present for notes 1 – 4)
Sinead Clarke (SC)		(Present for notes 1 – 4)
Susan Dewar (SD)		(Present for notes 1 – 4)
Suzanne Kite (SK)		(Present for notes 1 – 4)
Tracey Doherty (TD)		(Present for notes 1 – 4)

In attendance:		
Jane Lynn (JL)	Business Analyst – Resource Impact Assessment Team, NICE	(Present for notes 1 – 4)
Juliet Kenny (JK)	Public Involvement Advisor, NICE	(Present for notes 1 – 4)
Susan Latchem (SL)	Guideline Lead/Operations Director, NCGC	(Present for notes 1 – 4)
Elisabetta Fenu (EF)	Senior Health Economist, NCGC	(Present for notes 1 – 4)
Lauren Ramjee (LR)	Health Economist, NCGC	(Present for notes 1 – 4)
Lina Gulhane (LG)	Joint Head of Information Science,	(Present for notes 1 – 4)

	NCGC	
Kate Ashmore (KA)	Documents Editor/Process Assistant, NCGC	(Present for notes 1 – 4)
Margherita Fanos (MF)	Research Fellow, NCGC	(Present for notes 1 – 4)
Tamara Diaz (TDi)	Project Manager, NCGC	(Present for notes 1 – 4)

Apologies:

Caroline Keir (CK)	Guidelines Commissioning Manager , NICE
Penny Wosahlo (PW)	Allied Health Professional
Lucy Watts (LW)	Lay member
Sarah Hodgkinson (SH)	Senior Research Fellow, NCGC

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the first meeting of the End of Life Care Guideline Committee. The Committee members and attendees introduced themselves.

No members of the public asked to observe the meeting.

The Chair informed the Committee that apologies had been received. These are noted above.

The Chair outlined the objectives of the meeting.

2. Confirmation of matter under discussion, and declarations of interest

Initials	Declarations of Interest	Type of interest	Decision taken
JA	<ul style="list-style-type: none"> Member of British Psychological Society (BPS) 	Specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> Member and previous chair of British Psychological Society, Faculty for Psychologists working in Oncology and Palliative Care. 	Specific personal non-financial	
	<ul style="list-style-type: none"> Macmillan badged health professional (post adopted by Macmillan, not funded by them). 	Specific personal non-financial	
	<ul style="list-style-type: none"> Occasional teaching on doctorate in clinical psychology programmes at university of Liverpool and at Lancaster University 	Non-Specific personal financial	
SA	<ul style="list-style-type: none"> NIHR National Specialty lead for Cancer Research outside the Acute Hospital. 	Non-specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> Chair of NICE guideline development group on Care of the Dying Adult. 	Non-Specific personal	

		financial
<ul style="list-style-type: none"> NIHR HTA research grant (effectiveness of early palliative care for advanced non-small cell lung cancer patients). 		Specific non-personal financial
<ul style="list-style-type: none"> Prostate Cancer UK research grant (development and validation of an online holistic needs assessment and care plan for prostate cancer patients). 		Non-specific non-personal financial
<ul style="list-style-type: none"> MRC research grant (clinical trial of saracatinib for bone cancer pain). 		Non-specific non-personal financial
<ul style="list-style-type: none"> Royalty fees from Oxford University Press (Textbook of Supportive Care in Respiratory Disease). 		Non-specific personal financial
<ul style="list-style-type: none"> Lecture fees for annual University of Amsterdam Master class on Palliative Care. 		Non-specific personal financial
<ul style="list-style-type: none"> PhD examiner (payment and expenditure). University of Odense, Denmark 		Non-specific personal financial
<ul style="list-style-type: none"> <u>Funding for the following have gone to University department -</u> <ul style="list-style-type: none"> Lecture fees from Amgen, AstraZeneca, Grunenthal, Mundipharma Consultancy fees from AstraZeneca, Grunenthal, Mundipharma 		Non-specific non-personal financial
<ul style="list-style-type: none"> <u>Funding for the following have gone to NHS Trust R&D department -</u> <ul style="list-style-type: none"> Research funding from Mundipharma (management of opioid-induced constipation) Research funding from AstraZeneca (prevalence and impact of opioid-induced constipation) Research funding from Grunenthal (management of cancer pain) 		Non-specific non-personal financial
<ul style="list-style-type: none"> Chair of Royal College of Physicians National End of Life Care Audit 		Non-specific personal financial
<ul style="list-style-type: none"> Member of NICE guideline development group on Multiple Myeloma 		Non-specific personal non-financial
<ul style="list-style-type: none"> Member of Royal College of Surgeons National Confidential Audit on Oesophago-gastric Cancer. 		Non-specific personal financial
<ul style="list-style-type: none"> Chair of National Cancer Research Institute Clinical Studies Group on Supportive and Palliative Care 		Non-specific personal financial
<ul style="list-style-type: none"> Elected Council Member, British Pain Society 		Non-specific personal non-financial
<ul style="list-style-type: none"> Member of Target Ovarian Cancer Scientific Board 		Non-specific personal

		non-financial	
	<ul style="list-style-type: none"> Member of Professional Advisory Board and Scientific Committee of Maggie's Centre 	Non-specific, personal non-financial	
	<ul style="list-style-type: none"> Steering group member of British Thoracic Oncology Group 	Non-specific personal non-financial	
	<ul style="list-style-type: none"> Chair of Respiratory Study Group of Multinational Association for Supportive Care in Cancer 	Non-specific personal financial	
	<ul style="list-style-type: none"> Resuscitation Council – Unified emergency care treatment plan 	Non-specific personal non-financial	
	<ul style="list-style-type: none"> Editor of Current Opinion in Supportive and Palliative Care 	Specific personal non-financial	
	<ul style="list-style-type: none"> On Editorial Board of BMJ Supportive and Palliative Care 	Specific personal non-financial	
JB	<ul style="list-style-type: none"> Macmillian 'badged' professional. 	Specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> Represented Association of Palliative Care Social Workers (APCSW) on the national ambitions group. 	Specific personal non-financial	
SC	<ul style="list-style-type: none"> Salaried GP - I see patients in the last year of life in my surgery, run Gold Standard Framework Meetings. 	Specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> GP Advisor Macmillan Cancer Support - I work for Macmillan on Regional work and National, some related to End of Life although most of my work is on consequences of cancer treatment and survivorship. 	Non-specific personal non-financial	
	<ul style="list-style-type: none"> Clinical Lead Cheshire End of Life Partnership - this is a charity based in Cheshire that provides education, facilitation and strategic leadership around End of Life Issues. We provide teaching all aspects of End of Life including the six steps programme for care homes. 	Specific personal non-financial	
	<ul style="list-style-type: none"> Cheshire End of Life Partnership - funded by our local partners which include hospices, CCGs and Counsels. 	Specific Non-personal financial	
	<ul style="list-style-type: none"> Clinical Director and lead for cancer and end of life South Cheshire CCG - I work as a Clinical Director for the CCG overseeing planned and urgent care and have also worked as a commissioner for End of Life Care for a number of years. 	Specific personal non-financial	
SD	<ul style="list-style-type: none"> Member of the Clinical Guideline Committee on "Care of the Dying Adult" NICE 2015 guideline. No remuneration. 	Specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> Article for the Journal of Renal Nursing 2016. No remuneration. 	Specific personal	

4.0.03 DOC Committee minutes

		non-financial	
	<ul style="list-style-type: none"> Member of the Clinical Advisory Board of Macmillan UK. Meet 3 times a year. No remuneration. 	Specific personal non-financial	
	<ul style="list-style-type: none"> Member of Royal College of Nursing. 	Non-specific personal non-financial	
	<ul style="list-style-type: none"> Talk at ASSL of Palliative Medicine conference in Glasgow on 09/03/2016. Expenses for train and overnight stay paid. 	Non-specific personal financial	
TDoH	<ul style="list-style-type: none"> Member of the Royal College of Nursing. 	Non-specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> MSc final year continuing professional project/systematic literature review on Education and Training on Advance Care Planning for Health Care Professionals. 	Specific personal non-financial	
AFi	<ul style="list-style-type: none"> Self employed as a GP Principal at Bracondale Medical Centre. 	Non-specific personal financial	Declare and participate
	<ul style="list-style-type: none"> Primary Care Medical Educator, responsible for a group of 30 GPs in Stockport. I deliver education on palliative care principles and practice. It is funded by Health Education North West deanery. 	Non-specific personal financial	
	<ul style="list-style-type: none"> Employed as a Clinical Lead for IT and Locality Vice Chair by Stockport CCG. Member of the committee which oversees the electronic palliative care coordination system in Stockport. 	Specific personal non-financial	
	<ul style="list-style-type: none"> Previously employed as Clinical Support Fellow in End of Life Care to advocate and support the delivery of generalist palliative care, at the RCGP.. 	Specific personal non-financial	
	<ul style="list-style-type: none"> Received royalties (<£1000 per year) from a book (an education resource for GPs in training helping them to pass training exams) that describes some palliative care scenarios. 	Non-specific Personal financial	
	<ul style="list-style-type: none"> Travel and locum expenses being paid by Pulse Live to deliver a workshop on the NICE CODA guideline (23/3/16) 	Specific personal financial	
	<ul style="list-style-type: none"> I sit on the Editorial Board of the British Journal of General Practice and receive expenses from the RCGP in relation to this 	Non specific Personal financial	
	<ul style="list-style-type: none"> I sit on expert advisory committee for the Summary Care Record and received expenses from the RCGP. 	Non-specific personal financial	
	<ul style="list-style-type: none"> I am a member of the RCGP, SAPC (Society of Academic Primary Care) and the IPPCN, an international palliative care network with a focus on research – not funded in any way and not subject to any direction. 	Specific personal non-financial	
	<ul style="list-style-type: none"> Member of EAPC Steering Group to develop the work of the EAPC Primary Palliative Care Taskforce which produced an advocacy resource to promote primary palliative care. 	Specific personal non-financial	
SF	<ul style="list-style-type: none"> Member of the Association of Chartered 	Specific	Declare and

	Physiotherapists in Oncology and Palliative Care; special interest group of the CSP.	personal non-financial	participate
	<ul style="list-style-type: none"> Phyllis Tuckwell Hospice Care is a registered stakeholder for the EOLC guideline committee. 	Specific personal non-financial	
	<ul style="list-style-type: none"> Director of the Friends of the Beacon registered charity. 	Specific personal non-financial	
AF	<ul style="list-style-type: none"> Director of not-for-profit 'Living Well, Dying Well' which provides End of Life training. 	Specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> Trustee of Clare House Children's Hospice. 	Specific personal non-financial	
SK	<ul style="list-style-type: none"> Member (non-office holder) of the Association for Palliative Medicine. 	Specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> On the editorial board (palliative care) for the British Journal of Hospital Medicine (expenses only). 	Non-specific personal non-financial	
	<ul style="list-style-type: none"> Expenses and fees paid for the NCPC/Macmillan conference, March 2016. 	Specific personal financial	
	<ul style="list-style-type: none"> Regional End of Life Care Lead, Yorkshire and the Humber, December 2014 – March 2016, one PA per week remunerated by NHS England. 	Specific, non-financial interest	
EW	<ul style="list-style-type: none"> Deputy CEO and Director of a charity run hospice that delivers NHS care (not for profit) – Arthur Rank Hospice Charity. 	Specific personal non-financial	Declare and participate
	<ul style="list-style-type: none"> Hospice UK – chair of Eastern region Executive and Clinical Leads in Hospice and Palliative care (ECLiHP) (attend a monthly meeting with Hospice UK). 	Specific personal non-financial	
	<ul style="list-style-type: none"> Regional executive Clinical Heads network – we receive payment from the Gold Standards Framework to deliver the programme. 	Specific non-personal financial	

The Chair and a senior member of the Developer's team noted that the interests declared did not prevent attendees from fully participating in the meeting.

4. Presentations

- 1) The Chair introduced Susan Latchem, Guideline Lead/Operations Director (NCGC), who gave a presentation on NCGC working practices.
- 2) The Chair and Sam Ahmedzai gave a presentation on the scope and the matrix of stages in the last months of life. The Committee then discussed the issues presented in relation to this guideline.
- 3) The Chair introduced Lina Joint Head of Information Science (NCGC), who gave a presentation on the role of an information scientist.
- 4) The Chair introduced Margherita Fanos, Research Fellow (NCGC), who gave

a presentation on introduction to reviewing.

- 5) The Chair introduced Lauren Ramjee, Health Economist (NCGC), who gave a presentation on health economics.
- 6) The Chair introduced Sam Ahmedzai, Clinical Advisor to the Guideline Committee who delivered a presentation on a draft Matrix for Service Delivery in the last year of life.
- 7) The guideline committee then split into two sub-groups to discuss the range of services that play a part in the last year of life and how they fit into the six phases during the last year of life.

Any other business

The Committee was informed about administrative matters relating to guideline development. There being no further business the meeting ended at 4:00 p.m.

Date of next meeting: 12/04/2016

Location of next meeting: Donald Hunter Room, Royal College of Physicians, 11 St Andrews Place, London, NW1 4LE.