

Date and Time: 30 October 2014 10:00 – 16:00

Minutes: Draft

Care of the dying adult: Clinical care of the dying adult in the last days of life

Guideline Development Group Meeting 1

Place: Royal College of Physicians, 11 St Andrews Place, Regent's Park,
London. NW1 4LE.

Present:	Sam Ahmedzai	Chair (SA)
	Susan Latchem	Guideline lead/Operations Director (SL)
	Elisabetta Fenu	Health Economics Lead (EF)
	Josh Ruegger	Research Fellow (JRu)
	Katharina Dworzynski	Senior Research Fellow (KD)
	Lina Gulhane	Joint Head of Information Science (LG)
	Lindsay Dytham	Document Editor/Process Assistant (LD)
	Sarah Hodgkinson	Senior Research Fellow (SH)
	Tamara Diaz	Project Manager (TD)
		Adam Firth
	Adrian Blundell	Geriatrician (AB)
	Annette Furley	Lay member (AnF)
	Cheryl Young	Care home representative (CY)
	David Edwards	Palliative care nurse (DE)
	Diana Robinson	Lay member (DR)
	Gwen Klepping	Specialist palliative care pharmacist (GK)
	Joy Ross	Palliative care physician (JR)
	Mike Grocott	Intensive care physician (MG)
	Susan Dewar	District community nurse (SD)
NICE Staff:	Caroline Keir	Guidelines Commissioning Manager (CK)
	Emma Chambers	Project Manager, Patient Involvement Programme (EC)
Apologies:	Maureen Carruthers	Community matron/Advanced nurse (MC)
	Natalie Laine	Lay member (NL)

Notes

1. Introductions and apologies

SA welcomed the group to the 1st meeting of this GDG. Apologies were received from MC and NL.

2. CK presented to the group on 'Working with NICE'.

3. EC presented to the group on 'Patient involvement' and the NICE Public Involvement unit.

4. SL presented to the group on the 'NCGC work programme and declarations of interests'.

5. SA presented to the group on the Scope of the guideline.

6. Declarations of Interests (DOIs)

The Chair asked all GDG members to declare any conflicts of interest.

SA declared the following personal pecuniary interests: Received lecture fees for Pain Forum lecture tour in March and April 2014. Travelling expenses and hotel accommodation were covered. Lectures included an analysis for the adequacy of the consumption of opioid analgesics, Assessing & Treating Pain in Patients with Substance Abuse Concerns, and Case presentation, some relating to end-of-life care.

SA declared the following non-personal pecuniary interests: For all of the following, fees were received by the University department:

- Lecture fees from pharmaceutical companies, charities, and academic groups.
- Fees from pharmaceutical companies for advisory boards.
- Fees from pharmaceutical companies for drug trial consultancies.
- Research grants from pharmaceutical companies
- Fees for attending charity advisory boards and research committees.

AB declared the following personal pecuniary interests: Due to receive royalties from the publication of a textbook on geriatric medicine due to be published in April 2015. Royalties would not be paid until December 2015.

AB declared the following personal family interests: Wife is a GP who is lead for palliative care at her practice.

AB declared the following non-personal pecuniary interests: Joint organiser of an annual GP refresher course which has pharmaceutical sponsorship. No personal payments.

AB declared the following personal non-pecuniary interests: Non-trustee on board of Nottinghamshire Age UK. Geriatrician representative on the Nottinghamshire End of Life Care Strategy Group. Non-funded educational presentations about end of life in frailty.

GK declared the following personal non-pecuniary interests: Involved in updating the Oxford Handbook for Clinical Pharmacy (update for 3rd edition due Spring 2015); wrote the EOL care section. There was no payment involved. Committee member on the Palliative Care Pharmacist Network which has taken on pharmaceutical sponsorship since 2013 from Napp, mainly for development of its website. GK is part of the committee group that makes shared decisions over where funding is used for the website development or annual conference but is not solely responsible for decisions. As part of her job as a specialist palliative care pharmacist for Oxford University Hospitals NHS Trust she is involved in the development of guidance and protocols for symptom management of palliative and end of life care patients. She is chair of the Palliative Care Medicines Management Group for OUH comprising healthcare professionals from Sobell and Katharine House Hospices. Gwen acknowledged that she will not actively get involved in similar activities for the next 12 months unless directly involved with personal employment with OUH.

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DE declared the following personal non-pecuniary interests: Member of the Royal College of Nursing Ethics Committee. Member of Public Health England Quality Assurance Group for the End of Life Care Communication Standard. Member of the National Council for Palliative Care Ethics Forum. Member of the combined Birmingham Cross City Clinical Commissioning Group & Birmingham South Central Clinical Commissioning Group, End of Life Care Clinical Advisory Group.

DE declared the following non-personal pecuniary interest: Care Quality Commission Specialist Advisor on End of Life Care. (This is to participate as a member of inspection teams. My organisation is paid for my time doing this work.)

AF declared the following personal pecuniary interests: Self employed as a GP in a practice. Employed in a post jointly funded by the Royal College of GPs (RCGP) and Marie Curie Cancer Care. Not subject to any specific direction within this role. Received royalties from a book (an education resource for GPs in training helping them to pass training exams) that describes some palliative care scenarios. Honoraria also received from RCGP for an advanced care planning resource as part of his role for the college.

Further paid role sitting on the proactive care board for Stockport CCG – no specific remit around palliative care currently but this may develop in the future.

AF declared the following personal non-pecuniary interests: Is a primary care medical educator, responsible for a group of 30 GPs in Stockport. Some areas of palliative care are covered but not specifically EOL care. It is funded by Health Education North West deanery – a nationally recognised education post.

Sits on expert advisory committee for the summary care record and received expenses from RCGP and NHS IQ. Sits on an on-going CQC group for a thematic review of inequalities in EOL care – part of the RCGP role and received expenses from CQC. A member of the RCGP, as well as an international palliative care network with a focus on research – not funded in any way and not subject to any direction. Director of a charity, Ivy Manchester Limited, who run a Christian Church in Manchester, but he does not actively provide any services for EOL care in this role.

AF declared the following personal family interest: Wife is employed in an NHS trust as a physiotherapist (not delivering EOL care).

MG declared the following personal pecuniary interests: Receives occasional honoraria for a group of meetings he is involved with organising with a group of 4 other people – 10 meetings throughout the year. The subject is intensive care and anaesthesia in general that occasionally touches on EOL care every 2-3 years. The group has never been directly sponsored for this. EOL care has not been discussed in the past year.

He chairs various meetings and is on editorial boards but not directly related to EOL care. Travel expenses only are received for these roles.

MG declared the following personal non-pecuniary interests: He is on the board of the Faculty of Intensive Care Medicine. Has written an article about dying in intensive care but this does not specifically relate to topics for review – a copy has been sent to SA.

MG declared the following non-personal pecuniary interest: He is involved in 2 social enterprise companies but does not receive payment from either of these. One looks after a bioresource for a large research consortium and the other is about medical innovation but neither relate to EOL care.

DR declared the following personal pecuniary interests: Has a small shareholding in Reckitt Benckiser (yields less than £1,000 pa)

PPI work - the following may pay expenses and/or honoraria for meetings, workshops or conference attendance; and for reviewing research proposals.

National Institute for Health Research. PGfAR funding panel from June 14. Occasional lay peer

Notes

reviews. National Cancer Research Institute. National Cancer Intelligence Network, NICE UK DUETs Steering Group. Health Research Authority, University of Leeds (IMPACCT study); Leeds Clinical Research Facility Executive (from Feb 14); CQC; NHS England; Healthcare Quality Improvement Partnership - Service User Network; NICOR at UCL; Cancer Research UK (Research Coach from June 2014); Royal College of Radiologists Academic Committee and Lay Network (from September 2014).

DR declared the following personal family interest: Sister-in-law works for UCL in Credit Control Section.

AnF declared the following personal non-pecuniary interest: Is a business advisor to the “Living Well, Dying Well” charity.

None of these DOIs required further action for items on the day’s agenda.

7. LG presented to the group on ‘Searching for the evidence’
8. KD presented to the group on ‘Introduction to reviewing’
9. EF presented to the group on ‘Introduction to health economics’

Date, time and venue of the next meeting

GDG 2: 31 October 2014, 10:00 – 16:00 in the Boardroom, NCGC offices, 180 Great Portland Street, London, W1W 5QZ.