

Committee membership list - Membership of End of life care for infants, children and young people: planning and management guideline Committee

Membership of End of life care for infants, children and young people: planning and management guideline Committee

Membership list

Name	Job Title, Organisation
Chair	
David Vickers (Chair)	Consultant Paediatrician, Cambridgeshire Community Services NHS Trust
Interim-chair (from April 2016)	
Emily Harrop (Interim Chair from April 2016)	Consultant in Paediatric Palliative Care, Helen & Douglas House Hospices Honorary Consultant, Oxford University Hospital NHS Trust
Members	
Peter Barry	Consultant Paediatric Intensivist, University Hospitals of Leicester
Karen Brombley	Nurse Consultant for Children and Young People's Palliative Care, Helen Douglas House Hospices Honorary Nurse Consultant, Oxford University Hospital NHS Trust
Lucy Coombes	Caroline Menez Research Sister and Clinical Nurse Specialist, Children and Young People's Outreach and Symptom Care Team, Royal Marsden NHS Foundation Trust
Stacey Curzon (from November 2015)	Youth Worker, Rainbows Hospice for Children and Young People
Bobbie Farsides	Professor of Clinical and Biomedical Ethics, Brighton and Sussex Medical School
Jane Green	Patient and carer member
Satbir Jassal	General Practitioner, Bridge Street

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	Medical Practice
Paul Nash	Senior Chaplain, Birmingham Children's Hospital NHSFT and Co-convenor Paediatric Chaplaincy Network (GB&I)
Fauzia Paize (from May 2015)	Neonatologist, Liverpool Women's NHS Foundation Trust
Zoe Picton-Howell	Patient and carer member
Amy Volans	Lead Clinical Psychologist and Systemic Family Psychotherapist, Diana Children's Community Palliative Care Team East London NHS Foundation Trust
Claire Wensley	Consultant Paediatrician, York Teaching Hospital NHS Foundation Trust
Sharon English (until March 2015)	Consultant in Neonatal Medicine Leeds Centre for Newborn Care Leeds Children's Hospital, LTHT
Elissa Coster (until September 2015)	Children and Families Worker, The Brain Tumour Charity
Topic co-opted members	
David Hamilton	Bereavement support co-ordinator and counsellor, Rainbows Hospice for Children and Young People
Afia Manaf	Pharmacist, Paediatric Critical Care, Royal Manchester Children's Hospital
Susan Lee	Specialist Nurse Organ Donation, NHS Blood and Transplant

Date last reviewed: 18/05/2016

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Declaration of Interests

The effective management of conflicts of interests is an essential element in the development of the guidance and advice that NICE publishes. Please refer to the NICE website for the [Policy on Conflicts of Interest](#).

Member	Interest declared	Type of interest	Decision taken
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Member	Interest declared	Type of interest	Decision taken
Peter Barry	No interests to be declared.	-n/a	Declare and participate
Karen Brombley	Masters dissertation on 'the factors that influence choices about place of care and death in children and young people.	Personal non-financial specific	Declare and participate
Karen Brombley	Submitted abstract to Cardiff about factors that influence choices about place of care and death in children and young people.	Personal non-financial specific	Declare and participate
Karen Brombley	Advisory volunteer role to Well Child charity - their remit is for recommendations on allocation of funding to nursing posts.	Personal non-financial non-specific	Declare and participate
Karen Brombley	Member and deputy chair of pain and palliative care MCRN group.	Personal non-financial non-specific	Declare and participate
Karen Brombley	Speaking at a regional study day on Advanced Care Planning - about the practical side of completing Advanced Care Plans (how, where, when etc)	Non-Personal non-financial specific	Declare and participate
Karen Brombley	Contributed to a Delphi Study	Non-Personal non-financial specific	Declare and participate
Lucy Coombes	In April 2015, will commence a 3 year position as a palliative care research sister. The post is funded by the Caroline Menez Trust through the Royal Marsden	personal financial non-specific	Declare and participate

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	Hospital.		
Lucy Coombes	Part of a team developing a research protocol regarding the R&D/ethics on what symptoms life limited children experience towards end of life. Funding of £6000 received from Shooting Star Chase Hospice.	non-personal financial specific	Declare and participate
Lucy Coombes	contributed to a journal article on 'Palliative and end of life care for children with diffuse intrinsic pontine glioma: results from a London cohort study and international survey'. The article is a retrospective cohort study of children with diffuse intrinsic pontine glioma (DIPG) aged 0-18 years who received treatment at Great Ormond Street or the Royal Marsden. An inventory of symptoms was compiled along with interventions received and a look at current service provision. The discussion is about the current state of palliative and end of life care for children with DIPG.	non-personal non-financial specific	Declare and participate
Lucy Coombes	As part of current role in team, responsible for recruiting patients,	Non-personal non-financial non-specific	Declare and participate

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	ensuring the protocol is followed, taking PK studies etc for a phase 1 open label drug study on Naloxegol which is an oral medication for opioid induced constipation.		
Lucy Coombes	Oral presentation accepted at the EAPC conference in Dublin in June 2016 with the title of 'the use of the 'surprise' question in paediatric palliative care. Aim to assess the sensitivity and specificity of the question 'would you be supposed if this patient dies within the next 12 months?'	Personal non-financial non-specific	Declare and participate
Lucy Coombes	Poster accepted on audit of resuscitation plans by ICPCN for conference in May 2016 in Argentina. Not attending meeting in person so no expenses.	Personal non-financial non-specific interest	Declare and participate
Lucy Coombes	Teaching at national study day on excess respiratory secretions in March 2016.	Personal non-financial specific interest	Declare and participate
Lucy Coombes	The team she works with have received final approval to conduct a research study entitled 'Pain and symptoms in children with advanced cancer: A longitudinal study to develop a	non-personal non-financial specific	Declare and participate

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	<p>comprehensive symptom inventory'. She is named as chief investigator. They will using a tool already validated in children with cancer (the memorial symptom assessment scale for 7-12 year olds and 10-18 year olds) to see whether there are any missing or redundant items when used in children with advanced cancer. They will also be comparing correlations between parent, child and nurse scores.</p>		
Elissa Coster	Works as the Children's and Families Worker at the Brain Tumour Charity	Personal financial non-specific	Declare and participate
Elissa Coster	Developing end of life resources for children, young people and young adults at the Brain Tumour Charity	personal non-financial specific	Declare and participate
Elissa Coster	Member of the recently established national neuro-oncology nurses meeting.	Personal non-financial non-specific	Declare and participate
Stacey Curzon	No interests to be declared		Declare and participate
Sharon English	Author of chapter in textbook 'Neonatology at a Glance' on neonatal palliative and end of life care - due to be published in 2015.	Personal financial non-specific	Declare and participate

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Sharon English	Member of guideline committee for British Association of Perinatal Medicine (BAPM) on perinatal palliative and end of life care. Published 2011 with no remuneration.	Personal non-financial specific	Declare and participate
Bobbie Farsides	Trustee of Medical Research Foundation - www.medicalresearchfoundation.org.uk	Personal non-financial non-specific	Declare and participate
Bobbie Farsides	Member of UK Donation Ethics Committee and of sub-group considering Children and organ donation	Personal non-financial specific	Declare and participate
Bobbie Farsides	Member of the Nuffield Council on Bioethics until April 2015 and Chair of their working group on Children's Participation in Clinical Research report to be published April 2015.	Personal financial non-specific	Declare and participate
Bobbie Farsides	Part of the UK Donation Ethics Committee (they offer a stipend of £160 per day meeting and meets approximately four times a year). She was involved in drafting of the guidance on paediatric organ donation but has not spoken or written publicly on the matter.	Personal non-financial specific	Declare and participate
Bobbie Farsides	Member of the UK	Personal specific	Declare and

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	<p>Donation Ethics Committee which has published a position paper on Children and Organ Donation http://www.aomrc.org.uk/docman?gid=63&view=category it has also commented UKDEC provides £160.00 per day to cover attendance at committee meetings (usually four per year) but does not pay for any work on projects between meetings</p>	non-financial	participate
Jane Green (Nee Morgan)	<p>She is a co-applicant for 'Ambitions for palliative and end of life care'. A national framework for local action 2015 - 2020 that urges local leadership to be at the forefront of improvement in end of life care. (National palliative and end of life care partnership, www.endoflifecareambitions.org.uk)</p>	personal non-financial specific	Declare and participate
Jane Morgan	<p>Member of Together for Short Lives Parent Carer Advisory Group</p>	Personal non-financial specific	Declare and participate
Jane Morgan	<p>Community champion volunteer for Havens Hospices.</p>	Personal non-financial non-specific	Declare and participate
Jane Morgan	<p>Applied to study Child Nursing BSc (Hons) at Anglia Ruskin University in Chelmsford</p>	Personal non-financial non-specific	Declare and participate
Jane Morgan	<p>She reviewed a</p>	Personal non-	Declare and

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	book called 'Luna's red hat' which relates to a child's grief after the suicide of a parent.	financial non-specific	participate
David Hamilton	No interests to be declared.	-n/a	Declare and participate
Emily Harrop	Submitted abstract to Cardiff international conference (Summer 2015). This is on the subject of Buccal opioids for breakthrough. It's essentially based on a questionnaire result.	Personal non-financial specific	Declare and participate
Emily Harrop	Contributor to second addition of regional advance care planning document (February 2015)	Non-personal non-financial specific	Declare and participate
Emily Harrop	A member of National Institute of Health Research (NIHR) medicines for children research network pain and palliative care clinical studies group. This is a multi-disciplinary group that supports and prioritises research in the area of palliative care and pain. This is an unpaid position, which was competitively gained (ie application process). The group looks at / discusses / evaluates studies on all areas of pain /	Personal non-financial specific	Declare and participate

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	palliative care.		
Emily Harrop	Contributor to APPM Master Formulary 3rd Edition in November 2014.	Personal non-financial specific	Declare and participate
Emily Harrop	Named Consultant for Advance Care planning at Children's Hospital in Oxford (part of the John Radcliffe). A teaching and coordinating role within current Honorary Contract. No change in remuneration or role description.	Personal non-financial specific	Declare and participate
Emily Harrop	Panel member on BBC Radio 4's 'Inside the Ethics Committee' which included a discussion on ethical issues related to a case of a child receiving end-of-life care.	Personal non-financial specific	Declare and participate
Emily Harrop	Met with neonatal ethics team for the palliative care funding review.	Non-personal non-financial specific	Declare and participate
Emily Harrop	Abstract written to be submitted to 3rd International Paediatric Palliative Medicine conference in Rome (Nov 2016) on antenatal paediatric palliative medicine	Personal non-financial non-specific interest	Declare and participate
Emily Harrop	Teaching session delivered on antenatal PPM and advance care planning to SpRs training in paediatric palliative medicine	Personal non-financial specific interest	Declare and participate

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	(National study day)		
Emily Harrop	<p>Co applicant on NIHR RfPB application with Prof Ian Wong (London School of Pharmacy): 'Bridging the gap in pharmacological treatment for paediatric palliative care (PPC). A multicenter observational study'. (to be submitted 23rd March 2016)</p> <p>(1) What medications, formulations, dose regimens, method of administration and licensing status are being prescribed for symptom relief in children and adolescents with LLCs? (2) What adverse drug reactions have occurred and what is their frequency? We propose to conduct a multicentre, observational study to collect baseline information in regard to what medicines, formulations, dose regimens and method of administration are being prescribed for symptom relief in children and adolescents with LLCs and to identify and evaluate the nature and frequency of any</p>	Non-personal financial specific	Declare and participate

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	adverse drug reactions. This is something that I have been less directly involved with for a number of years in an indirect capacity since undertaking some additional training in clinical pharmacology. Even if funded, this work will not start until 2017.		
Paul Jacklin	Paid an honorarium to be on an eczema expert panel for Dr Tracey Sach's NIHR Career Development Fellowship.	personal financial non-specific	Declare and participate
Satbir Jassal	Having a paper published in Journal of Paediatric Health on 'Symptom management'. No recommendations are made and this was written before he joined the guideline.	personal non-financial specific	Declare and participate
Satbit Jassal	Has been asked to do training for Paediatric specialist registrars in January. This will be relating to the prescribing of medication and the legal implications after the death of a child. The training will have no direct relevance to the guidelines.	personal financial non-specific	Declare and participate
Satbir Jassal	Child Health Lead for West Leicestershire CCG.	Personal financial non-specific	Declare and participate

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Satbir Jassal	Medical Director of Rainbows Children's and Young Adult Hospice.	Personal financial non-specific	Declare and participate
Satbir Jassal	GP Palliative care lead for NHS England East Midlands	Personal financial non-specific	Declare and participate
Satbir Jassal	Member of the Association of Paediatric Palliative Medicine.	Personal non-financial specific	Declare and participate
Satbir Jassal	Honorary consultant at LOROS an adult hospice	Personal non-financial specific	Declare and participate
Satbir Jassal	Honorary lecturer at Cardiff University in palliative medicine	Personal financial non-specific	Declare and participate
Satbir Jassal	Writes the Rainbow manual which the WHO may adopt. This is the hospice's symptom control manual in paediatric palliative medicine.	Personal non-financial specific	Declare and participate
Satbir Jassal	Author and Editor for the APPM formulary.	Personal non-financial non-specific	Declare and participate
Satbir Jassal	Co-Authored the Oxford Handbook of Paediatric Palliative Medicine. Royalties of approximately £100 are received per annum.	Personal financial non-specific	Declare and participate
Satbir Jassal	Member of and has strong links with Together for Short Lives.	Personal non-financial non-specific	Declare and participate
Satbir Jassal	Lecture in Moscow on Practical Pain management, DNAR and Criteria for admission to hospice.	Personal specific non-financial	Declare and participate
Satbir Jassal	Some of the papers used as evidence in	non-personal non-financial specific	Declare and participate

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	a review for this meeting authored by Hunt contained perspectives from children who were cared for at Rainbows Children's and Young Adult Hospice where SJ is the Medical Director.		
Satbir Jassal	That some of the papers used as evidence in a review for this meeting authored by Hunt contained perspectives from children who were cared for at Rainbows Children's and Young Adult Hospice where SJ is the Medical Director.	non-personal non-financial specific	Declare and participate
Satbir Jassal	Submitted a paper on symptom management in paediatric child health and rewrote a chapter in The Oxford Handbook in Palliative Care which focuses on the philosophy of care and principles of symptom management.	Personal non-financial specific	Declare and participate
Susan Lee	No interests to be declared.	-n/a	Declare and participate
Afia Manaf	No interests to be declared.	-n/a	Declare and participate
Paul Nash	Co-authored 'Multi-faith Care of Sick Children and their Families' JKP. London. June 2015. Royalties directly to employer.	non-personal financial specific	Declare and participate

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Paul Nash	Tutor at Midlands Institute for Children, Youth and Mission	Personal financial non-specific	Declare and participate
Paul Nash	The lead for Red Balloon Resources, the publishing arm of Birmingham Children's Hospital chaplaincy team. This organisation produce resources in paediatric spiritual and religious care for palliative, end of life and bereavement care. These are sold not for profit to other care professionals.	Personal financial non-specific	Declare and participate
Paul Nash	Presenting a paper on Palliative Spiritual Care at Paediatric Care Conference in Glasgow (October 2015). Payment was received but made directly to employer.	non-personal financial specific	Declare and participate
Paul Nash	Director of new research study and resource centre, Centre for Paediatric Spiritual Care encouraging research into the area of spiritual well-being in children.	non-personal financial non-specific	Declare and participate
Paul Nash	Vice chair of Trustees for Beyond the Horizon, a bereavement and loss support charity.	Personal non-financial specific	Declare and participate
Paul Nash	The co-convenor of the Paediatric Chaplaincy Network (GB&I), an informal support group for those offering religious and	Personal non-financial specific	Declare and participate

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	spiritual care in hospitals, hospices and in the community.		
Paul Nash	Co-authored 'Spiritual Care with Sick Children and Young People' JKP. London. September 2015	non-personal financial specific	Declare and participate
Fauzia Paize	A co-applicant for 'Ambitions for palliative and end of life care'. A national framework for local action 2015 - 2020 that urges local leadership to be at the forefront of improvement in end of life care. (National palliative and end of life care partnership, www.endoflifecareambitions.org.uk)	personal non-financial specific	Declare and participate
Zoe Picton- Howell	Given a talk about patient/parent perspective at the launch of 'NCPOD's' child health programme 22/10/15	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Chair of RCPCH Parent and Carer Advisory Group	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Member of RCPCH Ethics and Law Committee	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Member of Academy of Royal Colleges Lay Advisory Group	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Tutor at the NHS Leadership Academy	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Tutor on Health Inequality and Disability Stream at Edinburgh University	Personal financial non-specific	Declare and participate

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	Medical School		
Zoe Picton-Howell	Author of Edinburgh Law School's Course, Law, Rights and Ethics for Paediatrics	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Author of Paediatric Modules of Edinburgh Law School's LLM Compassionate Care	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Author of blog Triangulation of Thought	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	PhD Researcher Edinburgh University Law School researching how doctors make difficult medical decisions for disabled children with complex health needs.	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Author of chapter in disability matters e-learning platform launched in February 2015. The chapter's content was related to Choices and Decision Making and how to support children and young people in making decisions and how to advise those that are incapable of making decisions.	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Interview on Radio 2 programme for carer's week about the experience of caring for her son.	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Article published for	Personal non-	Declare and

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	Together For Short Lives newsletter in September 2015 about her son	financial non-specific	participate
Zoe Picton-Howell	Lay member to the National Patient Enquiry into Patient Outcome and Death, Study Advisory Group	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Attended an event for UK Sepsis trust at reception at the House of Commons 08/09/2015	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Attendance as a delegate at 'Turn up the volume' conference as guest of conference organisers (carerightnow.co.uk)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Attendance at Health Service Journals leaders summit as a guest of Health Service Journal (HSJ, November 2015)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	NHS Employers/ NHS Confederation/ Horizon Centre naming their conference suite in Leeds Horizon Centre 'Adam's place' after her son Adam Bojelian and holding a reception to unveil a plaque on 18th December 2015	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	NHS Employers/ NHS Confederation holding/hosting annual Adam Bojelian Memorial talk, 1st talk to be	Personal non-financial non-specific	Declare and participate

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	given by Kathy Evans of NHS England on 24/03/16		
Zoe Picton-Howell	NCEFOD talk on Chronic Disability Programme (unpaid)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Disability Matters talk at the RSM conference 'Patients and Families, the new doctors' (unpaid) - on co-production of Disability Matters. 20/10/15	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Talk on Disability Matters from parent perspective at Disability Matters Roadshow (2nd November)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	will be speaking at the NHS leadership conference on the 02/02.16. Lessons from the life of Adam	personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	In December 2015, NHS confed/ NHS Employers hosted a reception and unveiled AdsPlace at their Horizon Centre	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	there was an article in the Yorkshire Post about Adam and his relationship with the NHS leaders	Personal non-financial non-specific	Declare and participate
David Vickers	Works for East Anglia's Children's Hospices as Medical Director via a service level agreement with his NHS Trust	Personal financial non-specific	Declare and participate
David Vickers	Former Trustee, Together for Short	Personal non-financial non-specific	Declare and participate

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	Lives (until September 2013), remains a member and a member of Practice and Development Advisory Council		
David Vickers	Co-author of paper submitted to Cardiff International CPC Conference June 2015 on a mode of provision of out of hours care.	Personal non-financial non-specific	Declare and participate
David Vickers	Speaker on 'Palliative Care' at the BJHM conference (MA publications, palliative care 2016).	Personal non-financial specific	Declare and participate
Amy Volans	Coordinates a special interest group for psychologists working with infants, children and young people with palliative care needs. As part of this she co-chairs the London Children's Palliative Care Network.	Personal non-financial specific	Declare and participate
Amy Volans	Submitted application to organise a workshop at the 7th International Cardiff Conference on Paediatric Palliative Care (July 2015). The acceptance of the proposal is to be confirmed. The title is "Parents' narratives about compassion in children's palliative care: voices from the	Personal non-financial non-specific	Declare and participate

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	multicultural east end of London".		
Amy Volans	Contributed to the British Psychological Society and Together for Short Lives responses to the NICE consultation on the End of Life Care for infants, children and young people scope and to the same groups' responses to the House of Commons Select Committee on Palliative and End of Life Care in November 2014.	Personal non-financial specific	Declare and participate
Amy Volans	Employer's MDT service has applied to contribute data to the NHS England Palliative Care Funding Review Team's currency testing data collection point. This will involve submitting "activity" and "cost" data about patient care provided by the service to the Palliative Care Funding Team at NHS England who will analyse and interpret the data.	non-personal non-financial specific	Declare and participate
Amy Volans	Participated in interview with journalist writing an article for the Guardian on how school teachers can support each other and the wider community when a	Personal non-financial specific	Declare and participate

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	student has Palliative needs.		
Amy Volans	Invited to speak at the Barts Hospital Bereavement Conference on how healthcare staff can support each other and sustain themselves in work with bereaved families.	Personal non-financial non-specific	Declare and participate
Amy Volans	Abstract accepted for the Cardiff International Children's Palliative Care Network Conference 'Parents narrative about compassion in Palliative care'	Personal non-financial specific	Declare and participate
Amy Volans	invited to attend meeting with Together for Short Lives at the Houses of Parliament.	Personal non-financial non-specific	Declare and participate
Amy Volans	Gave brief presentation at Together for Short Lives regional network summit about the range of psychological services and models currently offered in different regions of the UK	Personal non-financial specific	Declare and participate
Claire Wensley	Author of a palliative care chapter in Paediatrics at a Glance – Miall, Rudolf and Smith	Personal non-financial specific	Declare and participate
Claire Wensley	Presented a poster at the RCPCH conference Glasgow 2013 and the Royal Society of Medicine meeting December	Personal non-financial specific	Declare and participate

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	2012, "What delays discharge in children with life limiting conditions?"		
Claire Wensley	Works as an ad hoc Bank Doctor at Martin House Children's Hospice	Personal financial non-specific	Declare and participate
Claire Wensley	Member of the steering group for the Yorkshire and Humber Children and Young Persons Paediatric Palliative Care network	Personal non-financial specific	Declare and participate
Claire Wensley	Member of the executive committee for the Yorkshire and Humber Children and Young Persons paediatric palliative care network (lead for the clinical subgroup)	Personal non-financial specific	Declare and participate
Claire Wensley	Wrote a chapter for an undergraduate paediatric text book	Personal non-financial non-specific	Declare and participate
Claire Wensley	Two articles published by the RCPCH - 'What delays discharge in children with life limiting conditions?' (2012) and 'Unannounced, single site, interprofessional real time simulation' (2015)	Personal non-financial specific	Declare and participate
Claire Wensley	Will be speaking at Yorkshire and Humber Children's and Young people's palliative care network annual conference on 10th March 2015 on symptom control	personal non-financial specific	Declare and participate

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	specific symptom to be confirmed.		
Claire Wensley	On the 20th of February 2016 she will be teaching at a workshop at APM medical students conference in York on paediatric palliative care.	personal non-financial specific	Declare and participate

Date last reviewed: 18/05/2016