



First Annual Progress Report

2006 - 2007

1. Please provide brief information on the progress of your Collaborative over the last year, including the learning of the collaborative experience, the projected future development and perspectives of the Collaborative from three members (excluding the corresponding applicants) of your Collaborative (not more than 2 pages).

COMPASS is a research collaborative of three lead institutions (University of Edinburgh, Kings College London and University of Leeds) and members of 12 other associated institutions founded in 2006.

This is the first Annual Report of the NCRI COMPASS Collaborative. We believe that COMPASS has made excellent progress in its first year.

Notable achievements:

- The award to members of the collaborative of grants totalling more than £8 million that benefited from the existence of the collaborative, including two CR-UK programme grant renewals.
- The publication of more than 50 peer reviewed SuPaC related scientific papers, the content of which has benefited from the collaborative.
- The award of nine NCRI SuPaC Capacity Building Grants to its associates.
- The agreement of a constitution and establishment of a 16 member Management Board of all grant holders which has met three times (September 2006, January 2007 and June 2007).
- The establishment of a nine member independent Advisory Group chaired by Dr Jane Cope, the Chief Executive of NCRI.
- The successful appointment to all the collaborative funded posts including an administrator and a postdoctoral researcher in each of the three Centres, and additional statistics posts.
- The creation of a collaborative website <http://www.compasscollaborative.com>
- The holding of a successful Annual Scientific Meeting held in Leeds with 70 participants including not only the COMPASS grant holders but many other collaborators, the Capacity Building Grant holders, and two service users.
- The establishment of a Masterclass research training programme in all three lead centres.
- SuPaC talks by COMPASS members at the NCRI annual scientific meetings in both 2006 and 2007.



The collaborative experience

In addition to these tangible achievements there has been substantial and increasing scientific dialog and collaboration between the members. Interestingly this greater collaboration has not only been between centres but also within centres [in which COMPASS members are often administratively and geographically separated].

Successful collaborations with other non COMPASS researchers [both our founding collaborators and others who were not part of original application] have been cemented by the successful NCRI Capacity Building Grant Scheme.

Forging a collaborative is at times a challenging experience from which we are rapidly learning and a tension between competition and collaboration remains. An early desire to make collaboration happen is giving way to a more organic approach.

We are slightly behind schedule because of the unanticipated delay in appointing to the posts [in particular the recruitment of post docs of the necessary calibre which required multiple advertisements and reinforced the need for building capacity by training young researchers]. However, we remain committed to our original vision, goals and overall timetable.

Future developments

We anticipate that COMPASS will:

- Develop greater links with CECo our sister collaborative.
- Grow with increasing strengthening of collaborative groups.
- Develop more organically formed rather than management driven collaboration and less differentiation between work strands.
- Develop more shared grant funded projects.

Perspectives of members

The following are abbreviations - the full perspectives are included in Appendix 1

David Weller Professor of Primary Care, Edinburgh University (Board member). “The COMPASS collaborative, in its first year, has progressed at a pace which reflects both the energy and dynamism of its constituent members and the constraints and challenges of setting up a collaborative.”

Daniel Kelly, Reader in Cancer & Palliative Care, Middlesex University (non-Board member) “In the real world collaborations usually emerge out of successful experiences with colleagues as well as mutual interests and trust. It has been an interesting experience to witness a more formal mechanism for research collaboration coming to life over the first year of the COMPASS collaborative.”

Steven Barclay Research Fellow in General practice, Cambridge University (non-Board member) “During its first year, the COMPASS Collaborative has given me valuable support as an isolated Palliative Care academic.”



2. What objectives, proposed in your application, have your Collaborative Group achieved during the last year? Do you believe that the Group will be able to achieve all the objectives set over the 5 year period of the grant? If not, please give reasons? (not more than 1 page)

The main initial objective was the establishing of the collaborative. We have agreed a constitution and Management Board, held regular meetings, set up a communication system, and a website, and agreed our core work programme. This initial objective has been a huge task but was essential for paving the way to meet our longer-term objectives, which are increasing research capacity and delivering research outputs.

Research capacity

We have also increased the collaborative's research capacity by providing administrative support, methodological expertise, research education and user involvement. Our objective of identifying and starting to train postdoctoral research fellows to contribute to and benefit from the collaborative and its programme of work has been partially met, and will be carried forward to subsequent years.

Research outputs

We are already sharing research expertise and have achieved a sustainable critical research mass. We are working on methodologies for development and evaluation of interventions. We aim to create a robust platform for multicentre studies including randomised trials, and a longitudinal descriptive study has already been piloted. There are already outputs in high impact journals.

We are on track to complete our 5 year objectives as stated in the application. As all of the research output objectives (see below) are long term, none are yet complete.

The longer-term objectives in terms of research deliverables can not yet be judged. These were as follows:

1. Deliver a standard set of assessment and outcome measures appropriate to the stage of illness.
2. Develop and evaluate information technology to improve clinic and home based assessment.
3. Develop management strategies of proven effectiveness for a range of patient problems starting with emotional distress that has been tested in definitive multicentre trials.
4. Develop the recommendations on improving the mental health of cancer professionals in supportive and palliative care and identify what leads to staff burnout and how to avoid it.
5. Have solved methodological problems that are barriers to research.

Progress toward the milestones on the path toward meeting these objectives - is described in the next section.



3. Has your Group been able to meet the milestones set for last year? If not, please provide reasons? (not more than 1 page)

Milestones for collaborative organization

We aimed to have appointed all the staff, to have set up communications systems, to hold an Annual Scientific Meeting, and for each work group to have met and established a work plan with delegated tasks. All the staff have now been appointed and are as follows:

POST	LOCATION	NAME
Postdoctoral Fellow	Edinburgh	Laura Hodges
Postdoctoral Fellow	Edinburgh	Annet Kleiboer *
Postdoctoral Fellow	King's	Liz Jamieson
Postdoctoral Fellow	Leeds	Kate Hill
Administrator	King's	Susie Edwards
Administrator	Leeds	Richard Garry
Administrator	Edinburgh	Elspeth Currie
Statistician	King's	Wei Gao
Statistician	Leeds (Honorary)	Julia Brown
Statistician	Edinburgh	Gordon Murray

* funded indirectly by the University of Edinburgh

Communication systems have been set up and include routine use of teleconferencing, the use of a virtual knowledge park file share system housed in the University of Leeds, and the developing use of three way video conferencing. We had a very successful Annual Scientific Meeting for the whole collaborative held in Leeds in June 2007. Masterclasses are now happening in all three centres and are detailed elsewhere in this report.

Individual work strand milestones (The original milestones are shown in Appendix 2)

Strand 1 (COMPASS funded academic staff contributing are KH, WG and AK)

The work identifying the shared datasets and the systematic literature review has begun and Panel is being set up. The milestone for the pilot longitudinal study has been exceeded as the study has not only been started but has been completed and a further grant application submitted. Strand 1 has established effective collaborative working between London, Edinburgh and Leeds and is well prepared to move into the second year.

Strand 2 (COMPASS funded academic staff contributing are LH, AK KH and GM)

The randomised trials of feeding back patient assessment information to oncologists in Leeds, and of nurse delivered management of depression in Edinburgh were both successfully completed and the associated CR-UK programme grants renewed. Specific studies of the views of cancer doctors, nurses and patients on the best way to manage distress have begun and the systematic review of the relevant literature is underway.

Strand 3 (COMPASS funded academic staff contributing are LH, LJ)

The systematic review on the mental health of nurses and allied health professionals has begun. The systematic review of training of nurses and other allied health professionals to deliver psychological interventions is at the proposal stage, and we are taking advantage of the opportunity to evaluate the nurse training programme in Edinburgh.

In summary, all three strands have fallen slightly behind milestones because of the substantial delay in finding and appointing suitable postdoctoral fellows. However, all are now on track to catch up with planned milestones.



3. What are the Group’s milestones for the coming year? (not more 1 page)

Milestones for collaborative organization

These will include an emphasis on three activities; firstly to develop our collaborative research programme; second to develop our postdoctoral fellow training by establish a training programme for each of the fellows; and third to increase our engagement, both with members of the collaborative outside the group of grant holders and with other relevant bodies.

- The research milestones are shown according to work strands below.
- The training will be based on individualised training plans for each of the postdoctoral fellows, with shared activities and courses across the three Centres.
- The engagement with a wider group of collaborators has been given a tremendous boost by the award of nine Capacity Building Grants in relation to the COMPASS collaborative. This was further consolidated by the Annual Scientific Meeting at which many collaborators, including the Capacity Building Grant holders, attended. Having established the core functioning of the collaborative, we are now planning an increased number of Masterclasses and open scientific planning events to maximise this engagement.

Individual work strand milestones for second year

These may evolve slightly but currently remain as defined in the original application:

Strand 1	Strand 2	Strand 3
<p>Undertake work comparing measures using statistical approaches.</p> <p>Multi-centre longitudinal study underway across several collaborative centres.</p> <p>Literature review and consensus of measures continues.</p> <p>Study to further develop patient symptom screening systems: funding sought.</p>	<p>Literature reviews underway.</p> <p>Development work on new interventions for depression and emotional distress commenced. This will include pilot studies of elements of intervention to address specific questions including:</p> <p>(a) how the intervention will relate to primary care;</p> <p>(b) the oncologist’s role in acting on screening information;</p> <p>(c) develop training in interpretation and response to screening information from patients</p>	<p>Literature reviews completed.</p> <p>Development and testing of elements of new training programme to help cancer nurses recognize and manage emotional distress begun.</p> <p>Study of mental health of nurses/AHPs commenced</p> <p>Study of impact of team work and team training on mental health of cancer workforce commenced.</p>



4. Grants submitted and awarded – please list all that have directly resulted from the work of the Collaborative in the last year. Those that are not directly the result of the Collaborative but which are considered to have benefited from the Collaborative could also be included but need to be clearly marked.

Direct result of the Collaborative

Transcutaneous Electrical Nerve Stimulation (TENS) for the management of cancer bone pain. Randomised, blinded, crossover external pilot study to establish primary outcome measures and acceptability of using TENS to control cancer bone pain.

Cancer Research UK and Cephalon: 2006-2007 **£44,000**.

Team: MI Bennett, MI Johnson, SG Oxberry, S Brown, JM Brown

Detecting psychological distress in palliative care patients

Evaluation of screening tool and development of care pathway for managing psychiatric morbidity in terminal care. Rosemary Fellowship Trust: 2006-2007 **£57,000**

Team: MI Bennett, M Stockton, M Kumar

Improving the management of breathlessness in cancer patients – investigating different models of intervention through multi-centre trials.

NCRI Supportive and Palliative Care Research Collaboratives Capacity Building Grant **£78,931**

Team: Booth S, and Higginson I

Sleep disturbance as a correlate of fatigue and mood in cancer care.

NCRI Supportive and Palliative Care Research Collaboratives Capacity Building Grant

£80,000

Team: Fleming L, Sharpe M, Espie C.

Reducing fatigue in individuals with cancer undergoing chemotherapy through support and education provided by telephone

NCRI Supportive and Palliative Care Research Collaboratives Capacity Building Grant

£79,995

Team: Ream E, Richardson A, Wolfe, C

Developing a controlled trial for cancer-related fatigue

NCRI Supportive and Palliative Care Research Collaboratives Capacity Building Grant

£81,677

Team: Stone P, Minton O, Sharpe M, Richardson A

The further development of the AFTER Intervention for cancer patients with raised fears of recurrence.

NCRI Supportive and Palliative Care Research Collaboratives Capacity Building Grant :

£78,200

Team: Ozakinci G, Sharpe M, Humphries G.

Building research in difficult symptoms for good end-of-life care (BRIDGE)

NCRI Supportive and Palliative Care Research Collaboratives Capacity Building Grant.

£66,714.

Team: Wee B, and Higginson I



Benefited from the Collaborative

Improving analgesic concordance using a DVD based information resource for community based palliative care patients and their carers: feasibility study of a randomised controlled trial. NAPP Educational Foundation Research Fellowship:2006-2007: **£15,000**

Team: Bennett MI, Closs SJ, Chatwin J, Simpson KH

Developing a Macmillan Psychosocial Assessment Tool for Hospital Patients
Addenbrooke's Charities **£45,943**

Principal Investigator: Booth, S.

The social impact of cancer on people of South Asian origin: patient interview study.

NIHR Research for Patient Benefit Programme: 2007 – 2009: **£80,742**

Team: Bradley C, Wright P, Stark D

RCT of the effectiveness of oxygen for the relief of breathlessness

National Institute for Health, USA **\$112,346**

Team: Currow D, Abernethy A, Booth S.

Does the institutionalisation of pain assessment using the EPAT package reduce pain in cancer unit inpatients more than usual care: a cluster randomised trial.

CRUK Population and Behavioural Sciences Committee. 2006-2009: **£654,000**

Team: Fallon M, Sharpe M, Murray G, Colvin L.

Home but not alone: can user led support improve QoL in patients with Head and Neck Cancer?

Macmillan Cancer Support User-led Research Grant

Team: Fisher S, Wright P, Velikova G.

Scoping exercise: generalist services for adults at the end of life- research, knowledge, policy and future research needs

NHS Service Delivery and Organisation National R&D Programme,2006 **£79,978**

Team: Higginson I, Shipman C, White P, Barclay S, Dale J, Dewar S, Fulop N, Gysels M, Hotoptf M, Koffman J, Lorenz K, Richardson A, Murray S.

A randomised trial of high versus low intensity training in breathing techniques for breathlessness in patient with malignant lung disease: a feasibility study.

NCRI SuPaC Collaborative grant 2007-2008: **£51,450**

Team: Johnson MJ, Barton R, English A, Bennett MI, Nabb S

A breath of fresh air: improving care and services for patients living and dying with chronic obstructive pulmonary disease, and their carers.

Scottish Chief Scientist Office, Scottish Executive. **£205,387.**

Team: Pinnock H, Murray SA, Worth A, Sheikh A, Porter M, MacNee W, Kendall M, Levack P.

Cancer Pain / Cancer Cachexia

European Union Palliative Care Board Programme Grant **Euros 2.9 million**

Team: S Kaasa , K Fearon, GW Hanks, L Radbuck, J Prier, F de Conno, Irene Higginson, M Fallon et al

Improving end-of-life care in nursing homes.

St Columba's Hospice The Robertson Trust and Lothian Health **£ 60,000**,

Team: Murray SA, Hockley J



Smith and Nephew Post Doctoral fellowship 2006-2009: **£109,280**
Team: J Nixon, J Brown, J Closs

Promoting Early Presentation Project
Cancer Research Project Grant 2007-2008: **£75,000**
Principle Investigator: Ramirez A.

Delayed presentation of Chronic Myeloid Leukaemia
Novartis project grant 2007-2008: **£50,000**
Lead applicant: Ramirez A.

Better ways of managing depression in people with cancer.
Cancer Research UK Programme 2007 - 2012. **£4 million**
Team: Sharpe M., Murray G, Weller D

Establishing a Bowel Screening Research Unit
Chief Scientist Office 2007-2010: **£436,981**
Team: Steele RJC, Fraser CG, Kenicer MB, Carey FA, Morton C, Black R, Brewster D, Walker A, Weller DP.

Routine Assessment of Symptoms, Functioning, Social Difficulties and Quality of Life of Cancer Patients to Improve the Process and Outcomes of Care
CR-UK programme grant 2007-2012: **£1.5 million**
Principle Investigator: Velikova G, J Brown, D Stark

Prevalence of neuropathic pain symptoms in patients with cancer bone pain referred for palliative radiotherapy .A multi-site project in Canada, UK, and India to assess neuropathic pain symptoms before and after palliative radiotherapy.
Tom Baker Cancer Center, University of Calgary 2006-2008: **\$7,890**
Team: Wu J, Hagen N, Bennett MI



6. New Grants to be submitted in the next 6 months- please list those that have directly resulted from the work of the Collaborative. Those that are not directly the result of the Collaborative but which are considered to have benefited from the Collaborative could also be included but need to be clearly marked.

Direct result of the Collaborative

Improving health care through the collection and use of self reported patient centred information to augment the clinical consultation in routine NHS practice

NIHR

Team: Brown J, Tennant A, Selby P, Stark D, Conaghan P, Velikova G, Wright P, McCabe C, Sharpe M, Wallace P, Walker S, Holt R.

A year with advanced cancer: the changing experiences of illness effects, care received and costs for those living with advanced lung and colo-rectal cancer.

Cancer Research UK

Team: Higginson I, Richardson A, McCrone P, Hotopf M, Kendall M, Stark D, Barclay S, Chinn D, Brayne C, Maher J, Thompson S, Murray SA.

Randomised controlled trial of a mobile phone based remote symptom monitoring system in patients with cancer receiving chemotherapy

Funding body TBC

Team: Kearney N, Maguire R, Norrie J, Miller M, Richardson A, Walker A, Meurig S, Velikova G, O'Carroll R

The efficacy of acupuncture and self-acupuncture in managing cancer-related fatigue in breast cancer patients: a pragmatic randomised trial.

Breakthrough Breast Cancer

Team: Molassiotis A, Richardson A, Filshie J, Mackereth P

Benefited from the Collaborative

Evaluation of the "Prognostic Indicator Guide" to identify patients at high risk of dying within 12 months.

Outline submitted to Scottish Chief Scientist Office Feb 2007.

Team: Murray SA, Chinn D, Thomas K, Sheikh A.

Improving end of life care for frail older people: prospective longitudinal qualitative study.

Royal Society of Edinburgh: Lloyd's TSB Foundation for Scotland PhD awards.

Team: Murray SA, Kendall M

Nurse-delivered supportive intervention for family members of patients with lung cancer: a pragmatic trial.

Burdett Fund

Team: Richardson A, Plant H, Moore S, Tuffey V, Gulliford M

Psycho-Social Impact and Outcome Measurement in neutropenic sepsis in paediatric oncology

Candlelighters and the NHS researcher development award scheme

Lead applicant: Stark D

Promoting breast screening and early presentation of symptomatic breast cancer in Black African and Afro-caribbean women in South East London

Breakthrough Breast Cancer Project Grant

Team Ramirez A: Lead-applicant



5. Publications – please list those that have directly resulted from the work of the Collaborative. Those that are not directly the result of the Collaborative but which are considered to have benefited from the Collaborative could also be included but need to be clearly marked

Direct result of the Collaborative

Hagen N, Addington-Hall J*, Sharpe M, Richardson A, Cleeland C. The Birmingham international workshop on supportive, palliative and end of life care research (2006). *Cancer* 107(4): 874-881.

Smith AB, Rush R, Velikova G, Wall L, Wright EP, Stark D., Sharpe M. et al. The initial development of an item bank to assess and screen for psychological distress in cancer patients. *Psychooncology* 2006.

Benefited from the Collaborative

Adam B. Smith , Galina Velikova , E. Penelope Wright , Pamela Lynch and Peter J. Selby. Computer-assisted questionnaires may facilitate collection of quality-of-life (QOL) data: At a cost . *Computers in human behaviour* 2006, 22: 991-1000.

Armes J, Chalder T, Addington-Hall J*, Richardson A, Hotopf M A randomised controlled trial to evaluate the effectiveness of a brief behaviourally oriented intervention for cancer-related fatigue *Cancer* (in press)

Arraras JI, Kuljanic-Vlasic K, Bjordal K, Yun HY, Efficace F, Holzner B, Mills J, Greimel E, Krauss O, Velikova G. EORTC QLQ-INFO26: A questionnaire to assess information given to cancer patients. A preliminary analysis in eight countries. *Psycho-oncology* 2007 Mar;16 (3):249-54.

Bausewein C, Farquhar M, Booth S, Gysels M, Higginson IJ. Measurement of breathlessness in advanced disease: a systematic review. *Respiratory Medicine* 2007;101;399-410

Bennett MI, Livingstone H, Costello P, Allen K, Degg T. Symptom scores, serotonin and 5-hydroxyindole acetic acid levels in ovarian cancer patients with and without bowel obstruction. *Palliative Medicine* 2007; 21: 157-159

Brown E, Bennett MI. Survey of blood transfusion practice for palliative care patients in Yorkshire: implications for clinical care. *Journal of Palliative Medicine* 2007 (in press)

Brown SR, Thorpe H, Napp V, Brown J. Closeness to death and quality of life in advanced lung cancer patients. *Clinical Oncology* (in press)

Burgess C, Potts HWW, Hamed H, Bish AM, Hunter MS, Richards MA, Ramirez A. Why do older women delay presentation with breast cancer symptoms? *Psycho-oncology* 2006; 15: 962-968

Burton C, Weller D, Sharpe M. Are electronic diaries useful for symptoms research? A systematic review. *J Psychosom Res* 2007; 62(5):553-561.

Chow E, Hoskin P, van der LY, Bottomley A, Velikova G. Quality of life and symptom end points in palliative bone metastases trials. *Clin Oncol (R Coll Radiol)* 2006 Feb;18(1):67-9.



Clarke SA, Booth L, Velikova G, Hewison J. Social Support: Gender Differences in Cancer Patients in the United Kingdom. *Cancer Nurs* 2006 Jan;29(1):66-72.

Closs SJ, Staples V, Briggs M, Bennett MI. A qualitative study of the experience and impact of neuropathic pain symptoms: a focus group approach. *Journal of Pain and Symptom Management* (in press)

Cocks K, Cohen D, Wisloff F, Sezer O, Lee S, Hippe E, Gimsing P, Turesson I, Hajek R, Smith A, Graham L, Stead M, Velikova G, Brown J. An international field study of the reliability and validity of a disease-specific questionnaire module (the QLQ-MY24) in assessing the quality of life of patients with multiple myeloma. *European Journal of Cancer*. (in press)

Davies E, Linklater KM, Jack RH, Clark L, Møller H. How is place of death from cancer changing and what affects it? Analysis of cancer registration and service data. *British Journal of Cancer* 2006;95: 593-600.

Davies E, van der Molen B, Cranston A. Using clinical audit, qualitative data from patients and feedback from general practitioners to decrease delay in the referral of suspected colorectal cancer. *Journal of Evaluation in Clinical Practice* 2007;13:310-317.

Edmonds P, Vivat B, Burman R, Silber E, Higginson IJ. Loss and change: experiences of people severely affected by multiple sclerosis. *Palliative Medicine* 2007;21:101-10

Fallon M, Clausen E, Walley J, et al. Can the institutionalisation of cancer pain assessment as a 5th vital sign improve cancer pain control in the acute setting? *Palliative Medicine* 2006; 20(3): 231-232

Fallon MT, Fergus C. Evidence-base for the use of NMDA antagonists in malignant neuropathic pain in :Bennett M (Ed) Oxford Pain Management Library – *Malignant Neuropathic Pain* OUP 2006

Fallon M, Zeppetella G, Poulain P, Stein C Realising Unmet Needs in Breakthrough Pain *European Journal of Palliative Care* 2007 14:1

Gall C, Weller D, Esterman A, Pilotto L, McGorm K, Hammett Z, Wattchow D. Patient satisfaction and health related quality of life following treatment for colon cancer *Dis Col Rectum* (in press)

Grunfeld EA, Maher EJ, Browne S, Ward P, Young T, Vivat B, Walker G, Wilson C, Potts HW, Westcombe AM, Richards MA, Ramirez AJ. Advanced breast cancer patients' perceptions of decision making for palliative chemotherapy. *Journal of Clinical Oncology* 2006; 24: 1090-1098

Gysels M, Higginson IJ. Interactive technologies and videotapes for patient education in cancer care: systematic review and meta-analysis of randomised trials. *Supportive Care in Cancer* 2007;15:7-20

Gysels M, Richardson A, Higginson I. Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review *Health Expectations* (in press)

Henderson M, MacGregor B, Sykes N, Hotopf M. Use of benzodiazepines in palliative care *Palliative Medicine* 20(4):407-12, 2006



Henderson M, Scott S, Hotopf M. The use of the Clock Drawing Test in a hospice population *Palliative Medicine* (In press)

Higginson IJ, Davies E, Tsouros A. The end of life: unknown and unplanned? *European Journal of Public Health* 2007;doi:10.1093/Eurpub/ckm003

Jepson R, Thomson A, Hewitson J, Weller D. Patient perspectives on information and choice in cancer screening: a qualitative study. *Social Science & Medicine* 2007 (in press)

Kendall M, Harris FM, Boyd K, Sheikh A, Murray SA, Brown D, Worth A. What are the best methods of conducting end-of-life care research? A qualitative study. *BMJ* 2007;334:521,

Kendall M, Boyd K, Campbell C, Cormie P, Fife S, Thomas K, Weller D, Murray SA. How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers. *Family Practice* 2006; 23:644-650

Lokugamage A, Hotopf M, Butterworth S, Hardy R, Wadsworth MEJ, Kuh D. Breast cancer in relation to childhood parental divorce and early adult psychiatric illness in a British birth cohort study *Psychological Medicine* 2006, **36** 1307-12

Macdonald S, Macleod U, Campbell N, Weller D, Mitchell E. Systematic review of factors influencing patient and practitioner delay in diagnosis of upper gastrointestinal cancer *British Journal of Cancer* (2006) 94, 1272-1280

Molassiotis, A*, Gibson F, Kelly D, Dabbour R, Ahmad A, Richardson A, Kearney N. A systematic review of worldwide cancer nursing research (2006): 1994 to 2003. *Cancer Nursing*. 29 (6): 431-440.

Moore S, Sherwin M, Medina J, Ream E, Plant H, Richardson A. Caring for carers: a prospective audit of nurse specialist contact with families and carers of patients with lung cancer (2006). *European Journal of Oncology Nursing*, 10: 207-211.

Murray SA, Chinn DJ, Sheikh A. Access to psychological and psychiatric services needs to be improved for the dying *J Roy Soc Med* 2006;**99**:638-640

Murray SA, Kendall M, Grant E, Barclay S, Sheikh A. Patterns of social, psychological and spiritual decline towards the end of life in lung cancer and heart failure. *J Roy Soc Med* (In Press).

Murray SA, Mitchell GK, Burge F, Barnard A, Nowels D, Charlton R. It's time to develop primary care services for dying. *Journal of Palliative Care* 2006; **22**:

Murray SA, Sheikh A. Serial interviews for patients with progressive diseases. *Lancet* 2006; **368**: 901-902.

Murray SA, Sheikh A, Thomas K. Advanced care planning in primary care. *BMJ* 2006;**333**: 868-869

Murtagh FEM, Addington-Hall J*, Higginson IJ. The prevalence and symptoms in end-stage renal disease: a systematic review. *Advances in Chronic Kidney Disease* 2007;**14**:82-99

Murtagh FEM, Addington-Hall J*, Higginson IJ. The value of cognitive interviewing techniques in palliative care research. *Palliative Medicine* 2007; **21**:87



Murtagh FEM, Chai MO, Donohoe P, Edmonds MP, Higginson IJ. The use of opioid analgesia in end-stage renal disease patients managed without dialysis: recommendations for practice. *Journal of Pain and Palliative Care Pharmacotherapy* 2007;**21**:

Price A, Hotopf M, Higginson IJ, Monroe B, Henderson M. Psychological Services in Hospices in the UK and Republic of Ireland *J Roy Soc Med* 2006 **99** 637-639

Ream E, Richardson A, Alexander-Dann C, Supportive intervention for fatigue in patients undergoing chemotherapy: randomised controlled trial (2006). *Journal of Pain and Symptom Management*, 31(2): 148-161.

Richardson A, Medina J, Brown V, Sitzia J. Patients' needs assessment in cancer care: a review of assessment tools. *Supportive Care in Cancer* (in press)

Richardson A , Plant H, Moore S, Medina J, Cornwall A, Ream E. Developing supportive care for family members of people with lung cancer: a feasibility study. *Supportive Care in Cancer* (in press)

Smith AB, Wright EP, Rush R, Stark DP, Velikova G, and Selby PJ. Rasch Analysis of the Dimensional Structure of the Hospital Anxiety and Depression Scale. *Psycho-oncology* 2006, 15(9):817-

Stein K, Sugar C, Velikova G, Stark D Putting the 'Q' in quality adjusted life years (QALYs) for advanced ovarian cancer - An approach using data clustering methods and the internet. *Eur J Cancer*. 2007 Jan;43(1):104-13. E pub 2006 Nov 13.

Strong V, Waters R, Hibberd C, Rush R, Cargill A, Storey D, Sharpe, M. Emotional distress in cancer patients: the Edinburgh Cancer Centre symptom study. *Br J Cancer* 2007.

Tataru D, Robinson D, Møller H, Davies E. Trends in the treatment of breast cancer in Southeast England following the introduction of national guidelines. *Journal of Public Health* 2006; 28(3):215-217.

Taylor C, Graham J, Potts HWW, Candy J, Richards MA, Ramirez AJ. The impact of hospital consultants' poor mental health on patient care. *British Journal of Psychiatry* 2007; 190: 268-269

Thorpe H, Jayne DG, Guillou PJ, Quirke P, Copeland J, Brown JM. Pre-operative patient predictors of intra-operative conversion from laparoscopic-assisted to open surgery for colorectal cancer. *British Journal of Surgery* (in press)

Velikova G, Weis J, Hjermstad MJ, Kopp M, Morris P, Watson M, Sezer O; EORTC Quality of Life Group. The EORTC QLQ-HDC29: A supplementary module assessing the quality of life during and after high-dose chemotherapy and stem cell transplantation. *Eur J Cancer*. 2007, 43: 87-94

Whelan J, Dolbear C, Mak V, Møller H, Davies E. Where do teenagers and young adults receive treatment for cancer? *Journal of Public Health* 2007

Wattchow DA, Weller DP, Esterman A et al. General practice versus surgical based follow-up for patients with colon cancer: Randomised controlled trial. *British Journal of Cancer* (2006) 94, 1116-1121

Weller D. Colorectal cancer in primary care. *BMJ* 2006; 333: 54-55



Weller D, Campbell C. Early lung cancer detection: The role of primary care. *Primary Care Respiratory Journal* 2006; 15: 323-5

Wilkinson S, Love S, Westcombe A, Gambles M, Burgess C, Cargill A, Young T, Maher J, Ramirez A. Effectiveness of aromatherapy massage in the management of anxiety and depression in patients with cancer . *Journal of Clinical Oncology* 2007; Vol:25 (5) 532-539

* Members of the CECo collaborative.



8. Please list all research events and activities over the last year

Strands

Strand 1

Leaders Irene Higginson (overall lead based at KCL), Dan Stark (lead for Leeds), and Scott Murray (lead for Edinburgh) - and since her appointment Kate Hill - have met regularly face to face and via conference calls to review progress and plan activities. This has resulted in collaborative grant applications, including a large multicentre study, and has involved wider collaboration within members and beyond. In particular, this included supporting Sara Booth and Bee Wee in their successful SuPaC applications examining symptom management.

Strand 2

Leaders Michael Sharpe (overall lead based in Edinburgh), Galina Velikova (lead for Leeds) and Alison Richardson (lead for KCL), with Julia Brown and Gordon Murray (statistics), have had several face to face meetings supplemented with monthly teleconferences to review the findings of the previous trials in Leeds and Edinburgh and to ensure progression with the work implementation plan. Since her appointment, Laura Hodges is leading on these meetings. More frequent informal meetings between researchers in Leeds and Edinburgh have taken place as required.

Strand 3

Leaders Amanda Ramirez (overall lead based at KCL), Alison Richardson (KCL) and Michael Sharpe (lead for Edinburgh) have conducted monthly meetings in the form of video and teleconferences between researchers in Edinburgh and London. Since her appointment, Liz Jamieson is responsible for leading these discussions. Informal telecommunications have taken place regularly between the strand leads and the research fellows. We will be joined by Galina Velikova (lead for Leeds) to focus on the issues in training medical and nursing staff to deliver psychological interventions

Postdoctoral Fellows

The three post-doctoral research fellows are in regular telephone and email communication. The fellows met in person during the ASM in June, and plan to meet quarterly to keep one another informed of their work, share training opportunities, and receive peer supervision and support. The fellows will alternate on leading these meetings and in producing an update of work for the Management Board.

Annual Scientific meeting

We held our first Annual Scientific Meetings in Leeds in June 2007. This was regarded as a great success. There were 70 participants including not only the COMPASS grant holders but many other collaborators, the Capacity Building Grant holders and two service users. The meeting included research presentations, seminars, and especially successful was a 'speed dating' event for researchers to find collaborative partners. We collected written feedback from attendees and this was extremely positive (see Appendix 3)

Conferences

Members of the collaborative have presented at many conferences including last year's NCRI meeting.



9. Please list research events and activities planned for the coming year

Over the coming year the whole collaborative will continue to have Board Meetings three times yearly with frequent contact between the members of each work Strand.

Within each of the three main centres there is increasing contact with regular meetings between the principal investigators and local associates with developing use of video conferencing.

Since the first year there are three new areas of research activity which will develop further, and these are (a) communication with Capacity Building Grant Holders, (b) supervision of the postdoctoral fellows, and (c) links with the NCRI clinical study groups.

- The Capacity Building Grant holders are in frequent contact with their associated COMPASS Board Members as their research plans unfold.
- The appointment of the postdoctoral research fellows has provided both an additional impetus to work strands and a need for local training and supervision, with other COMPASS members acting as expert panels.
- Another evolving area of research activity is communication between COMPASS and the NCRI clinical study groups. We have now identified specific individuals who will liaise between specific study groups and the COMPASS Board. The study groups of most relevance to the collaborative are Psychosocial Oncology, Palliative Care and Primary Care.

Annual Scientific Meeting

The second COMPASS Annual Scientific Meeting will be held in Edinburgh in June 2008 and will combine showcasing of research highlights with training and opportunities to develop collaborations.

Conferences

Members of the collaborative have presented at the most relevant conferences. For the coming year, the highlight is the NCRI annual scientific conference in Birmingham (see Appendix 6). Professor Ramirez is giving a plenary lecture, and COMPASS and CECo have jointly planned symposia. The COMPASS symposium is on the topic of symptom management and is hosted by Professor Sharpe.



10. Please list all training programmes and activities over the last year

The main research training activities are those delivered as part of the local centre seminars and research Masterclasses described below.

The COMPASS Annual Scientific Meeting contained a major research training component with presentations and discussion sessions.

Seminars and Master Classes

King's College London

The open seminar programme at KCL has had seminars given by leading UK and international researchers. These monthly seminars are attended by a range of people, including researchers, students and clinicians from within the College and interested parties from universities, hospices and palliative care teams across the South.

The seminar series is augmented by Masterclasses, the first of which was on Managing Breathlessness, co-supported by The Cicely Saunders Foundation. This 1 day international symposium, relevant to clinicians and researchers who manage patients with breathlessness, was held on Friday 24th November 2006. The day included an evaluation of the latest developments in drug treatments and services for breathlessness and an appraisal of the neurophysiology. It brought together many national and international speakers on the theme of breathlessness. Several keynote lectures and presentations were given on the day, material from which is now available online (www.kcl.ac.uk/palliative/events).

University of Leeds Masterclasses

The University of Leeds has successfully started its Masterclass programme, with three having already taken place this year (see Appendix 3 for details of the topics and speakers).

The first of these in November 2006 was a meeting for the Northern Region Palliative Care Physicians' Group looking at different aspects of research in the field of palliative care. A second Masterclass, also in November, offered a study day for clinical nurse specialists working in palliative care and for other Allied Health Professionals who were beginning to engage in research activity. The programme was interactive with lectures combining with group work to identify research ideas and to practice project design. The third event in May, which comprised a lecture and discussion session on oral care in advanced disease, went well and was attended by over 60 palliative care clinicians (both doctors and nurses) from the Yorkshire cancer network.

University of Edinburgh Masterclasses

The Edinburgh seminars and Masterclasses have comprised talks and 'meet the expert' sessions.

Seminars have been co supported by the Edinburgh Psychological Medicine CR-UK programme and have capitalised upon visits to Edinburgh by UK and International researchers to provide lectures. Topics covered to date have included collaborative care management of depression; systematic reviewing of treatments for depression; the challenge of delivering psychological interventions to cancer patients and the management of symptoms in lung cancer patients.



11. Please list training programmes and activities planned for the coming year

In addition to our three times yearly Board Meetings which now include open science idea-generating sessions, approximately monthly open Research Masterclasses are planned for all three centres (King's College, Leeds and Edinburgh.)

The principle research training event for next year will be the 2008 Annual Scientific Meeting which will be held in Edinburgh. This meeting will aim to build on the success of the 2007 meeting held in Leeds and will include not only research talks and presentations but research workshops and 'meet the expert' sessions

In addition to these collaborative based events, individual members of COMPASS continue to take an active role in planning and executing a wide range of supportive and palliative care research training activities and events.



12. Please give a brief account of the user involvement last year (not more than 1 page).

User involvement is a cross-cutting theme within COMPASS that has a high priority within the COMPASS work plan. User involvement has the full and strong support of the Management Board. The Board includes a dedicated lead for user involvement and we have a ring-fenced user involvement annual budget. Our stated aim is to achieve effective user involvement in COMPASS activities by building and maintaining long-term relationships with service user groups and by encouraging and enabling user involvement at all levels of COMPASS activity. Progress has been made in the user involvement strategy during 2006/07:

- **User Involvement Group:** A number of COMPASS researchers have formed a User Involvement Group to achieve involvement in the collaborative. The group has been key to the delivery of the user involvement work listed below, and will work to drive user involvement in the research strands.
- **COMPASS Steering Group:** Following discussions with a number of service users across the collaborative, we now have two service user members on the COMPASS Steering Group. Both members are people with direct experience of cancer supportive and palliative care, and the members are associated with two different research groups and projects in the collaborative.
- **Capacity Building Grant applications:** Advice regarding user involvement was provided to applicants for Capacity Building Grants
- **User Involvement Toolkit:** We have developed a web-based 'toolkit' that provides an introduction to user involvement for COMPASS researchers and suggests ways in which researchers can work with service users. Whilst intended as a tool for COMPASS researchers, the web pages and resources have full public access. The toolkit was launched at our Annual Meeting in June 2007, and will be updated regularly.
- **Joint working with CECo:** Both the COMPASS and CECo collaboratives recognise the potential for joint working around User Involvement. The two collaboratives' user involvement leads have met during 2006/07 to agree working principles and to discuss possible areas for collaborative work.
- **COMPASS research:** User involvement is visible in different parts of the COMPASS collaborative. People affected by cancer are actively involved in a range of activities with the Cancer Care Research Centre at the **University of Stirling**, with fifteen groups of people meeting regularly across Scotland to feed into the centre's research agenda. The Primary Palliative Care Research Group at the **University of Edinburgh** works with two groups of patients with cancer and carers in the development of new projects, and is planning a user-led study on fatigue. Service users continue to be significantly involved in the direction and delivery of research conducted by **King's College London** and **Worthing Hospital**, for example on a recent project to develop a national framework for the assessment of supportive and palliative care needs for adults with cancer.

Priorities for 2007/08 are to:

- Test and refine the user involvement toolkit.
- Pursue joint working with CECo, possibly in the form of joint training on user involvement.
- Further develop plans for user involvement within each research strand
- Develop plans for the capture and dissemination of COMPASS user involvement activities.



13. Please give a brief account of the management and co-ordination of the Collaborative, including challenges faced and changes made to the original proposed structure. (not more than 1 page)

The collaborative is managed by a Board with representatives from each of the three Lead Centres and also from the wider collaborative. Day to day management is by an executive of three members of the Board including the Chair of the Board. The Management Board has access to an Advisory Board (see Appendix 4) chaired by Dr Jane Cope. The aim of the Advisory Board is to act as “a critical friend” and provide strategic guidance to the Management Board. Each of the three work strands has a leader and is accountable to the Board. The administrators and postdoctoral students are attached to each of the three lead Centres and also have specific responsibilities for the work of the Strands.

Challenges faced

1. Engaging the whole collaborative

The first year of the collaborative has been taken up with getting to know each other and establishing effective joint work patterns. This has led to a relative neglect of the much wider group of collaborators who are named on the original application, and that we have now started to rectify this. The Capacity Building Grant scheme and the Annual Scientific Meeting have been effective ways of achieving this wider engagement (see Appendix 5). We will build on it further by extending our Board meetings so that they include substantial time on brain storming and research planning that will be open to collaborators.

2. Developing collaborative attitudes

Collaboration is not always seen as worthwhile by successful researchers who are typically focussed and competitive. We have also had to accept that Universities are under increasing pressure to compete, especially in this year preceding the 2008 Research Assessment Exercise. We have learned that competition and independent working will inevitably continue alongside specific areas of focussed collaboration.

3. Managing a large organization

COMPASS is large. There are not only the three main centres but also the many other sites the collaborators work in and recently, the additional Capacity Building Grant holders. Managing this diverse and loosely connected organisation so that it feels inclusive and grows organically, but also remains focussed, is challenging.

4. Costs and benefits of collaboration

There is a danger that the time spent administering by senior researchers will take away from, rather than add to, the total UK capacity for SuPaC research. To guard against this we are adopting light touch management and ensuring that as much of the activity as possible is focussed on research and not merely on the collaborative process.

Summary

We have completed the first year of COMPASS successfully. We have faced and will continue to face the challenges to be expected from joint working across subject areas and Universities, but despite this the collaborative has not only remained intact but has flourished. We feel we have established foundations upon which we can start to build useful collaborative projects so that in coming years our reports will be able to include increasing numbers of grants and publications which have directly benefited from the funding of the COMPASS collaborative.



Appendix 1

PERSPECTIVES OF COLLABORATIVE MEMBERS

David Weller Professor of Primary Care, Edinburgh (Board member)

The COMPASS collaborative, in its first year, has progressed at a pace which reflects both the energy and dynamism of its constituent members and the constraints and challenges of setting up a collaborative. Establishing a consortium in a relatively new and complex area such as SuPaC research must inevitably involve a steep learning curve. Consequently in its first year the collaborative has needed to focus on core management tasks. There's no doubting the transaction costs of keeping a collaborative such as this together, and there will need to be ongoing effort to promote true collaboration between the three strands and centres – but I feel there is good cause for optimism as genuine sense of collegiality is developing and focus on the management group meetings is shifting from process onto research - this clearly left members in higher spirits! Some specific comments:

- The post doctoral researchers are critical in promoting collaboration as this project matures and in ensuring that sub-themes (such as primary care) are incorporated.
- The splitting of administrative help between the centres can mean that management processes are challenging and efforts are needed to ensure coordination
- Efforts will also be required to keep our wider collaborators engaged
- We've been fortunate in being able to set up an advisory group and, in particular, to have Dr. Jane Cope leading it.
- The Masterclasses are a tangible output in which good progress is being made.

In summary, the first year has represented a good start and we have a clearer picture of how this collaborative is going to work over the next few years, the challenges we are likely to face and the areas in which ongoing efforts will be required. I suspect once we are more in the business of designing trials, refining instruments and discussing results (rather than the mechanics of setting up a collaborative) people will be able to more readily appreciate the benefits of this venture.

Daniel Kelly, Reader in Cancer & Palliative Care, Middlesex University, London. (Member of wider collaborative)

In the real world collaborations usually emerge out of successful experiences with colleagues as well as mutual interests and trust. It has been an interesting experience to witness a more formal mechanism for research collaboration coming to life over the first year of the COMPASS collaborative. The three research strands have provided a focus for future work and are central to the focus of projects being identified. There appears to be genuine enthusiasm for encouraging wider collaborations, however, the mechanisms for doing so have yet to be established. I think some members of the wider collaborative might have hoped for more input over the past year. That said successful collaborations are likely to emerge if people remain open to new ideas and feel that they can benefit from being involved. This is a question of communication and inclusiveness as much as anything else. My own interest in sociological aspects of palliative care, for example, could be developed further within the COMPASS collaborative. This would help reveal some of the contextual influences that might determine why interventions succeed, or, indeed fail within practice. Having been involved in its planning I feel the annual conference will provide the ideal forum to reinforce new, as well as existing, working relationships; new ways thinking about palliative care research and closer collegiate working. There is a vast amount of talent and expertise within the COMPASS group and I feel it has the potential to establish a programme of research that could really improve the care of patients.



**Steven Barclay Research Fellow in General practice, Cambridge
(Member of wider collaborative)**

During its first year, the COMPASS Collaborative has given me valuable support as an isolated Palliative Care academic. My home base in the Cambridge University Department of Public Health and Primary Care gives me very strong generic scientific support, but has no subject-specific expertise. Over the years I have developed strong links with Prof Higginson and colleagues in the Department of Palliative Care and Policy at King's London, where I am an Honorary Senior Lecturer. During 2006 I was very grateful for the advice of several members of COMPASS in working up my successful application for a Department of Health / Macmillan Post Doctoral Research Fellowship. Profs Ramirez and Higginson gave me a mock interview during the lunch break of one of our meetings in Leeds. A further mock interview with Prof Sheikh and Dr Chinn in Edinburgh crystallised some key issues further. As my named mentor, several discussions with Prof Murray have been very insightful and formative. Some of this support I would have had through networks other than COMPASS - but to have access to a wider corpus of senior academic expertise has been very stimulating and productive for a person in my position of relative isolation.

Summary

In summary the above comments are helpful in crystallizing both the challenges and potential benefits of constructing a collaborative as well as the need to set up a structure which allows collaboration to grow organically rather being forced.



Appendix 2

Original Milestones for first year as stated in application

Strand 1	Strand 2	Strand 3
<p>Data sets identified and prepared for work comparing measures using statistical approaches.</p> <p>Panel (including users) and consensus methods established to identify measures, commence literature reviews</p> <p>Longitudinal assessment study and pilot of methods: funding sought</p>	<p>Literature review undertaken and consensus meeting (including users) on interventions for distress and depression held</p> <p>Current treatment trials of management of distress and depression completed and the implications of their findings explored.</p> <p>Studies to address issues arising have been planned and funding for these sought</p>	<p>Literature review and consensus meeting (including staff and users) on training non-mental health care professionals to manage emotional distress begun</p> <p>Project grant funding sought</p> <p>Literature review on the mental health of nurses and AHPs involved in cancer care begun</p>



Appendix 3

COMPASS Research Collaborative Annual Scientific Meeting Leeds June 28th - 29th 2007

Thursday June 28th (evening)		
19.00	Evening drinks – Leeds Radisson Hotel	
19.30	‘Speed dating for research’ event	
20.30	Dinner – Leeds Radisson Hotel	
Friday June 29th		
08.30	<i>Coffee and registration</i>	
09.00-12.00 Morning Session – Plenary		
09.00	Welcome and introduction to the COMPASS collaborative	Professor Michael Sharpe Chair of the Management Board
09.15	The three research strands	
	• Strand 1 Assessment and measurement	Professor Irene Higginson
	• Strand 2 Development and evaluation of interventions	Dr Galina Velikova
	• Strand 3 Implementation of interventions in practice	Professor Amanda Ramirez
10.15	User involvement ‘toolkit’	John Sitzia and Professor Scott Murray
10.30	<i>Coffee</i>	
11.00	Presentations by Capacity Building Grant holders	
12.15	<i>Lunch and posters</i>	
13.30 – 15.30 Afternoon Session – Parallel sessions		
13.30	Presentations from the Wider Collaborative	
14.30	Strand based group work	
15.15	Feedback from strand leads	
15.25	Closing address	Professor Michael Sharpe
15.30	<i>Coffee</i>	



Participants Evaluation of COMPASS Annual Scientific Meeting

Collated scores from all evaluation forms received: forms returned by 31 delegates (meeting attended by 70 delegates)

	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree
The meeting gave me a clear insight into the research activity of the COMPASS collaborative			1	16	14
The meeting gave me valuable information on current Supportive & Palliative Care research			2	16	13
The meeting was a good opportunity to share research ideas			1	12	18
I have met people who I would consider collaborative research with in future			7	10 (N/A: 2)	12
I now understand where my research fits in with the COMPASS collaborative			4	16 (N/A: 3)	8



Appendix 4

COMPASS Advisory Group

Professor Neil Aaronson

Head, Division of Psychosocial Research & Epidemiology
The Netherlands Cancer Institute
Amsterdam
The Netherlands

Dr Jane Cope (Chair)

Administrative Director
NCRI

Professor Francis Creed

Professor of Psychological Medicine
Division of Psychiatry
University of Manchester

Professor John Ellershaw MA FRCP

Professor of Palliative Medicine
University of Liverpool
Director, Marie Curie Palliative Care Institute
Liverpool

Ms Nancy Lester

Director of Operations
Coordinating Centre
UK Clinical Research Network

Ms Carolyn Morris

Service user representative

Dr Norma Morris

Department of Science & Technology Studies
University College London

Mr Peter Rainey

Service user representative

Professor Michael Traynor

Head of Centre for Research in Healthcare Practice and Policy
School of Health & Social Science
Middlesex University



Appendix 5

COMPASS and the NCRI Capacity Building Grant Scheme

Name of applicant	Institution of applicant	Full title of application	COMPASS link person(s)
Dr Paddy Stone	St George's University of London	Developing a controlled trial for cancer-related fatigue syndrome	Michael Sharpe Alison Richardson Matthew Hotopf
Dr Leanne Fleming	University of Glasgow	Sleep disturbance as a correlate of fatigue and mood in cancer care	Michael Sharpe Alison Richardson
Dr Emma Ream	Kings College London	Developing a nurse delivered telephone intervention to address chemotherapy induced cancer-related fatigue	Alison Richardson
Prof Ken Fearon	University of Edinburgh	Cancer cachexia/symptom clusters	Marie Fallon
Dr Sara Booth	NHS Cambridge	Breathlessness	Irene Higginson
Dr Bee Wee	NHS Oxford	End of life research	Irene Higginson
Miriam Johnson	University of Hull	Breathlessness management	Mike Bennett
Dr Gozde Ozakinci	St Andrews University	The further development of the AFTER Intervention for cancer patients with raised fears of recurrence	Michael Sharpe
Dr Barry Laird	University of Glasgow	RCTs in difficult cancer pain	Marie Fallon



Appendix 6

NCRI conference Birmingham September 2007.

Plenary lecture – 30th September

Promoting early presentation with cancer

*Amanda Ramirez

King's College London, UK

Parallel session Symptom management- 1st October

Monday 1 October: 15.15 - 17.30

Host: * Michael Sharpe

Edinburgh Cancer Research Centre, University of Edinburgh, UK

Speakers

Introduction: improving the management of symptoms in people with cancer - trials and tribulations

* Michael Sharpe

Edinburgh Cancer Research Centre, University of Edinburgh, UK

A randomised trial of a multi-component intervention for major depressive disorder in cancer patients

* Michael Sharpe

Edinburgh Cancer Research Centre, University of Edinburgh, UK

A randomised trial of cognitive behaviour therapy for fatigue in cancer survivors

Gijs Bleijenberg

Radboud University, Nijmegen Medical Centre, The Netherlands

Integrating principles of cognitive behavioural therapy in palliative care: a cluster randomised trial of nurse training

* Matthew Hotopf

Institute of Psychiatry, Weston Education Centre, London, UK

Proffered Papers

A randomised controlled trial to evaluate the effectiveness of a brief behaviourally oriented intervention for cancer-related fatigue

Jo Armes

King's College London, UK

A randomised controlled trial of a patient-held quality of life diary for patients with inoperable lung cancer

Moyra Mills

Queen's University Belfast, Northern Ireland, UK

Patients' and doctors' attitude to the routine use of quality of life assessment in oncology practice

* Galina Velikova

Cancer Research UK Centre, Leeds, UK

[* COMPASS grant holder, ** CBG holder]

