



Public Minutes of the COMPASS Management Board meeting

26th January 2010 - Leeds

Present: Dan Stark (DS) (Chair), Mike Bennett (MB), Julia Brown (JB), Elizabeth Davies (ED), Irene Higginson (IH), Peter Rainey (PR), Michael Sharpe (MS), Galina Velikova (GV), David Weller (DW), Richard Garry (RG), Susie Edwards (SE) **Apologies:** Marie Fallon (MF), Liz Forbat (LF), Matthew Hotopf (MH), Scott Murray (SM), Amanda Ramirez (AJR), Alison Richardson (AR), Aziz Sheikh (AS), Lisa Martin (LM)

Welcome & Minutes from the previous meeting

DS welcomed everyone to the meeting. The minutes of the previous meeting were accepted as an accurate record. The possibility of the BMJ co-hosting the final ASM was raised and the Board discussed potential benefits of this to the collaborative, such as having papers published in the main journal, or asking editors of relevant journals to give a talk at the event. The conference could be a bigger event, with free attendance for COMPASS members as usual and the BMJ community being charged separately. The Board were happy for the possibility of a joint conference to be discussed further. The possibility of someone from the BMJ "Making a Difference" campaign joining the Advisory Group should be put to Jane Cope as chair of this group.

Management Proposals: How the joint chairmanship of the collaborative will work

DS and IH reported that they were happy progressing as joint chairs and had not experienced any problems thus far.

Discussion of the report from the Rapid Review

The document from the Rapid Review was discussed and the need for funders to move away from funding smaller projects and to provide appropriate funding for larger programme studies was reiterated. Although there had been a shift towards more collaborative working, funding was still not being offered to suit this model. Comments on the Rapid Review document can be sent to Karen Groot until 28th February 2010.

The importance of higher complexity scores to attract funding for trials was raised, as was the potential usefulness of involving the CRNs to act as platforms to promote specific research in defined geographic areas. Dr Karen Poole (Advisory Group; NCRN) may be able to help with this. Nothing further was known about the meeting of funders designed to increase awareness of available funding that was proposed as part of the Rapid Review, but arrangements for this are believed to be in progress. The Wellcome Trust was raised as a potentially good source of funding, though it is unclear if they have any opportunities in fields relevant to COMPASS.

Feedback from the Advisory Group meeting; matters arising

1. Future funding - funding bodies for research and information on new initiatives

The introduction of management fellows was discussed; these are offered to people with SDO funding as a practical measure to look at implementation of the research in practice. The CBG scheme was raised at the Advisory Group meeting as something that the SuPaC management committee had viewed as successful, although there was no word on whether any further grants would become available at present. The administrators are developing a list of funding opportunities relevant to COMPASS.

2. Position papers - collaborative working and research priorities - End of Life & Survivorship

The Survivorship paper was discussed; this had evolved from the previous discussion document and was designed to bring together the current thoughts on Survivorship in light of the Rapid Review document, NCSI report and vision document. The paper looks at the priorities coming out of the evidence review and takes into account the changes in funding landscape and the lifetime of the collaborative. The message is to build on the strengths of the collaboratives. The paper could be submitted to the journal of the RSM for publication; those people who had worked on the paper would be listed as authors.

The status of the EOLC paper was recapped - this was prepared by MB, IH and ED as an editorial and is currently with Palliative Medicine journal. The EOLC and Survivorship papers would be separate and simply cross-reference each other. The EOLC paper in the 2008-2009 Annual Report acts more as a stock-take of COMPASS activity in this area and will not be developed further.

Research ideas under the Survivorship and End of Life Care banners

The aim of these was to funnel research ideas to funders through NCRl channels, however there had not been much interest from COMPASS members, most probably as it has since been established that the collaborative would not be funded further. As the future priorities have now been set, and there are other relevant calls for proposals open/coming up shortly it may not be attractive to proceed with this unless there was the opportunity to work with the funders directly.



What we do with the time and money left; pros and cons of a no-cost extension

The pros and cons of a no-cost extension were discussed. One possibility would be to ask for a short extension to prepare the final report and to act as a close-down period.

The importance of maintaining momentum through the latter stages of the grant was raised. A positive course of action may be to focus more on holding meetings to support proposal development and grant writing, and to meet with the NCRI and other funders etc. This could serve both to find out more about the likely shape of future funding and to plan for the future of COMPASS.

Wider Collaborative mentoring

The paper by LF was tabled and acknowledged. Any comments to be sent to DS via email.

User Involvement

The user group is putting together a leaflet detailing how best to engage with the Consumer Research Panel as some of the participants are new to research. A UI Masterclass is being prepared - this will be held in several locations, the first of which is likely to be London in Spring.

COMPASS/CECo meeting joint with the RSM in London in May 2010

The programme and advert for the meeting were tabled and acknowledged. The Board thought the programme for the day looked good.

COMPASS ASM 2011: Convene organising committee/ location/ dates/ BMJ sponsor

An organising committee will need to be convened for this, but it was agreed that the potential involvement of the BMJ should be determined first.

Strand postdoctoral and statistician written reports

The reports were tabled and acknowledged (see appendix).

AOB

Ways to engage GV more in the COMPASS management towards summer 2010 could be discussed at the next Executive Committee call.

Next COMPASS meeting:

Board meeting – Tuesday 29th June 2010; London



Appendix: COMPASS postdoctoral research fellow and statistician progress reports

Name: Louise Atkins

Period covered by report: September 09 – December 09

Date report submitted: 22.01.10

Objectives at start of this reporting period (as written in the last progress report):

1. Review of quality assurance of complex interventions: submission to BMJ in the next reporting period.
2. Contribute to the development of quality assurance strategies for a radiographer-delivered psycho-educational intervention to promote early presentation (PEP Intervention) in older women with breast cancer: to continue refinement and piloting of a package of quality assurance for the PEP Intervention. It is anticipated that this will be completed by end of 2009.
3. Systematic review of the mental health of doctors, nurses and allied health professionals: completion of final report early in the next reporting period.
4. Qualitative study of the impact of complaints on hospital doctors: this work will be revisited in the next reporting period to determine whether time resources are available to complete write up.

Description of progress (confine to no more than 250 words):

1. Review of quality assurance of complex interventions: the paper remains in advanced draft format with the aim of submitting it as an analysis paper to the BMJ early in 2010.
2. Contribute to the development of quality assurance strategies for a radiographer-delivered psycho-educational intervention to promote early presentation (PEP Intervention) in older women with breast cancer: I have contributed to the development and evaluation of three scales to measure quality of delivery of the PEP Intervention in terms of the content delivered, style of delivery and extent to which participants engage with the health professional delivering the intervention. The content scale has been piloted on several video-recorded interventions. I have conducted literature searches as part of the development of the two scales to measure style of delivery and participant engagement.
3. Systematic review of the mental health of doctors, nurses and allied health professionals: the final report now contains definitions of terms, descriptions of measures, methods and summaries of the 51 included papers.
4. Qualitative study of the impact of complaints on hospital doctors: progress with this workstream remains the same as the previous reporting period due to competing priorities.
5. Evaluation of a training programme for health professionals to deliver a complex intervention: a grant has been obtained to build an evaluation of a training programme for health professionals to deliver breast cancer awareness messages (Train the Trainer: Breast Health Promotion Programme).

Outputs:

Poster presentation of quality assurance of a health professional-delivered intervention to promote early presentation in breast cancer: Implications for practice at BPOS (December, 2009).

Objectives for next reporting period:

1. Review of quality assurance of complex interventions: submission to BMJ in early 2010.
2. Contribute to the development of quality assurance strategies for a radiographer-delivered psycho-educational intervention to promote early presentation (PEP Intervention) in older women with breast cancer: to complete the development and evaluation of three checklists of quality of delivery of the PEP Intervention.
3. Systematic review of the mental health of doctors, nurses and allied health professionals: completion of the final report in early 2010.
4. Randomised controlled trial of the PEP Intervention: contribute to the daily running of the trial.
5. Evaluation of a training programme for health professionals to deliver a complex intervention: produce a protocol for the evaluation of a training programme for health professionals to deliver breast cancer awareness messages. The aim is to evaluate the extent to which this programme increases knowledge, skills and confidence in trainees to deliver breast cancer awareness messages.



Name: Gao Wei

Period covered by report: 2 Sep 2009-16 Dec 2009

Date report submitted: 16 Dec 2009

Objectives at start of this reporting period (as written in the last progress report):

- To submit the clinical paper of the shared GHQ-12 data analysis;
- To start the methodological analysis on GHQ data soon after the submission of the clinical paper;
- To develop GPRD data analysis plan;
- To explore opportunities from existing data resources; identify other potential opportunities for data analysis of measures and outcomes, contributing to COMPASS collaborative and Strand I objectives;
- Familiarize and update relevant statistical methodologies (eg. missing data and longitudinal data analysis) in the areas of palliative care and cancer studies;
- Contribute to conference calls and collaborative activities.

Description of progress (confine to no more than 250 words):

- We will resubmit the first analysis paper focusing the clinical implications of psychological distress along cancer trajectory from our shared GHQ data; the first submission attempt to the journal of clinical oncology has not been successful;
- We've started the second analysis focusing on psychometric properties of the GHQ-12, a screening measure for psychological distress;
- We've received the GPRD data under MRC license, we are now developing analysis plan to look at prescription pattern of analgesics in cancer patients;
- We've submitted an outline protocol to bid for NIHR funds to look at geographical and temporal variation in place of death in UK. This analysis will use national death registry data and will provide up-to-date patterns of place of death for both cancer and non-cancer death;
- Pooled Zarit data analysis: See current drafts and submitted papers through to next steps towards publication, making revising and submitted papers/revising as appropriate. We've refined the full-scale ZBI analysis and the draft manuscript is being reviewed by investigators;
- Familiarize and update relevant statistical methodologies (eg. missing data and longitudinal data analysis) in the areas of palliative care and cancer studies;
- Conference calls ongoing and collaborative activities; through exploring the opportunities of secondary data analysis to develop/establish more wider collaborations with internal and external researchers (Strand I researchers, COMPASS statisticians) through participating regular teleconference, seminar, scientific meetings etc..

Objectives for next reporting period:

- To see current draft and submitted draft through to next steps towards publication, making revising and submitted papers/revising as appropriate;
- To finalize the methodological analysis on GHQ data and write-up for peer-reviewed journal;
- To finalize the analysis plan for the GPRD data and proceed to familiarize and clean data;
- To explore opportunities from existing data resources; identify other potential opportunities for data analysis of measures and outcomes, contributing to COMPASS collaborative and Strand I objectives;
- Familiarize and update relevant statistical methodologies (eg. missing data and longitudinal data analysis) in the areas of palliative care and cancer studies;
- Contribute to conference calls and collaborative activities.



Name: Trish Holch

Period covered by report: October 2009-January 2010

Date report submitted: January 20th 2010

Objectives at start of this reporting period (as written in the last progress report):

- To commence the development of guidelines for the management of emotional distress in cancer patients
- Continuation of the previous Compass Collaborative Project along with Dr Kate Absolom: Detecting and managing emotional distress in cancer patients: Analysis of semi structured interviews with health professionals.

Description of progress (confine to no more than 250 words)

Research

Development of guidelines for oncologists to manage emotional distress in cancer patients: progress thus far: i) Mapping of existing services to manage emotional distress in the institute of oncology, ii) Formation of a guideline development group (GDG) to inform and give relevance to development, iii) Ensuring current literature is informing practice in terms of intervention suggestions in guidelines, vi) Writing guidelines and disseminating them for iterations within the GDG and independent observers, Time frame for completion June 2010

QSS2-Compass Collaborative-strand 2 project; Detecting and managing emotional distress in cancer patients: Analysis of semi structured interviews with oncologists, surgeons, CNS's and ward sisters with Dr Kate Absolom. Using framework analysis we are now mapping and interpreting data from the thematic charts. I will also be involved in writing up this study with an aim of submission in Summer 2010

Training (completed)

- Searching the literature and managing your references for your research project Nov 2009
- Making successful applications to the research for patient benefit (RfPB) programme Nov 2009
- Emotional Disorders in Oncology and palliative care Chris Hosker Liason Psychiatrist Dec 2009
- Increasing the impact of research though visual thinking Dec 2009 Faculty of Medicine and Health

Collaboration communication

Informal telephone conference with post-doctoral research fellows October 2009

Video conference Compass strand 2&3 video conference December 2009

Further conference planned in February 2010

Email contact with other post-doctoral research fellows

Objectives for next reporting period:

Training

Courses booked for 2010:

- Endnote training University Library training January 2010
- Planning and Managing Research Projects SDDU June 2010
- Introduction to Radiotherapy session: Radiotherapy Department (Institute of Oncology) May 2010
- Introduction to Microsoft Access: Psychosocial Oncology Research Group Statistician 'In-house' training session
- Writing up your research for publication SDDU June 2010
- Preparing research proposals SDDU June 2010
- Effective Research Student Supervision July 2010

Collaboration communication

Compass Annual scientific meeting to be held in Leeds January 2010

Further Compass strand 2&3 conference planned for February 2010

Research

Development of guidelines for oncologists to manage emotional distress in cancer patients: Objectives are to i) canvass opinion and views from patient groups, oncologists and social workers and senior out patient nurse and incorporate suggested changes into the guidelines. Continue to develop/write guidelines, disseminate for independent review and incorporate feedback, introduce guidelines into QuEST pilot study and assimilate feedback from this project

QSS2-Compass Collaborative-strand 2 project; Detecting and managing emotional distress in cancer patients: the mapping and interpretation of this data will continue in collaboration with Dr Kate Absolom. The next stage will be writing up these findings for publication.



Name: Annet Kleiboer

Period covered by report: Sept 2009 - Jan 2010

Date report submitted: 20-01-10

Objectives at start of this reporting period (as written in the last progress report):

Training

- Several Masterclasses have been planned for the coming year, local research seminars will be attended and user-involvement training will continue.

Collaboration communication

- Continue working together with S2 collaborators and other post-docs.

Research

- Data collection for the persistence of distress study will be ongoing.
- The study determining the feasibility and acceptability of the IVR system will be ongoing.
- Finalise thematic review on psychological distress.

Description of progress (confine to no more than 250 words):

Training

- Two Masterclasses have been organised 1) Sally Wyke 'Complex interventions to support self management', 2) Geoff Wong 'What is a realist review and what can it do for me? An Introduction to realist review'
- The BPOS conference in Cardiff was attended as well as the launch of the Scottish Mental Health Research Network.

Collaboration communication

- S2/S3 meetings have continued and are planned for the coming year. Post-docs have contact on a regular basis.

Research

- Data collection for the persistence of distress study is ongoing; the study has recruited 216 patients so far.
- The study determining the feasibility and acceptability of the IVR system is ongoing. We recently started collecting data from patients on the acceptability of the system.
- The thematic review on psychological distress is delayed until April.

Outputs:

Hodges L, Butcher I, Kleiboer A, et al. Patient and general practitioner preferences for the treatment of depression in patients with cancer: How, who, and where? *Journal of Psychosomatic Research* 2009;**67**:399-402.

Kleiboer A, Bennett F, Hodges L, Walker J, Thekkumpurath P, Sharpe M. The problems reported by cancer patients with major depression. *Psycho-Oncology* In press.

Kleiboer A, Walker J, Holm-Hansen C, et al. The persistence of psychological distress in cancer outpatients: preliminary findings of a symptom follow-up study BPOS 2009 2009, Cardiff.

Objectives for next reporting period:

Training

- The Masterclass series will be reviewed within the Edinburgh Compass group and a plan for the coming year will be made. Local research seminars will be attended and user-involvement training will continue.

Collaboration communication

- Continue working together with S2 collaborators and other post-docs.

Research

- Data collection for the persistence of distress study will be ongoing.
- The study determining the feasibility and acceptability of the IVR system will be ongoing.
- Finalise thematic review on psychological distress.



Name: Lucy Ziegler

Period covered by report: September 2009- January 2010

Date report submitted: 20 January 2010

Objectives at start of this reporting period (as written in the last progress report):

- National Cancer Survivorship Review of Interventions completed and report submitted
- All Delphi study rounds completed and analysis complete
- Paper from systematic review re-submitted for publication
- IMPACCT study

Description of progress (confine to no more than 250 words):

- The scoping review commissioned by the National Cancer Survivorship Initiative on interventions for problems experienced by cancer survivors was completed in December 2009. The final technical report on interventions was submitted on 11 Jan 2010
- All stages of the Delphi study are now complete and data analysed. Total participants: focus groups (n=27), postal questionnaire (n=7), online questionnaire (n=24). Poster on outcome of the Delphi study was presented at BPOS Dec 09 and methodological paper on Delphi under preparation.
- Substantial revisions made to systematic review paper and split into 2 separate papers. The first paper reports challenges conceptualising distress and proposes a conceptual model. The second presents data on measure performance at key stages of cancer trajectory.
- IMPACCT (Improving management of pain in patients with advanced cancer in the community) study. Protocol written, literature review undertaken and ethics application submitted. Currently piloting topic guides and interview schedules.

Outputs

Presentations:

Ziegler L, Hodges L, Hook J, Stark D National Cancer Survivorship Scoping Review of interventions. Preliminary Findings COMPASS Scientific session, September 2009 Norton House Edinburgh, Scotland

Ziegler L, Hodges L, Hook J, Stark D Scoping of Interventions designed to improve the health and wellbeing of cancer survivors. . National Cancer survivorship Review of research Into Cancer Survivorship, September 2009 Tavistock Place, London

Ziegler L, Garry R, Bennett M, Higginson I, Murray S, Stark D .Developing an Appraisal Framework for self report measures. A Delphi Study.
British Psycho-social Oncology Society Conference, December 2009 Cardiff
Wales

Papers:

Determining Research Priorities for Cancer Survivorship: consultation and evidence review. Systematic scope and collation of research evidence regarding interventions. Zeigler L, Hook J, Stark D, Neilly L, Hodges L, Walker and Sharpe M.

Under revision:

Measuring psychological distress: A systematic review of self-report measure performance at key stages of the cancer illness trajectory. Ziegler, L Hill, K Neilly, Hill K, Higginson IJ, Bennett MI, Murray S, Stark, D Under revision for resubmission

Under preparation:

Ziegler, L Hill, K Neilly, Hill K, Higginson IJ, Bennett MI, Murray S, Stark, D What is psychological distress? The challenge of conceptualising and measuring psychological distress in oncology.

Ziegler L, Garry R, Bennett M, Higginson I, Murray S, Stark D. Gaining agreement on a framework for self-report measure selection through a Delphi consensus study. Methodological issues

Objectives for next reporting period: (January 26th - May 2010)

- Complete papers under preparation and submit for publication.
- Continue recruitment and data collection for IMPACCT study
- Continue to develop NIHR project grant application for submission May 2010