

WE ARE MACMILLAN. CANCER SUPPORT

GUIDANCE NOTES 2009
*FOR APPLICATIONS FOR
MACMILLAN CANCER SUPPORT FUNDING FOR*

DOCTORAL RESEARCH FELLOWSHIPS
POST-DOCTORAL FELLOWSHIPS
CAREER DEVELOPMENT FELLOWSHIPS
SENIOR RESEARCH FELLOWSHIPS

Remedi
enabling research in rehabilitation

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Introduction and Background

1. This document applies to the guidance notes for NIHR Doctoral Research Fellowships (NIHR-DRF), Post-Doctoral Fellowships (NIHR-PDF), Career Development Fellowships (NIHR-CDF) and Senior Research Fellowships (NIHR-SRF). Please note that in order to attract applicants from as wide a field as possible Macmillan Cancer Support is working alongside the NIHR Fellowship Scheme and we are happy to receive applications based on the NIHR format and application forms. For full details and to download documents of the NIHR research capacity development scheme at all four levels please go to <http://www.nccrcd.nhs.uk/>.
2. The National Cancer Research Institute (NCRI) has committed itself to increase the amount and quality of research in supportive and palliative cancer care through its report *Supportive and Palliative Care in the UK: Report of the NCRI Strategic Planning Group on Supportive and Palliative Care (SuPaC)*, July 2004 (available from the NCRI at www.ncri.org.uk). Six of the NCRI partners – Cancer Research UK, the Economic and Social Research Council, the Medical Research Council, the Department of Health, Marie Curie Cancer Care and Macmillan Cancer Support – have committed funding to collaborative research grants and to support new post-doctoral and senior lecturer posts.
3. In addition the SuPaC Management Committee recognized that the expertise within the Collaboratives would not completely address some of the under-researched areas and other needs identified by the Strategic Planning Group (SPG) and the NICE Supportive and Palliative Care Guidance for Adults with Cancer. In order to attract investigators with potential into these research areas and add value to the two established Collaboratives, the SuPaC Management Committee set aside funds for a Capacity Building Grant Scheme (CBGS) aimed specifically at supporting isolated or new investigators in achieving their research potential and addressing some of the gaps in the evidence base. It is hoped that, by linking isolated researchers with the funded Collaboratives which could provide the necessary scientific and/or infrastructure support, appropriate skills and sustainable capacity can be fostered. Applicants who would like to contact either Collaborative for advice should read Appendix B for details.
4. The Department of Health through the National Institute for Health Research (NIHR) is supporting the SuPaC initiative by encouraging applications to the NIHR Fellowship Scheme. Macmillan's contribution to this strategy for the past four years has been through the commitment of new funding for posts. In addition we are pleased to announce that in 2009 Remedi, a charity which supports medical research in rehabilitation, is offering a post-doctoral award on similar terms and conditions as Macmillan. Applicants who would like to be considered for Remedi (in addition to Macmillan) should apply using Macmillan's procedures as laid out below. (Please see Appendix C for Remedi information.)

5. The Macmillan awards have now become highly regarded, but we are usually only able to offer two or three awards per annum. In order therefore that applicants maximize their chances of gaining an award, we strongly encourage applicants to apply direct to NIHR and to let us know about their preference for Macmillan funding by sending a lightly amended version of the same forms direct to Macmillan (indicating where appropriate a preference for funding by Remedi). However, for some candidates only a Macmillan/Remedi application will be appropriate (see point 12 below). The deadline is the same for all these streams of funding:

Wednesday 7th January 2009 1pm.

6. As stated above this document applies to the guidance notes for NIHR Fellowships at all four levels:

Doctoral Research Fellowships NIHR-DRF
Post-Doctoral Fellowships NIHR-PDF
Career Development Fellowships NIHR-CDF
Senior Research Fellowships NIHR-SRF

Here we provide information relating to awards to be funded by Macmillan Cancer Support **in supportive and palliative cancer care** and it must be read in conjunction with the standard NIHR notes (obtained from the website above). It covers additional information and conditions required for funding, some of which differ from the standard NIHR conditions. Unless stated otherwise Macmillan requirements apply to Remedi. Appendix A contains information on Macmillan Cancer Support's research strategy and priority areas for research. Appendix C gives information about Remedi. The standard NIHR guidance notes should be used for an application for funding from Macmillan/Remedi unless specifically mentioned in this addendum. *Please note that the Remedi award is for post-doctoral clinical applicants only.*

7. All applicants for these awards are also encouraged to read the report of the NCRI Strategic Planning Group on Supportive and Palliative Care referred to above.

Eligibility

8. Macmillan awards are open to both clinical and non-clinically trained individuals working within the NHS, social care or recognised HEIs including current Macmillan professionals across the UK. Prior experience of working with either charity is **not** essential, but it is important that candidates take account of the notes below on specific sections of the application form where applicants must indicate clearly their reasons for wanting funding from Macmillan Cancer Support and/or Remedi.
9. Applications are welcome from individuals working in any scientific discipline and sector that can demonstrate a role and contribution to improving the health or health care of cancer patients and their carers and a commitment to a research career in this area.

10. Applicants for Post-Doctoral, Career Development and Senior Research Fellowships should also highlight evidence of team building/mentoring skills.
11. Funding will cover applicants across the UK. However, applicants from Scotland, Wales and Northern Ireland should follow the procedure detailed in the standard guidance notes in order to remain eligible for funding by their respective Devolved Administration should Macmillan Cancer Support not fund their award.
12. Candidates who find themselves otherwise eligible but are outside the time limits for NIHR awards (WTE 12 months PhD registration for DRF, 3 years and 7 years post-doctoral work respectively for PDF and CDF) are still welcome to submit a Macmillan application.

Scope

13. Macmillan funding is available for non-clinical researchers for 3 years full-time or up to 5 years part-time pro rata.
14. Support is **only** available part-time for clinical researchers because of the importance we place on a significant clinical grounding for clinical researchers. This can be for 4 or 5 years part-time funding according to standard NIHR conditions. However, Macmillan Cancer Support and Remedi have a preference for the higher proportion of clinical time and encourage clinical applicants to apply for 5 years part-time (ie 60% WTE).
15. We are particularly interested in candidates who:
 - Are clinicians or non-clinicians with a broad relevant background in supportive and palliative cancer care
 - Can demonstrate sound working relationships with centres of academic expertise in the core topics and methods of the proposed study area
 - Have an understanding of developing NHS policy issues relating to cancer care and support the United Kingdom
 - Have recent research experience (for Post-Doctoral and Career Development Fellowships at doctoral or post-doctoral level)
16. **Awards funded by Macmillan Cancer Support or Remedi will not cover University overheads or meet full economic costs of proposed research, ie will meet the directly incurred costs only.**

Application Procedures

17. Applications for awards for funding from Macmillan Cancer Support and Remedi will be handled by Macmillan. The basis for assessment for funding will be the same as for the NIHR except that the last criterion will include specific reference to our interests in research, ie:

The likelihood of the individual making a long-term contribution to research and development in supportive and palliative cancer care for the benefit of people affected by cancer within Macmillan Cancer Support's research priority areas. In this respect we strongly advise all potential applicants to contact Macmillan's Research Team (see page 8) to discuss their application. In addition contact with the NIHR awards managers (see standard guidance) is likely to be very beneficial.

18. In the case of preference for Remedi please see Appendix C and note that specific advice can be obtained from that organization (see page 8).

Completing the Application Form

19. The form to be sent to Macmillan should be completed as indicated in the standard guidance notes **but include** the additional information indicated for the specific sections below.
20. The standard guidance notes indicate that additional supporting information will not be considered. However, in the case of applications from existing Macmillan Cancer Support professionals a supporting statement will be required from the professional's Macmillan Development Manager (see notes to SECTION F – DECLARATIONS AND AUTHORISATIONS).
21. The specific or additional information required for consideration for funding from Macmillan Cancer Support (and Remedi) relates to the following sections of the application form:

SECTION A - APPLICATION SUMMARY

Preference

If successful your preference would be for Remedi funding, please write this clearly in ink on the top of page 2 of the paper copies of your application

9: Award Schedule

Please note the information above under Scope in relation to our preference for the duration of awards for clinical researchers to be 5 years.

SECTION B – APPLICANT’S PROFILE TO DATE

5: Employment History

Please include details of any Macmillan Cancer Support post held (with dates).

13: Additional Information (SRF no 15)

Within this section, please include any relevant clinical or research work undertaken with regard to supportive and palliative cancer care and/or Macmillan Cancer Support (or Remedi).

SECTION C – APPLICANT’S PROPOSED RESEARCH

5: Proposed Research/Project/Programme

Please explain each piece of work with respect to Macmillan Cancer Support’s priority areas for research (see Appendix A) and how the research will be of benefit to people affected by cancer.

Please note that neither Macmillan Cancer Support nor Remedi funds research into the causes or cure for cancer, nor clinical trials of medicines or medical devices.

You should also utilize this section to state clearly the reasons why you would like your award to be funded by Macmillan. You should explain how funding from Macmillan will enhance your proposed work and what benefit the proposed work would bring to people affected by cancer and to Macmillan itself. In the case of a Remedi preference please also explain your choice in similar terms.

Please be aware that this information is an essential part of the assessment process

7. Research Costs (SRF no 8)

In completing this section please note that neither Macmillan Cancer Support nor Remedi pays university overheads or full economic costing.

12: Consumers

Please note that it is a condition of funding that people affected by cancer (“Consumers” as defined in the standard guidance) are involved as appropriate at each stage of the research process. This is to ensure that the research is **relevant** to their needs and has an **impact** on their lives. Macmillan Cancer Support is able to offer advice and support in the involvement of people affected by cancer in research, as is INVOLVE formerly NHS Consumers in Research – www.invo.org.uk/

SECTION D – TRAINING AND DEVELOPMENT

1: Proposed Training and Development Programme *(Please note this is no 2 for DRF awards)*

Please include in this section an explanation of how this specific funding will benefit your career. It is also important to indicate what your longer-term career plans are with respect to supportive and palliative cancer care.

Please be aware that this information is an essential part of the assessment process

2: Proposed Departments

Please indicate in the summary of the department's record in supportive and palliative cancer care any research it has done for, or of relevance to, Macmillan Cancer Support/Remedi. Please also include the department's experience and record in involving people affected by cancer in research. As part of its commitment to the NCRI initiatives, Macmillan Cancer Support has found it helpful for its awards to be based in departments that are associated with the NCRI SuPaC Collaboratives or to receive mentorship from staff from such departments (see below).

3: Research and Career Development Mentorship *(4. Supervision for DRF awards)*

In describing your arrangements for mentorship or supervision please indicate what involvement your proposed mentor(s) or supervisor(s) has had, if any, with Macmillan Cancer Support, and whether and how this process will help you address issues of relevance to Macmillan Cancer Support, including potential involvement/association with one of the two NCRI SuPaC Collaboratives (as indicated above). Applicants are encouraged to seek mentors who are grant-holder members of one of the two NCRI SuPaC Collaboratives (see Appendix B).

Applicants who are currently Macmillan Cancer Support professionals may wish to address other areas of their development through mentorship/supervision. Applicants and or their proposed mentors/supervisors may wish to discuss their role with Macmillan Cancer Support, and are encouraged to do so especially where this role is related to issues of particular relevance to Macmillan. Where appropriate links to these issues should also be highlighted in this section. In the same way research and career development issues of relevance to Remedi should be emphasised here.

SECTION E – INSTITUTIONAL SUPPORT

2 & 3. Basis of Fellowship and Apportionment of Candidate's Time

Please see the notes above under Scope for applications from clinical researchers.

SECTION F - DECLARATIONS AND AUTHORISATIONS

Please note that applications from existing Macmillan Cancer Support professionals will need a supporting statement for their application from their Macmillan Development Manager. This should be provided as a letter on headed paper addressed to Macmillan's Research Manager (contact details below).

Applications

The completed application should also contain two printed copies of the correct application form, complete with all original signatures. Also two printed copies of section H part 2 – Finance signed by the Finance Officer and an authorising signatory, plus copies of the relevant institutional pay scale. Where relevant please supply letters of agreement from NHS and other organizations (please follow NIHR guidance for this). We also require an electronic copy of all sections of the application, preferably on a CD. Please send to:

Dr David Wright
Macmillan Fellowship Application 2009
Research Department
Macmillan Cancer Support
89 Albert Embankment
London
SE1 7UQ

Deadline: Wednesday 7th January 2009 1pm.

Guidance and Advice

Further information is available if required. Potential applicants and/or their mentors are welcome to discuss any aspect of their application or Macmillan Cancer Support's or Remedi's conditions and requirements with:

Dr Jim Elliott
Research Advisor
Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ
Tel. 020 7091 2020
Email: jelliott@macmillan.org.uk

Dr David Wright
Research Manager
Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ
Tel. 020 7091 2020
Email: dawright@macmillan.org.uk

Dr Katie Booth
Secretary to the Research Capacity Development Committee
Macmillan Research Unit
University of Manchester
University Place Room 5 320
Oxford Road
Manchester M13 9PL
Email: katie.booth@manchester.ac.uk

For Remedi: www.remedi.org.uk

Rosie Waite
Director
Remedi
Elysium House
126-128 New Kings Road
London SW6 4LZ
Tel 020 7384 2929
Email: rosie.wait@remedi.org.uk

Appendix A: Macmillan Cancer Support's research strategy and priorities for research

Macmillan Cancer Support's Strategy for Research

Macmillan's purpose in supporting research is to ensure that research underpins and supports its core strategy to improve the lives of people affected by cancer. Therefore the research that Macmillan supports should address the needs of people affected by cancer and or the core activities of the organisation that enable it to deliver its objectives to improve the provision of supportive and palliative care and support for cancer patients

In order to achieve its purpose Macmillan will fund and support research and research related activity that:

- Supports the improvement and development and evaluation of care and support services for people affected by cancer
- Enables it to pursue effective campaigns
- Increases the effectiveness of its fundraising and other support activities
- Develops research capacity in supportive and palliative cancer care

Macmillan will not fund research that:

- Seeks to identify the causes or cure for cancer
- Involves clinical trials of medicinal products or medical devices
- Does not address a specific commissioning brief or call for proposals

The research programme will address its purpose both directly and indirectly through the following main areas of activity:

- Commissioning research and evaluations to meet the needs of the organisation for new or improved services and effective campaigns and fundraising
- Contributing to the development of the research capacity in the UK in supportive and palliative cancer care and support through the National Cancer Research Institute and more widely
- Promoting the use of research-based knowledge and other related information in clinical and managerial decision making across the organisation

Macmillan has identified a number of research priority areas that were developed with the involvement of people affected by cancer, which will be regularly reviewed and updated as appropriate:

- Helping people affected by cancer make choices
- Identifying best practice in service delivery
- Implications of long term survival
- End of life care and support
- Supporting self management
- Involving people affected by cancer in research

And two cross-cutting themes that will be addressed where possible in prioritising specific research questions and in the commissioning of research:

- Communication and information
- Equality and diversity

Examples of questions and areas of interest to Macmillan Cancer Support in each of the research priority areas

Helping people affected by cancer make choices

What helps people with cancer make choices?

What is the role of a 'significant other' (for example partner, family member or close friend) in decision-making?

What helps people to decide whether or not to enter a trial?

Macmillan's Research Unit at the University of Manchester has undertaken a literature review in this priority area that can be provided to potential applicants – please contact Macmillan's Head of Research

Identifying best practice in service delivery

The review of the literature conducted for the NICE Supportive and Palliative Care Guidance is a comprehensive review of the evidence around best practice in service delivery for supportive and palliative care. However, evidence from qualitative studies dealing with social support for patients and their carers was omitted from this review. Macmillan's Research Unit at the University of Manchester has undertaken a review to fill this gap and is a meta-ethnography of evidence derived from qualitative studies exploring issues around social support for patient and carers.

In addition the following are also areas of interest to Macmillan, many of which relate to cancer survivorship and the impact of cancer on everyday life (see also the table below):

How can we pick up on support needs once the patient moves back to the care of the GP?

Why is communication still a problem, when so much work has been done in this area?

What information do you need at the point of diagnosis? Who do you need to see (eg consultant, nurse, etc)? Who should give the diagnosis?

We need to evaluate the effectiveness of information giving, identify areas of good practice and spread these so that the service is consistent around the country.

How can we reduce the amount of conflicting information given to a person with cancer?

What are the barriers (including environmental barriers, social and ethnic barriers and personal communication barriers) to good communication?

How can users be involved in teaching good communication skills? How do you assess the benefits of this and should communication skills training be ongoing?

How can users' input support professionals on difficult/complex issues?

What is an optimum level of cancer care provision across the patient journey?

How can we involve patients in the recognition of symptoms by the primary health care team throughout the whole journey? The anecdotal evidence is that patient

suspicion is disregarded, particularly at the primary care level. What are the failure points in the pathway from patient suspicion to diagnosis?

What would regular assessment ('assessment' was seen as being someone who would be prepared to listen, read between the lines and really ask questions) of patients' and carers' mental well-being and practical and support needs, for the whole cancer journey from the point of diagnosis onwards do to improve the quality of life? What are the features of whole journey management by the primary care health team?

What are the support needs of people with rarer cancers? How can these be met?

Why use of information by the primary health care team to proactively support carers is patchy

Implications of long-term survival

How do you get back to 'normal' life' after you have been told that your cancer is in remission?

How is a patient's quality of life affected by chronic conditions and treatment?

How are we best able to measure the long-term psychological side effects on cancer patients and their families?

What are the needs of people who are deemed 'incurable', but have been discharged from hospice care as 'too well'?

What are the physical problems of long-term survival and how can this best be evaluated?

How do you effectively feed back the long-term effects of treatment to clinicians, so that side effects do not happen to anyone else?

Macmillan's Research Unit at the University of Southampton has undertaken a literature review in this priority area that can be provided to potential applicants – please contact Macmillan's Head of Research.

End of life issues

The views and needs of children

The place and manner of death

How can we 'normalise' death?

Supporting self management

Evaluate existing self-management programmes and their relevance for people affected by cancer including the use of complimentary therapies

How far are complementary therapies integrated into orthodox cancer care?

What is the evidence that complementary therapies are effective in relieving symptoms and reducing side effects of treatments?

How far are therapists providing care to cancer patients appropriately qualified and insured?

What is the evidence that organic food is superior to non-organic food from the perspective of the person with cancer and what problems are encountered by people on low incomes in accessing them and vitamin and mineral supplements?

Relaxation and visualisation – how can this help?

Macmillan's Research Unit at the University of Southampton has undertaken a literature review in this priority area that can be provided to potential applicants – please contact Macmillan's Head of Research.

Involving people affected by cancer in research

Macmillan's Research Unit at the University of Southampton has undertaken the Macmillan Listening Study to listen to the research priorities of people affected by cancer. A systematic appraisal of the research evidence in the top priority area, **the impact of cancer on everyday life**, was undertaken in follow up to the Macmillan Listening Study. The range of issues where further research is required are illustrated in the table below. Copies of both the Macmillan Listening Study and the Systematic Appraisal are available from Macmillan Cancer Support. It should be noted that this is not a set of research questions as such but rather a list of what is already known and under-researched areas of importance to people affected by cancer. It will be necessary to develop specific questions from these areas as the focus for the proposed projects.

Table taken from the systematic appraisal of the research evidence in the top priority area identified by people affected by cancer from the Macmillan Listening Study to show for each research theme what is already known and where more research is needed

| Research priority | Sub-theme | Findings | |
|-----------------------------------|--|---|---|
| | | What is already known | Under-researched areas |
| Impact of cancer on everyday life | Impact of cancer from the point of diagnosis | <ul style="list-style-type: none"> The psychological impact has been studied to a large extent. There is wide variation in incidence of clinically significant mental health problems that cancer patients have. Patients with these problems require support from appropriate clinical services. | <ul style="list-style-type: none"> Strategies patients can use to manage the emotional/psychological impact of cancer on patients' everyday lives. |
| | Impact on family and friends | <ul style="list-style-type: none"> Cancer has a significant impact on the quality of life and psychological distress of family members (e.g., adult children of cancer patients, partners of elderly patients, children of cancer patients). Social support is important for family caregivers as well as patients, and the use of adequate support appears to be a positive influence on the psychological well being of families of elderly cancer patients. | <ul style="list-style-type: none"> How to support family caregivers has received little attention. The impact of cancer on friends remains unknown. |
| | Impact of positive mental attitudes/stress on recovering | <ul style="list-style-type: none"> Numerous studies have been conducted in this area. Psychological factors including negative emotional states have shown to have little or no impact on recovery. Whilst some evidence demonstrates that psychosocial interventions can improve quality of life and increase survival time such evidence requires careful scrutiny. There is no conclusive evidence for increased survival time following psychosocial interventions. | <ul style="list-style-type: none"> Further research is needed for more conclusive evidence in this area. |

| Research priority | Sub-theme | Findings | |
|-------------------|---------------------------------|---|---|
| | | What is already known | Under-researched areas |
| | How to improve mental attitudes | <ul style="list-style-type: none"> • Some interventions have been shown to enhance emotional adjustment in the short term but long term effects are not consistently demonstrated e.g. group therapy for women with advanced breast cancer. • Some interventions may have longer term benefits e.g. group therapy, education, counselling and cognitive behaviour therapy however robust evidence is required to support this. • Relaxation training and mindfulness meditation have been shown to have positive effect on emotional adjustment and relief of tension although evidence is limited. • Hypnotherapy has been found to reduce physical distress although conclusive results were not drawn due to the poor quality of studies. • The positive effect of music therapy on anxiety and mood has been reported, although the effect was not statistically significant. • Massage and aromatherapy massage were found to provide short term benefits on psychological wellbeing, but the effect on anxiety was supported by limited evidence. | <ul style="list-style-type: none"> • More research is needed to demonstrate benefits of interventions to enhance mental attitudes. |
| | Impact of aftercare on patients | <ul style="list-style-type: none"> • Information needed most often by patients is treatment related. Health professionals are the most frequent source of this information and the Web is also used. Patient information needs change over time. • Some interventions to improve the quality of life of patients with lung cancer may be effective (e.g. nursing interventions to manage breathlessness). | <ul style="list-style-type: none"> • There was little evidence to indicate what practices are effective in meeting the objectives of follow-up services for patients treated for breast cancer. • Specific service issues such as how long follow-up should last, the frequency of appointments and/or which health professional should deliver the service were also unclear. • Evidence is limited to demonstrate whether aftercare services meet the needs of cancer patients and how they impact on the lives of patients. |

| Research priority | Sub-theme | Findings | |
|-------------------|---|---|--|
| | | What is already known | Under-researched areas |
| | Impact of cancer on patients' social functioning | <ul style="list-style-type: none"> • Women with lymphedema (a side effect of breast cancer treatment) reported avoiding socialising and social isolation. • Fatigue may also result in reduced social contact. • A strong social network and social support is important to counter social isolation. | <ul style="list-style-type: none"> • More practical issues related to social network and social support in order to help patients increase their level of social functioning have not been studied. |
| | Impact of pain on quality of life | <ul style="list-style-type: none"> • There is evidence that increased pain is associated with increased distress, lower social support and engagement in fewer social activities, although the results are supported by limited evidence. | <ul style="list-style-type: none"> • Further research of higher quality is required in this area. |
| | Role of diet | <ul style="list-style-type: none"> • Despite a large amount of research in this area, there is no clear association between diet and cancer recurrence or patients' survival. • Weight loss is common in patients with cancer and therefore early detection through nutritional screening is important – weight loss can affect response to treatment, survival and quality of life. • Most dietary information for patients appears to focus on the avoidance of malnutrition rather than offering specific dietary advice. | <ul style="list-style-type: none"> • Further research of higher quality is required to investigate the role of diet in cancer survival. |
| | Effect of living with one's family on cancer recovery | <ul style="list-style-type: none"> • Being married has been shown to be protective in terms of outcomes for breast cancer although the quality of the relationship is important. | <ul style="list-style-type: none"> • There is insufficient evidence in this area. |

| Research priority | Sub-theme | Findings | |
|-------------------|--|--|--|
| | | What is already known | Under-researched areas |
| | Relationship between survivorship and exercise or other factors of lifestyle | <ul style="list-style-type: none"> • There is evidence that exercise is effective in decreasing fatigue levels, emotional stress, blood pressure, duration of neutropenia, thrombocytopenia and pain. Exercise is also effective in improving cardiorespiratory fitness during and after cancer treatment, and vigour post-treatment. Exercise has been shown to increase quality of life, sleep and cognition, and may also improve a number of immune system parameters that may be important in cancer defence. • Former smokers have a significantly lower risk of cancer than subjects who still smoke and they are less likely to experience a recurrence of cancer if they stop smoking. • There is no conclusive evidence that exercise has long term gains (e.g., cancer recurrence or survival) although the short term benefits are well documented. | <ul style="list-style-type: none"> • Factors other than exercise, such as the effect of cessation of alcohol consumption and the use of sun-screens on cancer recurrence and survival time, remain unclear. • The link between exercise and long term disease outcomes still remains to be determined. |

Appendix B: Information on the NCRI SuPaC Collaboratives

The grant holder members and summary of their proposed research together with the strategy of research of the two funded Collaboratives are:

The COMPASS Collaborative

Dr Mike Bennett, Leeds Pallium Research Group, St Gemma's Hospital
Mrs Julia Brown, Northern and Yorkshire Clinical Trials Unit, Leeds
Dr Elizabeth Davies, King's College London
Dr Marie Fallon, Edinburgh Cancer Centre, Western General Hospital
Professor Irene Higginson, King's College London
Professor Matthew Hotopf, King's College London
Dr Scott Murray, University of Edinburgh
Professor Amanda Ramirez, King's College London
Professor Alison Richardson King's College London – Corresponding Applicant
Professor Peter Selby, Cancer Research UK, Leeds
Professor Michael Sharpe University of Edinburgh – Corresponding Applicant
Professor Aziz Sheikh, GP section, University of Edinburgh
Mr John Sitzia, Worthing & Southlands NHS Trust
Dr Daniel Stark, Cancer Research UK, Leeds
Dr Galina Velikova, Cancer Research UK, Leeds
Professor David Weller, University of Edinburgh

The COMPASS collaborative will unite researchers from 12 UK universities and create a strong research grouping that can effectively research the development, evaluation and implementation of supportive and palliative interventions. The collaborative has expertise in researching all stages of illness from diagnosis to death, and all settings from hospital to primary care to hospice. We have special expertise in complex non-drug interventions.

The work will be coordinated in three interrelated strands:

Assessment and measurement

What are the best ways of assessing patients? We will agree a standardised core set of assessment and outcome measures and determine their utility for different stages of illness. In order to achieve efficient assessment we will further develop existing clinic based computer touch-screen delivered methods and explore home-based telephone delivered assessment.

Development and evaluation of interventions

What are the best treatments? Based on our current clinic-based trials examining the effect of providing symptom assessment information to clinicians and of supplementing this with nurse-delivered interventions, we will develop and evaluate new interventions and explore how they can be applied in hospices and in primary care.

Implementation of interventions in practice

How can we change practice? We will build on our studies of training health professionals to deliver supportive and palliative care and develop and evaluate better ways of doing this. We will also examine how to improve the mental health of

the cancer workforce that, in turn, will improve the quality of care of cancer patients. Using this coordinated and staged approach we will address a range of patient problems. We will establish joint working by studying emotional distress and then study other problems including fatigue, breathlessness and care planning in general. The aim is to create the evidence base for a patient-centred, planned and deliverable system of care appropriate to the individual's needs, illness stage and setting.

Our aim is to establish a science-based, inclusive, focussed, well managed collaborative that offers research expertise in the development, evaluation and implementation of treatment in Supportive and Palliative Care (SuPaC). We have special expertise in complex interventions (interventions that have multiple components such as education, psychotherapeutic case management, rehabilitative and complementary and alternative medicine).

Aims:

- Enhance research in SuPaC by developing a shared research expertise and sustainable critical research mass.
- Increase research capacity by providing much needed administrative support, high quality methodological expertise, research mentorship and education, and user involvement.
- Build and maintain long-term relationships with service user groups to achieve effective user involvement.
- Develop methodologies for the development and evaluation of complex interventions so that they are appropriate for different settings and stages of illness; from diagnosis to death.
- Create a robust platform for multi-centre studies, including randomised trials.
- Maximize outputs in high impact journals.

Objectives:

- Deliver a standard set of assessment and outcome measures appropriate for stage of illness.
- Develop and evaluate information technology to improve clinic and home based assessment.
- Develop management strategies of proven effectiveness for a range of patient problems starting with emotional distress that have been tested in definitive multi-centre trials.
- Develop recommendations on improving the mental health of cancer professionals in SuPaC and identify what leads to burnout in staff delivering SuPaC and methods to avoid it.
- Have solved methodological problems that are barriers to research in this area.

Cancer experiences Collaborative (CECo)

Professor Julia Addington-Hall University of Southampton – Corresponding Applicant
Dr Ziv Amir, University of Manchester
Professor David Clark, Lancaster University
Professor Jessica Corner, University of Southampton
Dr Claire Foster, University of Southampton
Dr Katherine Froggat, University of Sheffield
Dr Anne Grinyer, Lancaster University
Professor Mari Lloyd-Williams, Liverpool University
Professor Karen Luker, University of Manchester
Professor Alexander Molassiotis, University of Manchester
Professor Sheila Payne, University of Sheffield
Professor Jane Seymour, University of Nottingham
Dr Carol Thomas, Lancaster University
Professor Chris Todd, University of Manchester
Mr Roger Wilson, Cancer Survivor, Chair of the NCRI Consumer Liaison Group

We aim:

1. to work together to make substantive progress in research capacity and the quality of research in supportive and palliative care over the next five years
2. to do so in a way that ensures that progress is maintained beyond this period.

We will address three inter-related research themes:

- innovative approaches to complex symptoms;
- planning for the care of older adults towards the end of life; and
- narratives of cancer and other life limiting illnesses.

These will provide platforms on which to build our research capacity-building activities. We recognise that experiences of serious and advanced illness are shaped by a wide range of physical and social factors and this makes consumer perspectives vital to their understanding. We therefore adopt user involvement as a key strategy. We will look afresh at challenging problems, develop new conceptual and theoretical frameworks and add analytical depth to interpretation of the evidence-base. We will build research capacity, support emerging researchers and seek to improve the quality and impact of our own research. Firmly rooted in clinical realities and problems, we will create a vibrant community of collaboration to build capacity, raise research standards, leverage new resources, publish in high impact journals, encourage emergent ideas, support relevant organisations, develop new methods and bring about a 'step change' in both research capacity and the quality of supportive and palliative care research, such that service development becomes knowledge rich and clinical innovation is evidence based.

The aims and objectives of our collaborative are as follows:

Aims:

1. To work together to make significant and substantive progress in both research capacity and the quality of research in supportive and palliative care over the five years of the Collaborative
2. To do so in a way that ensures that progress is maintained beyond this period.

Objectives:

1. To bring together a Collaborative of researchers with established track records in SuPaC from a range of health and social science disciplines in five different academic centres of SuPaC research, to work together with users and clinicians to become a vibrant research community that is recognised as an international centre of excellence and which is greater than its existing parts, thereby creating synergy and a stimulating scholarly environment, enabling the sharing of infrastructure and resources, preventing the duplication of effort, providing attractive and supportive learning environments for junior and novice researchers, and leading to overall improvements in both research capacity and the quality of research.
2. To work with academics outside SuPaC with expertise relevant to the Collaborative's three research themes so that the Collaborative's work is informed by and integrated with contemporary theory, policy and research in relevant health and social science disciplines, and thus to enhance the excellence of its research when compared to other work in these disciplines, not just within palliative and supportive care.
3. To have close dialogue with a range of clinicians within cancer and non-cancer palliative and supportive care, to ensure the work of the Collaborative is firmly rooted in clinical realities and problems
4. To establish and support a Partnership Group and other mechanisms to ensure users' views influence the Collaborative's work, whilst seeking other methods for including people affected by cancer and other life-limiting illnesses through participatory, user-led and action research projects.
5. To use the Collaborative's research themes as platforms to develop and test common methods of negotiating research ethics and research governance submissions, data capture and handling, and of enhancing recruitment in multi-site qualitative and quantitative studies.
6. To establish excellent communications between Collaborative members, including full use of web, telephone and video-based technologies.
7. To increase research methods expertise within SuPaC, at basic and advanced level, via the provision of web-based materials, workshops, mentorship, and access to statistical and health economic expertise.
8. To attract and retain high quality clinical researchers to SuPaC care research by providing scholarships of three months for non-medical clinicians and mentoring to clinicians with developing interests in and by enabling more experienced researchers (both clinical and non-clinical) to develop their own independent research programmes and to become Principal Investigators with sustained research programmes.
9. To provide support to organisations within palliative care (especially independent hospices) that currently lack a well-developed research culture, enabling them to develop research appreciation and expertise and to become research active.

10. To publish the findings of Collaborative research studies in high impact academic journals, as well as in appropriate professional and lay publications.
11. To obtain peer-reviewed research funding to enable substantial progress to be made in the Collaborative's three research themes,
12. To bring about a 'step change' in the quality of SuPaC care research, such that service development becomes knowledge rich and clinical innovation is evidence based.
13. To manage the resources of the Collaborative efficiently, effectively and fairly in order to meet its overall aims.

Our Collaborative has two particular defining features.

First, our focus is on the experiences of people affected by cancer, by which term we refer to those with the disease; their family, friends and companions; health and social care professionals; volunteers and members of advocacy and self-help groups; and the wider public. We recognise these experiences to be multi-faceted and shaped by a wide range of physical and social factors. User involvement is therefore a key strategy in the Collaborative and will be a major research focus underpins all three research themes. We will also extend understanding of the impact of cancer, investigate how variations in experience are shaped, and ensure that clinical and service interventions are informed by and appropriate for all people affected by the disease, in the context of providing optimal treatment and care.

Second, we will act collectively as a 'critical friend' to those providing and commissioning SuPaC services, by looking afresh at challenging problems in a questioning and analytical manner. We will develop new conceptual and theoretical frameworks to illuminate issues, to lend analytical depth to interpretation of the evidence-base, and to enable us to generate and evaluate creative and innovative responses to the challenges of providing care. Our skills and expertise are drawn from palliative medicine, nursing, health services research, health psychology, sociology, primary care, gerontology, psychiatry, complementary therapies, social policy, social work, public health, statistics, health economics, epidemiology, and oncology. The Collaborative also includes service users and health and social care professionals to ensure our work is grounded in the day to day realities of living with cancer and of service provision.



Appendix C: Remedi Research Fellowships 2008/09 Guidance Notes

Remedi is a medical research charity that has been established for nearly 35 years. The main interest of the Trustees is to support high quality scientific research into methods of alleviating disability arising from illness or injury. Remedi has an excellent record in helping to provide an evidence base for rehabilitation. This is an area of medicine that is not well funded by larger charities or the National Health Service. Initial funding by Remedi of key research projects has enabled many worthwhile projects to go on and secure full funding from larger charities, such as the Medical Research Council and The Wellcome Trust. Without Remedi, it is probable that many such research projects would have failed to get started. In the last 15 years over £4m has been awarded to a wide variety of medical research projects.

In recent years the Trustees have been made aware of the relative paucity of research into rehabilitation in malignant disease. They were also aware that many more individuals are surviving cancer but are left with significant health and welfare problems.

The Trustees therefore decided that they would like to foster high quality research for rehabilitation in cancer. The Trustees feel that the best way to achieve this is to fund a clinical fellowship alongside those that Macmillan Cancer Support is providing.

Remedi's reason for collaborating with Macmillan as a partner in this process is because of the Trustees' confidence in the robustness of the Macmillan approach. This includes the expectation that the Fellow will continue to do part-time clinical work, something Remedi also strongly believes in.

The Trustees wish to make it clear that they will not support research into the causation, prevention, investigation, medical or surgical treatment, or end-of-life issues associated with malignant disease. The Charity is specifically interested in research that will assist people recovering from, or cured of, cancer to return to their place in society.

Examples of potential interest include:

- How to aid and enable the person to return to work
- Helping patients to increase their level of social functioning
- Strategies people can use to manage the emotional/psychological impact of cancer on everyday life.
- How to support family caregivers and friends.
- Why do so many people after cancer treatment suffer long term fatigue?
- What is the relationship between survivorship, exercise or other factors on lifestyle?
- What is the role of diet in cancer survival?

This is not necessarily an exclusive list because of the impact of cancer in so many areas of people's lives.

It is a prerequisite that the applicant has the full support from their sponsoring department and can demonstrate this in their application. The Remedi Fellowship is available to applicants from medicine or other related professions. The applicants must be able to demonstrate that the award of the Fellowship will lead to continuing commitment to improving the outcome for those people who survive cancer.

Being sponsored by Remedi offers the successful applicant the opportunity to be associated with a partner who is recognised as being a supporter of high quality medical research, with a specific interest in helping people to overcome the disabling effects of medical conditions. Remedi is particularly known in the rehabilitation community, with a reputation for supporting new researchers and novel lines of investigation. It is our intention to continue with this Fellowship programme and therefore raise the profile both of the Charity and rehabilitation research.