

NCRI Cancer Conference 2008 User-led Research Grant Competition

Guidance notes for applicants

Introduction

Macmillan Cancer Support is running an open competition to award research grants for projects addressing the impact of cancer on everyday life and involving people affected by cancer in their design and conduct. Outline applications are invited to be submitted at the 2008 NCRI Cancer Conference for short-listing. Successful applications will then be worked up to full project proposals for which up to £60,000 will be available per project for two projects to start in 2009. The eligibility criteria for submission are:

- The projects must address one of the following:
 - a) an issue related to the impact of cancer on everyday life. This was the top priority area identified by people affected by cancer from the Macmillan Listening Study
 - b) the involvement of people affected by cancer in the research process
- Applications must be developed by a collaborative group and include people affected by cancer, if not actually led by one
- Applications must be supported and signed by a patient or carer delegate / member of the NCRI Consumer Liaison Group who is attending the conference prior to submission

Outline applications will be selected on the basis of:

- The potential for the project to produce results that will make a difference to the lives of people affected by cancer
- The nature and effectiveness of the involvement of people affected by cancer in the design and conduct of the research
- The feasibility of the study being delivered within the proposed timeframe

Applicants should state clearly the research question, why the question is important, and the anticipated utility of the study findings.

Research priority areas

The proposed projects must address one of the following:

- a) an issue of practical relevance to the lives of people affected by cancer within the general priority area of ***the impact of cancer on everyday life***. This was the top priority area identified by people affected by cancer in the Macmillan Listening Study. The range of issues where further research is required are illustrated in the table in the Appendix, which is taken from the systematic appraisal of the research evidence in this area that was undertaken in follow up to the Macmillan Listening Study. Copies of both the Macmillan Listening Study and the Systematic Appraisal will be available from the Macmillan Cancer Support exhibition stand at the Conference. 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

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develop specific questions from these areas as the focus for the proposed projects.

- b) the involvement of people affected by cancer in the research process. Macmillan Cancer Support is particularly interested in proposed studies that seek to explore the efficacy and impact of patient and carer involvement in cancer research. Macmillan are also interested in studies that identify best practice in involving people affected by cancer in research.

Role of the patient and carer delegates and NCRI Consumer Liaison Group (CLG) members

There will be patient and carer delegates at the conference, most of whom will be members of the NCRI CLG. Their role is to discuss outline proposals they are interested in with the applicant(s) and help further develop them as necessary to ensure that they are clearly **relevant** to people affected by cancer, are likely to have an **impact** on their lives, and that they have appropriate involvement of people affected by cancer (see below). Each outline application must be signed by a patient or carer delegate / member of the CLG to show that they are satisfied that the proposal addresses these requirements satisfactorily.

Patient and carer delegates can be identified at the conference by their orange-coloured name badges. Applicants will need to find a patient or carer delegate and then make arrangements to meet and discuss their proposals with one or more who express an interest. Any patient or carer delegate who is approached must be given enough time to consider it in detail and the opportunity to ask questions and receive satisfactory answers before being asked to sign the outline application.

Applicants whose outline proposals are short-listed to be developed into full proposals will be expected to inform and involve the patient or carer delegate who signs the outline application in the next stage. Their level of involvement will be negotiable and should not be seen as exclusive as far as user involvement in the project is concerned.

If you need any assistance in identifying people affected by cancer to support you in your application, please contact David Wright, Research Manager, Macmillan Cancer Support (Tel: 020 7091 2069, email: dawright@macmillan.org.uk). Alternatively you can contact the NCRN.

Completing the outline application form:

The outline application form is **two pages** in length and this should not be exceeded, nor should any of the individual sections be expanded.

The form can be completed by hand or electronically but note that NCRI will not be providing printing facilities at the conference should applicants complete it electronically in advance and want to make amendments at the conference.

Note that the Lead Applicant and a patient or carer delegate / NCRI CLG member must sign and date completed applications.

The description of the proposed project under the headings below should be in **plain English** throughout with any technical terms explained as simply and clearly as possible.

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Applicants

It is expected that applications will be developed by a collaborative group led by or including people affected by cancer. Please provide the full contact details of the Lead Applicant and the names and organisations / associations (as appropriate) only of up to five additional applicants who could be professionals including researchers, clinicians or managers, or people affected by cancer. Please also provide the name, contact telephone number and email address of the patient or carer delegate / NCRI CLG member supporting the application.

Project Summary

Please provide a summary of the proposed research within the space provided on page one of the outline application form. This should give a clear indication of the importance and relevance of the project to the lives of people affected by cancer or how they are involved in research. Please also indicate how long the project will take to complete.

Project Aims

Please list up to four main aims for the project and for each how it will make a difference to the lives of people affected by cancer or how they are involved in research.

Methods

Please describe all proposed methods to be used in the project including numbers of subjects where appropriate and for each state the reasons for using the proposed approach and how they will address the questions asked. All methodological approaches, both quantitative and qualitative, are welcomed providing that they are appropriate to the questions being addressed. Note that appropriate references will be required to support full proposals to demonstrate how the proposed work will add new knowledge and not duplicate other work. Therefore each project will be expected to include some review of existing literature unless this has already been done in preparation.

User Involvement

Please state how people affected by cancer (this term encompasses 'patients and the public', 'service users', 'consumers', 'patients and carers', and any others that may be used) have been involved in developing the outline application and how they will be involved both in developing a full proposal and then in conducting the proposed project including disseminating the findings and promoting their uptake. Consideration should be given to whether and how they should be involved at each and every stage of the research process and not simply and exclusively in the steering arrangements.

Note that it is a condition of funding that there is **appropriate** and **effective** user involvement in research funded by Macmillan Cancer Support to ensure that the research is both **relevant** to and has an **impact** on the lives of people affected by cancer. As a guide to deciding whether and how to involve people affected by cancer at any stage the following questions may help when considered both from the viewpoint of the research team and the people who be involved themselves:

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- Is there a task or role that can be undertaken by a person affected by cancer?
- Do they have the necessary skills to do the task(s) / role(s) or could they be quickly and easily trained to do so? And
- Would their involvement make a difference to the way the research is approached or conducted?

If for any aspect of the proposed research the answer to all three questions is yes then it is probably appropriate to involve them.

Proposed Outcomes

Please state the expected outcomes from the successful completion of the proposed research, i.e. what will happen as a result and how this will make a difference to the lives of people affected by cancer or how they are involved in research. The outcomes should relate directly to the aims listed above.

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Submitting the application

Completed applications that have been signed and dated by both the Lead Applicant and the patient or carer delegate / NCRI CLG member supporting the application should be placed in the box on the NCRI desk marked 'Macmillan Cancer Support User-led Research Grant Competition' by:

**12.00 on Wednesday 8 October
2008**

Assessment and invitations to submit full proposals

Outline applications will be assessed by a panel consisting of people affected by cancer and Macmillan staff responsible for user involvement. Up to eight outline applications will be short-listed for invitation to submit full proposals that will be sent for external peer review and then assessed by the same panel as above.

Applicants will be notified of the result of the short-listing of outline applications by mid November 2008

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Appendix: 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. |

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| 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. |

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| 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. |

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| 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. |