

# THE MACMILLAN PALLIATIVE CARE COLLABORATIVE

Working in partnership to  
advance knowledge in the  
area of advanced disease

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

# Foreword

Professor Jane Maher,  
Chief Medical Officer, Macmillan Cancer Support

The support Macmillan provides for people living with cancer is underpinned by evidence and best practice wherever possible. However, we are aware that there is the need for more research in some areas of advanced disease. An analysis published by the National Cancer Research Institute (NCRI) in 2002 had revealed that research into supportive and palliative care accounted for only about 4% of direct cancer research expenditure by NCRI partner funders (Department of Health, Medical Research Council, Macmillan and Marie Curie).

Macmillan has long commissioned and used research from a range of sources, but nearly 10 years ago we decided to create an innovative new group that would be more fit for our purposes. Not only would it help to fill some of the gaps in research but also it would be focused above all on achieving better care for patients by providing evidence for service innovation and improvement.

## A collaborative with a difference

The Macmillan Palliative Care Collaborative (MacPaCC), established by Macmillan in 2003, is a group of leading researchers from six universities across England and Scotland, most of whom are clinically active in primary palliative care. Several characteristics make the group different from other research groups and healthcare collaboratives:

- 1 The hybrid identities of its members.** They are dedicated to improving care and can speak the languages of academics, educators, service innovators and clinicians.
- 2 A closer than usual relationship with a funding organisation.** The commissioning process involved iterative and intense negotiations aimed at making the link to patient benefit explicit and clear.

### **3 Lay member actively involved.**

Roberta Lovick has continued to participate in the whole process from 2003 to the present, including decisions about both funding and communication of results.

### **4 Started with a “joint task”.**

In 2003, members were invited to undertake rigorous evaluation and research (quantitative and qualitative) into implementation of the Gold Standards Framework (GSF) for supportive and palliative care. This enabled members to gain confidence in working together and produced invaluable evidence for Macmillan and the national end-of-life care programme.

### **5 Collaborative behaviour encouraged.**

Members have regularly shared experiences, research methods, literature reviews and early results.

### **6 Recognised as a “community of influence”.**

MacPaCC is recognised as one of Macmillan’s most successful communities of influence. These are groups created and sustained over time by Macmillan in order to develop a collective voice and influence practice and policy in chosen areas. Macmillan has

invested not just in members’ research projects but also in face-to-face meetings, relationship-building and support, as well as a narrative record of the group’s way of working and achievements.<sup>1</sup>

## **Achievements over time**

The value of MacPaCC’s collaborative efforts – to cancer patients, Macmillan service teams, the Macmillan policy team, academics and the NHS – has continued to flow for almost a decade:

**1 Research and evaluation.** In the first three years alone, a national audit of GSF implementation was followed by an in-depth study within general practices, which was in turn complimented by a national survey of general practices as well as further studies of nursing roles in primary palliative care and GSF in care homes. Since then, members have continued to undertake valuable research and evaluation into primary palliative care, as this publication demonstrates.

**2 Evidence made available.** Within eight years, members had published over 100 peer reviewed papers and 100 presentations, along with over 30 editorials and eight book chapters – making

their work available to the wider academic community as well as policy makers and service developers. MacPaCC has been a valuable resource for the National Cancer Survivorship Initiative (<http://www.ncsi.org.uk/>).

### **3 Methods and tools developed**

– e.g. a process (known as “PICTOR”) for visually mapping and exploring the important relationships involved in supportive care; and a tool for calculating how receptive general practices are to GSF.

### **4 Funding for further research.**

Strengthened by the Macmillan “start-up funding”, members succeeded in attracting sizeable extra grants to this under-researched field, including a £400,000 from the National Institute of Health Research.

**5 A pool of expertise for today and the future.** MacPaCC and Macmillan have developed a close and productive partnership, helping Macmillan to develop its own thinking and knowledge on supportive care. This means that Macmillan and other organisations can not only readily call on the group’s expertise but can also bring members in to evaluate new services (e.g. the Midhurst initiative).

MacPaCC is due to report on its latest round of research (2009-12) during 2012. We are pleased to be able to produce this publication to showcase some of their current work, which is greatly valued by Macmillan and will continue to provide a useful contribution to the development of knowledge and practice in this important area.

<sup>1</sup> An account of MacPaCC’s achievements was published in Donaldson A, Lank E, Maher J (2011). *Communities of Influence: improving healthcare through conversations and connections*.

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# Macmillan Palliative Care Collaborative Research Teams

## Professor Scott Murray

St. Columba's Hospice,  
Chair of Primary Palliative Care  
Primary Palliative Care Research Group  
Centre for Population Health Sciences –  
General Practice Section  
University of Edinburgh

Scott leads the Primary Palliative Care Research Group which is a multi-disciplinary team based in General Practice at the University of Edinburgh. This group seeks to understand the experiences of patients with life limiting illnesses and their carers, and to develop and test best models of holistic care throughout the last year of life. Their strategic focus is on people with organ failure (such as heart failure and COPD) and the frail elderly, as well as on cancer; and on interventions which can deal with multiple dimensions of need, including spiritual or existential issues.

Scott is on the editorial advisory board of the BMJ Supportive & Palliative Care, and recently helped commission a series of articles on end of life care in the BMJ. In 2006 he was appointed to the inaugural

Chair of Primary Palliative Care at the University of Edinburgh, and is helping to strengthen undergraduate and postgraduate teaching and training in the community. He Chairs the International Primary Palliative Care Research Group, and regularly visits African countries, where he used to work, to conduct training and research.

## Dr Stephen Barclay

University Lecturer in General Practice and Palliative Care  
University of Cambridge

From July 2011, Stephen has been University Lecturer in General Practice and Palliative Care, Department of Public Health and Primary Care, University of Cambridge. Prior to that he was a Macmillan-funded Department of Health Postdoctoral Fellow (2006-2011), the first Macmillan Clinical Fellow (2002 – 2006) and Macmillan GP Facilitator (1995 – 1998). He is Honorary Consultant Physician in Palliative Medicine at Cambridge hospice and Speciality Director for Palliative Care, Cambridge School of Clinical

Medicine. He works clinically in both Palliative Care and General Practice. His research interests include Palliative and End of Life Care in Primary Care and Medical Student education in Palliative Care.

### **Dr Bill Noble**

Macmillan Senior Lecturer in Palliative Medicine  
The University of Sheffield

Bill's background in general practice and current clinical work as a consultant physician in palliative medicine informs his research and teaching.

He has worked on various committees and groups promoting and governing academic palliative care for organisations such as Macmillan Cancer Support, Marie Curie Cancer Care, the National Cancer Research Institute, the Royal College of Physicians and Dimpleby Cancer Care. As chairman of the Association for Palliative Medicine of Great Britain and Ireland from 2007 to 2010, Bill co-ordinated a strategic review, to take account of developments in the field of palliative care and the changing role of the specialty. He is Editor-in-Chief of BMJ Supportive & Palliative Care.

Research interests include communication skills training,

service evaluation, medical humanities, testing holistic needs assessments and developing palliative care in the community.

### **Prof Nigel King**

Professor in Applied Psychology  
University of Huddersfield

Nigel has a background in both health and organizational psychology, and a strong interest in the use of qualitative methods in real world research, especially in primary and community healthcare settings. He is Director of the Centre for Applied Psychological Research at Huddersfield, and Chair of the School Research Ethics Panel.

Nigel has carried out several studies in community palliative care, on areas including out of hours services, the implementation of the Gold Standards Framework, and collaborative working as experienced by staff, patients and carers. Other current interests include how significant others impact on patient experiences of chronic illness, and the psychosocial impact of "green exercise".

### **Ms Jane Melvin**

Senior Research Fellow,  
University of Huddersfield  
End of Life Care Facilitator, St. Helens & Knowsley Teaching Hospitals, NHS Trust.



Jane has over twelve years experience in cancer and palliative care nursing. Jane was a founding member of MacPaCC and works closely with Nigel King and carries out research with the University of Huddersfield. She was the national lead nurse for the roll out of the Gold Standards Framework in 2004 and had a unique role with Castlefields Health Centre in Runcorn, as a primary care cancer nurse and lead cancer nurse for Halton Primary Care Trust. Jane also developed and rolled out a national training programme for educating Community Matrons and worked with the Ministry of Defense in reviewing and developing pathways of care for soldiers returning from active duty in Afghanistan. Jane has always retained a clinical strand alongside research activities and is currently leading improvements in end of life care in an acute setting. Jane is currently in the final stages of completing her PhD.

### **Dr Dan Munday**

Associate Clinical Professor/ Honorary  
Macmillan Consultant in Palliative Medicine  
Division of Health Sciences  
Warwick Medical School

Dan has a background in anaesthesia and general practice. He retrained in palliative medicine 1998-2002 during which time he

undertook a PhD entitled: "Exploring Complexity in Palliative Care: A Practitioner Based Approach to Research and Development" which he completed in 2007. He divides his time equally between clinical work as a consultant in palliative medicine, where he leads a community palliative care team and applied academic work at Warwick Medical School, during which time he has the role of end of life care clinical lead for Coventry PCT

His research interests include: exploring the interface between primary and palliative care, emergency and out of hours care provision, patient and carer experience of palliative care provision and developing methods which will enable the link between research and service development.

### **Mrs Roberta Lovick**

Lay Person

Roberta is a founder member of the Collaborative and has provided extensive advice and support to the team in providing a view from the perspective of someone who has been a volunteer and cared for a family member with cancer. Her contribution to the development of MacPaCC and her insights as a lay person is essential to the ongoing development of the work.

# The Macmillan Palliative Care Collaborative Programme

Activities across the collaborative have the key aims of:

- better understanding and improving cancer care
- better understanding and improving palliative care in a range of settings
- better understanding of how cancer survivors can be supported.



We are currently looking at a range of issues which will help develop knowledge and understanding to contribute to the body of evidence in this area.

We have common themes of work looking at how the roles of different professions interlink and provide support for people affected by cancer.

- **Delivery of care:** how do specialist roles relate to generalist roles and how does this impact on cancer survivors? Does the role of the care setting play a role?
- **Care co-ordination** – examining the timing and provision of care allows us to explore how proactive follow-up early in the cancer trajectory can have an impact and improve patient experience. We are also examining how we better understand how patients move along the care pathway and how we can reduce emergency admissions.

- **Tools and frameworks:** Developing and evaluating tools and frameworks to support professionals in primary care and other settings to provide high quality care from diagnosis and at the end of life.
- **Cancer as a long-term condition:** Looking at other long term conditions and their experience of care in relation to cancer helps us understand the similarities and differences of cancer and other conditions.

As well as conducting high quality research, we also seek to further and develop knowledge in this area in other ways. The role of the Collaborative is to facilitate depth of thinking and thought leadership across these areas and to make recommendations for our Macmillan policy and services teams.

The Collaborative meets four times a year for two days and is made up of the MacPaCC research teams, people affected by cancer and senior directors at Macmillan. Other relevant researchers and thought leaders are invited to the meetings as required.

# Unpicking the threads

How generalist and specialist nurses work with patients, carers and each other in the community to support cancer patients.

**Nigel King, Jane Melvin**  
University of Huddersfield

**Joanna Brooks, Alison Bravington,  
David Wilde**

## Summary

This project aims to examine how specialist and generalist nurses work with each other and with other professionals, carers and patients in providing supportive care to cancer patients. Additionally it is exploring how models of care for patients with long term conditions (LTCs) might inform the development of services for cancer patients.

## Background

This study builds on the lead researcher's previous research carried out for Macmillan which investigated the role of community nurse roles in palliative and supportive care. The findings of the previous study suggest that there are aspects of the care and management of patients with LTCs which could be applied to cancer patients but that also the

co-ordination and communication between specialist and generalist nurses could be problematic.

According to the researchers, it is likely that the effectiveness of interactions between specialist and generalist nurses in primary and secondary care may have a major impact on patients and their families in the community. This study uses qualitative techniques to explore how specialist and generalist nurses understand each other and work together in supporting cancer survivors. The specific aims are:

- to examine how specialist and generalist nurses interact in supporting cancer patients
- to compare such working practices and relationships with those relating to services for patients with LTCs, in the same geographical area
- to examine collaborative working between both groups of nurses and social care providers



- to draw lessons for future good practice through the active involvement of participants in the interpretation of emerging findings.

The project is taking place in one community health trust in the north of England, and the acute Trust which serves the same geographical area.

## Methods

The project is using individual semi-structured interviews with a range of specialist and generalist nurses, and other health and social care professionals, and also with patients and carers (total  $n = c.90$ ). The interviews incorporate the Pictor technique, a visual method developed largely through work with Macmillan to enable participants to reflect on and explore experiences of collaborative working. Interview data are being analysed thematically using the Template Analysis approach.

## Findings

Data analysis is currently underway, and is focusing on:

- factors affecting collaborative working, including: roles definitions and distinctions, information sharing issues, and interpersonal relationships
- differences and similarities between care for cancer and long-term condition patients
- understandings of survivorship and their influence on practice
- the impact of the current context of change in the NHS.

## How will this advance our understanding in this area?

This work will give us a better understanding of how to support the lives of cancer patients. In particular it will highlight how nurses and other professionals in different roles and different sectors can work together to support cancer patients. It will also draw attention to barriers to effective collaborative working.

The project responds to policy developments in relation to the care of patients with serious and long-term illnesses in the community (Long Term Conditions Model, DH, 2005, 2006), which has influenced the organisation and delivery of services for patients with LTCs. It is also examining how support is provided for patients with long-term conditions and the extent to which this is applicable to cancer patients.

## Implications for service development

While caution is required in predicting implications at this stage of analysis, it is likely that they will include lessons for the management of relationships within and between teams to ensure optimal support for cancer and long-term condition patients from survivorship through to end of life.

*The study will report in April 2012.*

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# Pro-active follow-up in primary care from early in the cancer trajectory

The introduction of a framework developed by service users

**Scott Murray**, University of Edinburgh  
**Marilyn Kendall, Bruce Mason, Stephen Barclay, Marilyn Kendall, David Linden, Dan Munday, Roberta Lovick, Stella MacPherson**

## Summary

This study is testing the feasibility of active follow up of patients in primary care from cancer diagnosis onwards, using a structured clinical record. The study pilots a care framework generated by people affected by cancer to help primary care clinicians provide on-going holistic care, and will inform Macmillan if GP-based anticipatory care from diagnosis is feasible and acceptable to patients.

## Background

Two million people in the UK live with cancer and this will double by 2030. Research which tests a primary care model of supporting this growing population from diagnosis to cure or death is urgently required. Patients highly

value pro-active care led by a key health professional from cancer diagnosis and not just at the later stages.

## Methods

A two phase, mixed methods, action research study. An electronic Cancer Ongoing Review Document (CORD) was first developed by patients and professionals, for use with all patients with a new diagnosis of cancer. This was evaluated through documentary analysis of the CORDs, qualitative interviews with patients, family carers and health professionals, and record reviews. Interviews were recorded, transcribed and entered into NVivo for thematic analysis, and numeric data analysed using SPSS.

## Findings

The records of 107 patients from 13 practices were examined, and 45 interviews conducted with patients, family carers, and health

care professionals. CORDs were started for 54% of people with a new diagnosis of cancer, and generally usually used only once (range 1 to 9 times), but when used prompted clear and often graphic documentation of multi-dimension needs and understanding. General Practitioners felt it helped to structure consultations and cover psychosocial areas, but the CORD had to be better integrated in the practice IT system with computerised prompts in place. Few discussed the review openly with patients, and the template was often completed after the consultation. Patient and carers valued ongoing care and support from primary care, which was seen to offer holistic care and close relationships.

## Implications for service development

This study informs Macmillan that anticipatory cancer care from diagnosis, based in primary care, is feasible although there are barriers. The CORD is unobtrusive and patient-centred, promoting continuity of care and holism. This template and process is fit for purpose but, like all technical innovations, needs to be highly integrated within GP and community nursing computing and reporting systems and to be adequately incentivised. Rather than a single "cancer care review" as currently featured in the QOF, most patients would appreciate and benefit from an offer of ongoing pro-active





care after an initial review. A care framework akin to other chronic illnesses such as diabetes, which uses templates which are flagged up for review at agreed intervals, is possible in primary care, as long as patients are aware that they may also seek advice at any time for their symptoms, and there is excellent liaison with hospital care. Through the advocacy and work of Macmillan over the last few years, most aspects needed for holistic cancer care are already integrated in cancer templates in UK primary care systems such as VISION, but are not widely used. Policy guidance and incentives to do so are thus now very timely.

Thus suggestions for input to the forthcoming cancer QOF submission as follows:

- 1 Practices to continue undertaking a cancer care review within three months of diagnosis
- 2 The review to be structured using a template such as the CORD with prompts to promote more holistic care and better documentation, and
- 3 Ongoing review should be offered in primary care to all patients with cancer as best practice

This template may also be useful for the project developing the role of nurses in cancer review.

## Research outputs

- 1 Murray SA, Boyd K, Campbell C, Cormie P, Thomas K, Weller D, Kendall M. Implementing a service users' framework for cancer in primary care: an action research study. *Family Practice*. 2008. 25(2):78-85.
- 2 Kendall M, Boyd K, Campbell C, Cormie P, Fife S, Thomas K, Weller D, Murray SA. How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers. *Family Practice*. 2006. 23:644-650.
- 3 Murray SA, Kendall M, Boyd K, Grant E, Highet G, Sheikh A. Archetypal trajectories of social, psychological and spiritual wellbeing in family caregivers: secondary analyses of serial qualitative interviews with people with lung cancer and their family caregivers from diagnosis to death. *BMJ*. 2010. 304:c2581.

*The study concluded in December 2011.*

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# Plans and Care Expectations

## PACE study

**Stephen Barclay, Clare Crang**

University of Cambridge

**Scott Murray, Morag Farquhar,  
Dan Munday, Rosie Loftus,  
Cathy Shipman, Roberta Lovick,  
Robert Rintoul, Ravi Mahadeva**

### Summary

This study seeks raise the standards of care for all people at the end of life through investigating the existence and nature of the transition to palliative and end of life care in two contrasting illnesses; incurable lung cancer and advanced chronic obstructive pulmonary disease (COPD).

### Background

Research over the last 30 years has shown that whilst many people received excellent care in the last year of life from GPs and District Nurses, many do not, due to: late identification of nearing life's end; inadequate communication about the illness and its future implications; inadequate symptom control; insufficient nursing support; and uncoordinated care out-of-hours.

Raising the standard of care for all people remains a major challenge

that this study addresses, through investigating the nature of transition to palliative and end of life care in two contrasting illnesses; incurable lung cancer and advanced COPD.

Over two-thirds of lung cancer patients are incurable at presentation, some with a rapid trajectory to death that is potentially well served by current palliative care models. Others have a more gradual and chronic dying trajectory that may not fit so well with current services and care models. Death from COPD often occurs after a long period of functional decline, uncontrolled symptoms, emotional distress and social isolation. Current services frequently do not meet these patients' needs.

Using interview methodology this study seeks the views of patients with progressive cancer and COPD, their lay carers and health professionals on the appropriateness of a palliative care approach and conversations concerning the end of life. Interviews will explore their views on:

- the existence and nature of their transition from chronic illness to palliative and end of life care
- their care, support and information needs at this stage of illness
- the aspects of care they regard as key markers of high quality care at this stage of illness.

## Methods

Qualitative interviews are being undertaken with lung cancer and COPD patients, their lay carer (supporter), specialist nurse and GP. During these interviews participants are invited to complete a PICTOR diagram to portray those who are supporting them. Half of participants are invited to participate in a second interview 2 months later (lung cancer) or 4 months later (COPD).

## Findings

Data collection is still underway at the present time (February, 2012). To date we have interviewed 20 lung cancer patients and 13 COPD patients and their supporters. Data analysis will commence early summer 2012

## Implications for service development

This project will help identify best practice in service delivery, end of life care and support, and will involve people affected by cancer in research. The project also reflects the top priority research theme of the Macmillan Listening Study: the impact cancer has on life, how to live with cancer and related support issues.

The project will bring clear benefits to people affected by cancer by generating a better understanding of the nature of transition to palliative care for people living with cancer and non-cancer progressive illness, leading to:

- 1 improved provision of clinical care, support and information for patients and lay carers at this most difficult time of deteriorating health
- 2 identification of measures of good care of importance to patients, lay carers and health professionals that will serve to inform future developments of the NHS End of Life Care Strategy and the GP Quality and Outcomes Framework.

*The study concludes in June, 2013.*

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# Exploring, Understanding, and Reducing Emergency Cancer Admissions

## EURECA study

**Dr Dan Munday**, University of Warwick  
**Collette Clifford, Frances Griffiths,**  
**Roberta Lovick**

### Summary

This study explores the experiences of lung cancer patients, and their health care professionals, who have had an unplanned admission to hospital. Insights from the research will facilitate the development of community and hospital services designed to reduce or avoid unplanned admission at the end of life and to improve hospital management following admission.

### Background

Emergency admissions for cancer patients have increased by around 50% in the last eight years whilst elective admissions have only increased by 8%. Unplanned admission of cancer patients frequently lead to poor patient experience and lack of appropriate and timely care following admission.

The Palliative and End of Life Care Framework has highlighted the importance of preventing inappropriate admissions at the end of life.

The current approach in the NHS is to address the issue of unplanned admission in a variety of ways. However in order for these NHS strategies to be effectively implemented it is important to understand the reasons for admission for these patients, from the patient's perspective and those of healthcare professionals involved in their care and ambulance crews.

The study aims to understand the patient experience by:

- 1 understanding the mechanisms and contexts which lead to unplanned admission for patients with lung cancer and a comparative group of patients with COPD



- 2 understanding the experiences of patients following admission and the benefits or problems associated with hospital stay following unplanned admission.

The research aims to inform a future study which will:

- 1 develop a qualitative risk stratification framework of the conditions and contexts influencing the likelihood of patients having an unplanned admission

- 2 propose models of community cancer and end of life care to reduce the likelihood of such admissions occurring and to develop models aimed at improving the experience of admission.

The study is being conducted in three hospitals within the West Midlands.

### Methods

Ten patients with lung cancer and five with COPD are being recruited

in each site as soon after admission as possible. Patients alone or patients and their carers are interviewed in the hospital following recruitment and again following discharge. The interview process is designed to record the patients' narrative of their experience: i.e. what led to the admissions, why it happened at that particular time, whether other courses of action other than admission had been tried, who was involved in the admission process.

Patients are also asked to nominate two community professional and one hospital professionals who we can interview about their care, so that we can gain insight into the admission from a professional perspective.

Analysis of the interviews includes firstly constructing a time line of the patient's narrative of events and secondly thematic analysis is exploring the complex reasons for admissions, issues associated with admission and any themes which might suggest ways in which admission could be avoided.

## Findings

To date 26 out of 45 patients have been recruited. Analysis is at an early stage, however, as anticipated with this group of patients, breathlessness is a major reason for

admission. Most patients are clear in their minds that admission could not have been avoided and this view is maintained even after discharge from hospital.

## Implications for service development

The findings of this work will contribute to the evidence base for understanding unplanned admissions from the patient's perspective and the complexity of the process involved. It will inform the development of a model which will support the objective of the Palliative and End of Life Care Framework to prevent inappropriate hospital admissions at the end of life. The insights from this research will enable community and hospital services to be planned to both reduce admission rates and improve the management of patients who have been admitted. This has a clear impact for Macmillan and other services.

*The study concludes July 2012.*

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## Research outputs

A literature review of reasons for emergency admission of cancer patients was presented as a poster presentation at the NCRI conference 2011.

# A feasibility study of a holistic needs assessment questionnaire in a supportive and palliative care service

## SPARC

**Bill Noble**, University of Sheffield  
**Philippa Hughes, Michelle Winslow,**  
**Nisar Ahmed, Pete Bath**

### Summary

This hospital and community based feasibility study will determine the effects of a holistic needs assessment tool on health-related quality of life and self-identified concerns of patients referred to supportive and palliative care. The study will also determine the effect of the tool on interventions, consultations and referrals within the supportive and palliative care service.

### Background

Studies suggest that cancer survivors have needs which are not being met; they may have ongoing symptoms, be experiencing late effects of the disease, or suffering the impact of living with a chronic illness. Those near the end of life, with cancer or other conditions, also

have important needs. At present, there is no widely used systematic, evidence-based holistic approach to screening these patients for supportive and palliative care needs.

The randomized trial feasibility study will explore the recruitment, data quality and the expected effect size trial of a holistic needs assessment using the Sheffield Profile for Assessment and Referral to Care (SPARC). SPARC is a multidimensional screening tool which gives a profile of needs to identify patients who may benefit from additional supportive or palliative care, regardless of diagnosis or stage of disease. SPARC is intended for use by primary care, hospital teams or other services to improve patient management, either by current professional carers, or by referral to a specialist team.



This study is being carried out with in-patients, out-patients and home-care patients referred for supportive or palliative care. The overall aims of the research are:

- 1** to determine the effect of holistic needs assessment on health-related quality of life and self-identified concerns in patients referred for supportive and palliative care
- 2** to determine the effect of holistic needs assessment on interventions, consultations and referrals within supportive and palliative care
- 3** to measure the difference between patients identified as cancer survivors, those living with a long-term condition and those receiving end of life care, in terms of their concerns, quality of life and need for supportive or palliative care.



## Methods

We are now into the 13th month of recruitment. To date 594 patients have been invited to take part in the study, 161 have consented, 132 completed baseline questionnaires, 104 completed 2 week questionnaires, 80 completed 4 week questionnaires, and 66 completed 6 week questionnaires.

We require a further 23 patients in the study. We will continue to collect data until 128 patients have been recruited to the study (64 patients in each arm of the study). Analysis will be undertaken in April 2012. We will complete the study by the end of June 2012.

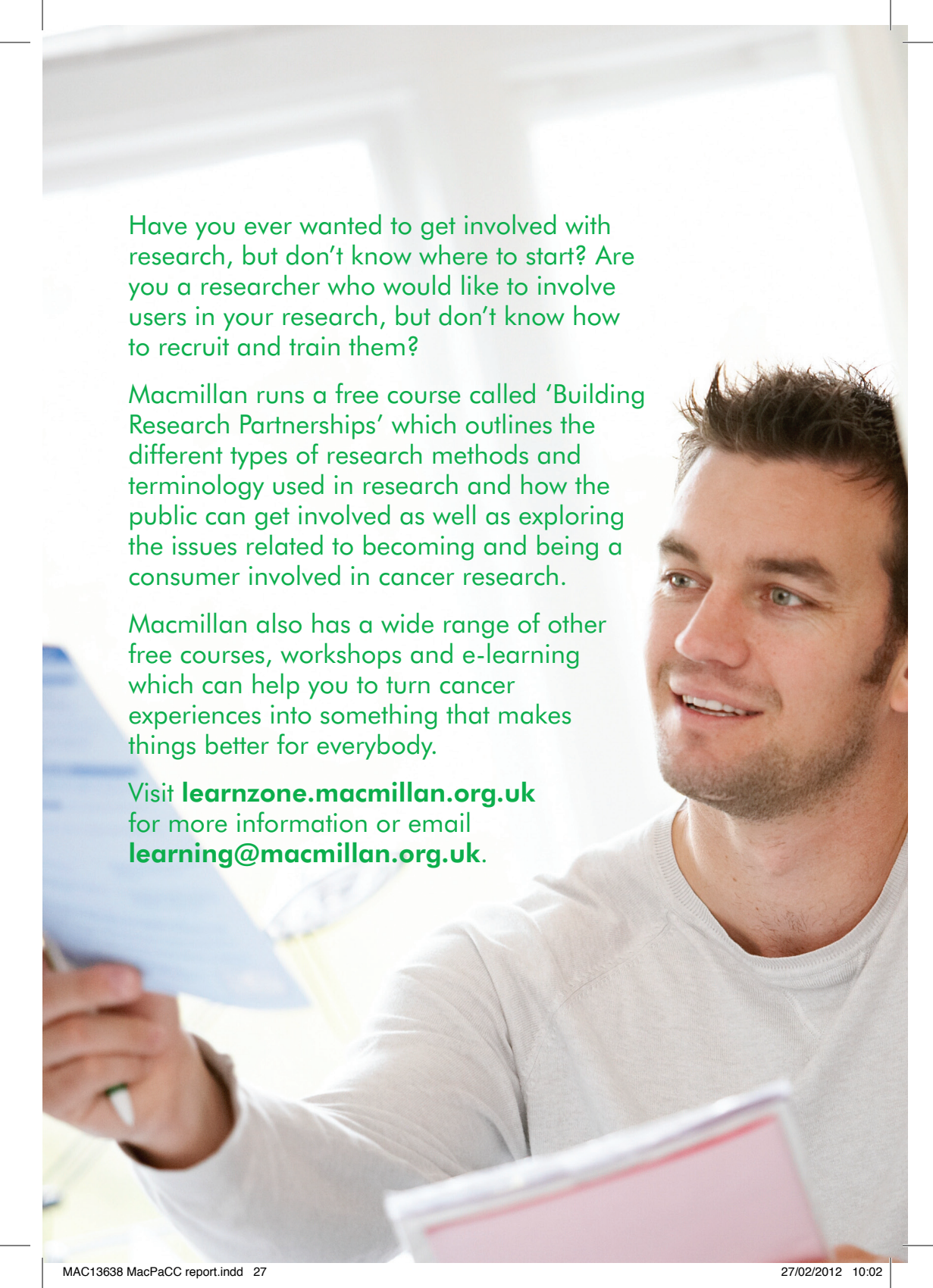
A total of 49 semi-structured interviews have been undertaken with patients (n=30), and health professionals (n=19) as part of a process evaluation of the trial.

## Implications for service development

This study will let us know whether SPARC makes a difference in quality of life, and in referrals for help, and whether the experience is different for different groups of patients. The work will allow the team to plan a definitive trial if this is needed. The timely identification of patient symptoms and concerns and prompt referral to appropriate specialist teams could potentially not only reduce the burden of individual patient suffering, but also lead to earlier discharge from expensive secondary and tertiary specialist care and save funds in the NHS. Similarly, earlier detection of these problems in out-patients could prevent unnecessary admissions and their attendant costs. The potential gains to patients and the NHS are large, for a relatively small investment in screening. The research has potentially significant implications for Macmillan services as well as campaigning and media for end of life care.

*The study concludes on 30 June 2012.*

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A man with short brown hair and a light beard, wearing a white crew-neck sweater, is looking towards the right of the frame. He is holding a blue document in his left hand and a pink folder or book in his right hand. The background is bright and out of focus, suggesting an indoor setting with large windows.

Have you ever wanted to get involved with research, but don't know where to start? Are you a researcher who would like to involve users in your research, but don't know how to recruit and train them?

Macmillan runs a free course called 'Building Research Partnerships' which outlines the different types of research methods and terminology used in research and how the public can get involved as well as exploring the issues related to becoming and being a consumer involved in cancer research.

Macmillan also has a wide range of other free courses, workshops and e-learning which can help you to turn cancer experiences into something that makes things better for everybody.

Visit [learnzone.macmillan.org.uk](http://learnzone.macmillan.org.uk) for more information or email [learning@macmillan.org.uk](mailto:learning@macmillan.org.uk).

Cancer is the toughest fight most people will ever face. But they don't have to go through it alone. The Macmillan team is there every step of the way.

We are the nurses, doctors and therapists helping people through treatment. The experts on the end of the phone. The advisers telling people which benefits they're entitled to. The volunteers giving a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

Our cancer support specialists, benefits advisers and cancer nurses are available to answer any questions you or your patients might have through our free Macmillan Support Line on **0808 808 00 00** Monday to Friday, 9am to 8pm.

Alternatively, visit **[macmillan.org.uk](http://macmillan.org.uk)**

Hard of hearing? Use textphone **0808 808 0121**, or Text Relay.

Non-English speaker? Interpreters available.



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Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). MAC13638.

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