



Cancer experiences: supportive and palliative care needs, problems and solutions

**The CECo research collaborative in Supportive
& Palliative Care**

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NCRI initiative on supportive and palliative care research

- **Analysis of research activity and capacity:**
 - Strategic analysis published in 2002 by NCRI
 - Research into supportive and palliative care accounted for only about 4% of direct cancer research expenditure by NCRI partners
 - In response to this the NCRI established a strategic planning group to make recommendations on actions that could be undertaken to enhance research in this field



Group's response: (May 2004)

- Volume and quality of research undertaken in the UK compared favourably with that undertaken elsewhere
- Considerable need and opportunity for this to be enhanced
- Fragmented research workforce with relatively little interdisciplinary working and little collaboration with researchers outside the field of cancer
- Problems relating to the training and development of the research workforce
- Inadequate numbers of funded posts at postdoctoral and senior lecturer level
- Lack of infrastructure support, including dedicated statisticians, data managers and administrative staff
- Lack of agreed outcome measures for specific aspects of supportive and palliative care research



Call for research collaborative proposals - November 2004

- ***Critical mass*** - a number of academic organisations working together as a single partnership
- ***Span of expertise*** - individuals and groups from a wide range of different research disciplines and clinical professions
- ***Methodological approaches*** to tackle challenges in this area
- ***Increase capacity*** of the UK to conduct high quality research in this area
- ***Maximum positive impact*** on policy and practice
- To nurture high quality ***researchers of the future***



Cancer Experiences Collaborative

- Application led by 13 palliative and supportive care academics from Lancaster, Liverpool, Manchester, Sheffield and Southampton universities, and Mr Roger Wilson, Chair of NCRI Consumer Liaison Group for NCRI.
- Co-Directors: Julia Addington-Hall and Sheila Payne
- Collaborative currently includes 40 named collaborators or collaborating organisations



Collaborators

○ Palliative Care Organisations

- Help the Hospices
- Local palliative care networks
- HOPE
- SIGOPAC
- Bereavement Research Forum

○ Academics

- from gerontology, public health, primary care, social work, health economics

○ Four major UK hospices

- St Christopher's, London; Countess Mountbatten House, Southampton; St Luke's, Sheffield; St Ann's, Lancaster.

○ Oncology services

- Professor Peter Johnson, Southampton; Professor Tim Eden, Manchester; Professor Malcolm McIllmurray, Lancaster



Our collective research expertise

- **User involvement:** Wilson, Corner, Foster, Amir, Payne, Clark, St Christopher's Hospice, Small
- **RCTs for complex interventions** Todd, JAH, Kendrick, Dowrick, Parker, Salmon, Downs, Hopwood, Molassiotis
- **Social Surveys:** JAH, Todd, MLW, ESRC Research Methods Centre
- **Clinical trials, and research in oncology settings:** Molassiotis, Corner, Howell, Johnson, McIlmurray
- **In-depth interviews:** Seymour, Clark, Payne; Grinyer, Thomas, Corner
- **Ethnography:** Seymour, Clark
- **HSR multi-method evaluations:** JAH, Todd, Clark, Payne, MLW
- **Action research:** Froggatt, Payne
- **Case studies:** Payne, Clark, Seymour
- **Clinical research in palliative care settings:** MLW, JAH, Davis, Makin
- **QoL and patient-based outcomes:** JAH, Johnson, Hopwood, Dowrick, Molassiotis
- **Research in primary care settings:** JAH, Todd, Kendrick, Moore, Lewith, Dowrick,
- **Health psychology theory:** Payne, Foster, Grande, JAH, Skinner
- **Gerontology:** Seymour, Gott, Coleman, Parker, Downs, Warner, Help the Aged



Involvement of service users is central to collaborative

Objective

Through

Partnership

Integration

to deliver

More relevant studies
of a higher quality
meeting proven needs

What do service users do with us?

Help develop our research programme

Define & help develop research protocols

Act as researchers and project leaders

Review our programme of research

Explain our research to other users



Aims

To work together to make significant and substantive progress in both research capacity and in the quality of research in supportive and palliative care over the 5 years of the Collaborative

To do so in a way that ensures that progress is maintained beyond this period

Our research themes are platforms on which to build our research capacity – building activities



To be successful, we need to:

Increase the number of high quality researchers in supportive and palliative care research

- increase **number** entering and staying in research
- increase **quality** of those of us in it

Increase the amount of high quality research

- increase **number** and **quality** of grant applications



Being a collaborative is an exciting opportunity:

- To fully engage with people affected by cancer
- To work with clinical colleagues to plan and execute clinically relevant research
- To work with experts from outside palliative and supportive care to produce research that is world class by any standard
- To grow the next generation of supportive and palliative care researchers, able to compete with their peers in medical and health research for high quality peer-reviewed funding, and publishing internationally-rated research
- To work together to achieve our mutual aims, rather than having to compete



Our research themes

- Two central research themes:
 - **Innovative approaches to symptom control**
 - Alex Molassiotis, Mari Lloyd-Williams, Clare Foster
 - **Planning for the care of older adults towards the end of life**
 - Sheila Payne, Katherine Froggatt, Jane Seymour, Ziv Amir
Julia Addington-Hall, Chris Bailey
- Underpinned by a third methodological theme:
 - **narratives of cancer and other life-limiting illnesses**
 - David Clark, Carol Thomas, Sheila Payne, Janice Brown
 - (now Methodology theme; Chris Todd, Nancy Preston)



From identifying and understanding the problem to evaluating interventions

- ***MRC Framework for development and evaluation of RCTs for complex interventions underpins much of our work***
 - Augmented by systematic literature reviews to identify what is known
 - And recognising importance (and problems) of other intervention designs
- **This indicates the importance we place on developing, testing and implementing interventions**
- **We can only conduct definitive RCTs when:**
 - The problem is fully understood
 - The theoretical basis of the intervention is fully explored and adequately developed
 - The intervention is adequately modelled
 - A feasibility trial has been funded and conducted
- **Palliative and supportive care held back by too many trials which have not met these criteria**



Research themes provide platform for capacity-building activities of collaborative

o Resources

- Workshops for novice researchers, as well as for those wishing to develop greater knowledge in specific areas, and ‘master classes’ by internationally recognised experts
- Three-month scholarships (at ‘I’ grade nurse level) to enable clinicians to work with research teams to develop PhD/fellowship applications, for example
- Mentorship
- Support for NCRI Small Grants Scheme



How we know we've been successful?

- **Attracted major grants**
- **Made real scientific progress**
- **Grown and developed new, emerging and established researchers**
- **Integrated people with cancer**
- **Created 'a research community without walls where the standard of intellectual debate and scientific endeavour is high, and where both are saturated by user perspectives and clinical issues'**

Cancer Experiences Collaborative

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Introduction

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