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## Participatory Research in Palliative Care: Actions and reflections

By Jo Hockley, Katherine Froggatt, Katharina Heimerl



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Participatory research is a relatively new method of researching practice especially within palliative care. It differs from other methodologies in that there is an expectation of action within the research process. The values that underpin participatory research are collaboration, empowerment, and reflection. In the current climate of collaboration and working with people in healthcare, participatory research methods are gaining increasing interest when there is a desire to bring about change. Organisational change is becoming an important focus as we look at ways of not only reducing costs but at the same time improving quality of care.

While palliative care puts the patient and family at the centre, *Participatory Research in Palliative Care* discusses a new research methodology that puts practitioners at the heart of the research process as collaborators who work together with researchers to resolve problems in practice.

Divided into three sections, it provides theoretical groundings of action research, a greater focus on exemplars from studies within palliative care, and discusses prominent issues when using such a methodology. All three sections are illustrated by an action research study undertaken by the author within a palliative care setting.

*Participatory Research in Palliative Care* is written by international, multi-disciplinary authors who explore a collaborative approach to embark on research. It will appeal to health and social care professionals, academics undertaking research within palliative care, and the management of organisations where people with end of life care needs are cared for, including long-term care homes.



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## **Editorial Review**

### **Review**

This book is to promote participatory research-a practically focused, rigorous approach to addressing core issues of concern to practitioners and recipients of care-as an appropriate research methodology within the field of palliative care...The book is divided into three sections. The first, Groundings, looks at the different theoretical frameworks of participatory research, each chapter illustrated with examples from actual participatory research. A desire for social justice seemed to be a recurring motivational theme. The second section describes exemplars of action research in palliative care - from improving bereavement support for people with intellectual disability in England, to improving pain management in Canadian long-term care facilities. The final section deals with issues in participatory research, including power, community, gender, as well as the rigour and quality of the research itself. Roger Woodfruff for IAHPC Newsletter, April 2013

### **About the Author**

Jo Hockley currently works as a nurse consultant leading the Care Home Project Team at St Christopher's Hospice, London, where she has been working since 1978. She has set up two hospital-based palliative care teams - one at St Bartholomew's Hospital, London and one at the Western General Hospital, Edinburgh. Since 2000, Jo has been concentrating on developing a palliative care approach for care homes. She undertook a PhD at the University of Edinburgh using action research to study death and dying in nursing care homes. This work underpins her current work in London, implementing the Gold Standards Framework in care homes across five primary care trusts. Jo is also involved in two research projects: a trial looking at the facilitation of developing end of life skills for staff in nursing care homes and an action evaluation of the NAMASTE CARE programme for people with advanced dementia in nursing homes. Jo is an editor of the End of Life Care Journal and has published widely on palliative care.

Katherine Froggatt qualified as a Registered Nurse in London following the completion of her Geography degree at Durham University. She worked in radiotherapy and the care for older people before moving into research in both university and hospital settings undertaking research and practice development in the areas of oncology and palliative care. Her interests in the care for older people, dementia, and palliative care have led her to undertake several projects concerned with care homes, end of life care, and public education using ethnographic and participatory research approaches. She currently works at the International Observatory on End of Life Care in the Faculty of Health and Medicine at Lancaster University.

Katharina Heimerl studied and now practices medicine in Austria and holds a licence as General Practitioner. She has a Master's degree in Public Health from the University of California at Berkeley. She joined the Faculty for Interdisciplinary research and Education (IFF) in Vienna in 1995 where she undertook her 'Habilitation' (PhD) in 2006 in the field of palliative care and organization development. From 2010 she has been Head of the Department of Palliative Care and Organizational Ethics at the IFF, University Klagenfurt in Vienna.

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