

RESEARCH PRIORITIES FOR PALLIATIVE CARE

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Clinical research and particularly medical research has traditionally been led by the investigator who has decided what to research. Applications for research funding are usually judged on scientific merit rather than on the basis of priorities related to health needs. In recent years funding bodies have taken a different approach and have attempted to establish strategies for research based on priorities determined by health needs. This approach is particularly important for palliative care where there is limited research capacity, limited resources and particular difficulties in carrying out research. These difficulties have been well described and, for example, poor recruitment and attrition remain major obstacles to the conduct of randomised controlled trials in this patient group. A major challenge is to develop measures to capture outcome data from patients who are frail, ill and dying, in a way that is practical and ethical.

The scope of research in palliative care encompasses epidemiology, clinical and health services research, and sociological, anthropological, philosophical, psychological and theological domains. The state of development of palliative care and health needs in general may be different in different countries and cultures. For all of these reasons specific priorities are likely to be different. However, there are common strategic priorities: to recognise that those working in palliative care have an obligation to deliver evidence-based care which means integrating individual clinical expertise with the best available external clinical evidence from systematic research (i.e. changing the culture); to develop and strengthen research capacity and the research community in palliative care; and to facilitate collaborative and interdisciplinary projects by providing the infrastructure to support research. Ultimately the aim is to improve patient care and the effectiveness of the strategy will be measured by whether or not it makes a difference to patients.