RESEARCH ETHICS COMMITTEES AND EPIDEMIOLOGICAL RESEARCH IN PALLIATIVE CARE

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In this presentation, I will discuss the role of research ethics committees in epdemiological research in palliative care, drawing primairly on the UK experience. Research ethics committees are often understandably concerned about asking dying and bereaved people to participate in research. I will review the barriers this can present to epidemiological research in palliative care, and will explore whether – as suggested by some research ethics committees – there are specific ethical issues in palliative care research which do not apply to other patient groups. I will also address the particular difficulties for epidemiological research by changing attitudes to obtaining informed consent before accessing medical records and information from death registrations. Threats to epidemiological research in palliative care posed by research ethics committees will be discussed, and some possible solutions suggested.