HOW PROSPECTIVE REGISTRATION CAN HELP RESEARCH IN PALLIATIVE CARE

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Many RCTs in palliative medicine are reputedly difficult to conduct successfully, raising issues of randomisation, attrition and selection of adequate outcome measures. However, gathering evidence on treatment effectiveness is important to the development of the discipline. It is therefore important that practitioners be able to access information about all relevant RCTs easily.

Prospective registration will help identify and track trials throughout their life cycle. It should help prevent duplication of research, encourage collaboration, and assist in systematic reviews. A working group including Current Controlled Trials, the UK Medical Research Council, UK Cochrane Centre, trialists, consumers, and the pharmaceutical industry has developed a unique identification system of International Standard Randomised Controlled Trial Numbers (ISRCTN). Lessons have been learnt from a pilot scheme (200-2001) and the eight-digit, randomly generated number is now being assigned to planned, on-going, and completed trials. The ISRCTN scheme will help develop registers with links to one another and bibliographic records, and facilitate searches across specialities. Palliative care has much to gain from reliable access to multidisciplinary trial data.

Legislation on prospective registration has already been passed in some countries, such as the USA. Major journals and institutions support the project. We hope that it will soon become a requirement for funding, REC approval and publication. For prospective registration to become the valuable research tool it can be, widespread support and legislation is essential.