End this secrecy over clinical trials

Kathy Redmond ■ EDITOR

Ninety-six of every 100 adult cancer patients do not enrol in a clinical trial. One reason is that many trials are shrouded in a veil of secrecy, and patients find it hard to locate one that addresses their specific condition. Existing registries list only a small percentage of trials in progress, the information they contain is frequently inaccurate or incomplete and not all of them are accessible to the public.

This culture of secrecy is now being challenged by the editors of some of the world's top medical journals. In an effort to combat selective reporting of clinical trial results, the International Committee of Medical Journal Editors (ICMJE) have decided that, as of July 2005, clinical trials on drugs and medical devices must be registered in a public repository at the trials' inception to be considered for publication in their journals (see Focus, p 68). A positive spin-off will be that patients will be able to find out more about ongoing clinical trials that they may be eligible for.

The trouble for European patients is that the ICMJE identified only one registry that fulfilled their criteria for a public repository – www.clinicaltrials.gov, sponsored by the US National Library of Medicine. This registry is open only to federal agencies sponsoring clinical trials, and companies that have submitted an Investigational New Drug Application to the US Food and Drug Administration, so few trials outside the US will be eligible. The *British Medical Journal* has criticised the ICMJE for being too prescriptive about their choice of registry, and there will be many who agree. But it is a step in the right direction, and we in Europe should now use the momentum it offers to set up a European registry of clinical trials.

This may not be as difficult as it seems. The European Medicines Agency (EMEA) has just launched a European clinical trials database (EudraCT) that provides national competent authorities with a common set of information on clinical trials taking place across Europe. Under current regulations, this database is not open to the public. But it could be. Surely it is in the interests of European citizens to give the public access to at least some of this information?

The European cancer community needs to be proactive in putting forward a case for a European registry of clinical trials, otherwise the European Commission may take the lead – an appalling prospect when one considers the recent nightmare of the Clinical Trials Directive.

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