

## HERALD

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## Privacy and health trials

PREMIER Morris Iemma's announcement last month of the inclusion of parts of the Hunter in trials of an electronic medical records network won approval from people in the health industry. And there wasn't a murmur from the trial area communities, perhaps because they were led to believe that those involved in the trials would have to give consent as to what information on their medical histories could be circulated and to whom.

They might feel differently now that it has been revealed that the trials will be exempted from the Health Records and Information Privacy Act. Traditionally, patients included in such trials in NSW have had to "opt in" by signing consent forms. However, the 65 years and older Hunter patients in this trial will have to apply to "opt out" if they don't want their records to become available across much of the Hunter health network.

The reason for the change is that the Health Department believes that the red-tape associated with an "opt in" system would be too costly. As a result, it sought and won approval from then Premier Bob Carr almost a year ago for an "opt out" method to be used for the trials.

It is a pity that the change was allowed because it could make people reluctant to be part of a pilot study aimed at improving patient safety across the whole Australian health system.

The states and territories, with the Federal Government, are working towards establishing a national medical records database within three years. At present patients' records are spread widely, in doctors' practices, hospitals, dental surgeries and pharmacies. Many records are hand-written and they cannot be accessed quickly if a patient's life is under threat. A national electronic database could be a lifesaver.

At the same time, privacy concerns cannot be ignored in setting up such a valuable system. People are especially sensitive about their health information, as Federal Privacy Commissioner Karen Curtis noted in her annual report last year. She said protection of privacy was fundamental to building an effective electronic health records system.

NSW Health must take that into consideration in the Hunter trials. All patients involved should be given a careful explanation of what information will be collected, where it will be held and who will have access to it. They should be allowed to "opt in" rather than be made part of the trials without their consent.



Lewis

## Deepest darkest

THERE is no word I'm aware of that captures the extreme disappointment that crashed over Jenny Winney as she stood in Nderit School in outback Kenya and realised that she and the children around her had been conned.

For almost three years the Adamstown Heights resident had been sending money, about \$13,000, to provide what she believes would offer the greatest hope to the area's desperately poor people, an education and an independent income.

She'd paid for, she had been led to believe, school equipment and books, pens and exercise books for every student, school fees for students who couldn't afford to pay their own, and scholarships to secondary boarding schools in the city. She'd provided water tanks for the school and community, and when she was told that a famine had left them starving she'd lifted her fund-raising to provide bags of grain and other food.

Jenny and her many supporters had provided the people of the nearby village, Milia Camp, the poorest people she had ever seen, with materials and tools to make their traditional craft objects for sale, and they'd bought a building near the school as



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Sammy Wamahara, as head teacher or principal, and he'd kept her informed, in creative detail, of how it was spent.

Jenny had been puzzled that the school didn't appear to know she was coming. Quickly, despite Sammy's concocted records, she realised the painful truth. Sammy Wamahara had kept all the money and had been appealing for more despite the fact that he had been transferred to another school a year before. It appeared he'd bribed a man said to be the school committee president to co-sign fictitious records of spending. Nothing had been spent on the school or village.