

National Rural Health Alliance E-forum – 20 July 2001

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From: Nick Stone n.stone@unimelb.edu.au
Subject: RIPE Website

The Rural Interprofessional Education (RIPE) Project is now underway at the clinical placement level and I regularly post updates and findings on the project website (URL below). Could you please advertise this website as there seems to be quite a lot of widespread interest in following this project.

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PRESCRIBING A PRIVACY CURE

(Reprinted from "The Australian", 1 May 2001).

DATA privacy an election issue? Don't laugh - this is serious.

For months, the medical software world has been a hotbed of suspicion and scuttlebutt as public health and corporate agendas clashed over issues of access to and use of confidential patient data.

Against a backdrop of rapid corporatisation of general practices and a concerted Federal Government push towards e-health, doctors are feeling the pressure.

A doctor's obligation to always act in the best interests of the patient doesn't necessarily sit comfortably with shareholder interests, while traditional confidentiality is hard to guarantee when personal records are whizzing around the internet.

Surprisingly, the spark which ignited public debate is the collection and use of "de-identified" data by private companies for "research purposes".

Plans by e-health software company Health Communication Network (HCN) to on-sell patient information obtained from doctors participating in a research program riveted attention on the tug-of-war between commercial and public health interests.

While doctors and patients have always co-operated in information sharing for quality assurance and research purposes, any suggestion that big commercial players are circling

personal medical data registers the maximum on the sensitivity scale.

So suspicion and concerns have arisen over HCN's trial General Practice Research Network program - what data is being collected and who is buying it.

Although the data is supposed to be "de-identified", mailing lists have been running hot with arguments over whether such data can be easily "re-identified".

Shadow health minister Jenny Macklin was one of the first to sound an alarm bell.

"Patient privacy should not be compromised because some doctors see potential for financial gain from the sale of de-identified data," Macklin says.

"Corporate groups with control over a large number of patient records have the potential to market personal medical information to pharmaceutical companies or researchers. Doctors and the corporations that employ them should not be able to onsell medical information without the consent of patients."

Macklin says the high prices currently being paid by medical corporations for "goodwill" in purchases of GP practices might reflect the large returns available from data mining.

"The Howard Government's silence on the uncontrolled growth in corporate medicine has been widely interpreted as a green light for some medical entrepreneurs to bend the rules," she says.

"Labor believes that a clear direction needs to be sent that corporatisation should not proceed unchecked and unregulated."

Doctors fear the profit motive driving corporatisation will result in an erosion of ethical standards and a reduction in quality of care, Macklin says.

"Medical records 'bought' when a practice is corporatised have a commercial value, and no clear rules exist for what a company can do with these records once it has bought them," she says.

"Companies that already own hospitals and other health services such as pathology or imaging services are beginning to see integration with general practices as a significant opportunity to gather previously separate information about patients."

Macklin is seeking comment on a discussion paper, Protecting the Patient's Interest, and has prepared a private member's bill to achieve Labor's five key objectives in the regulation of corporate medicine.

These include prohibiting kickbacks for making referrals, prescribing certain medications or sending people to private hospitals; requiring doctors to provide three choices of specialist when referring patients; and ensuring doctors disclose any financial interest they have in relation to goods or services that they recommend to patients.

The fifth plank is to establish rules for the sale or transfer of medical records to "protect the patient's right to know who has access to their personal medical information and to prevent such information being sold for commercial use".

Meanwhile, HCN is defending its GPRN initiative, insisting the company employs thorough and professional practices that protect the privacy of all participating patients and doctors.

HCN says the GPRN is an initiative developed to assist clinical practice by aggregating data collected by doctors using its Medical Director patient software.

Access to the database is provided free of charge to some university groups and research organisations to assist their public health research.

"For other organisations, HCN will provide a research facility on a 'fee for service' basis," it says. "For example, pharmaceutical manufacturers have a responsibility to ensure the appropriate prescribing of their products by GPs.

"The GPRN provides a valuable source of data in monitoring general prescribing patterns."

But the Australian Medical Association (AMA) has warned doctors to be cautious.

"The AMA has been pressuring government to make covert collection and on-selling of data illegal," AMA ethics committee chair Dr Trevor Mudge says. "In the interim, it's advisable for doctors who manage any part of their patient data electronically to seek from their

software supplier a specific statement that the system does not allow for covert data mining and collection.

"Given that most computers are attached to a phone line it's possible for a computer to be programmed to dial out in the middle of the night and download data to another source without the practitioner being aware of it happening."

Around 85 per cent of Australian GPs use HCN's Medical Director software, but at present only 170 GPs are involved in the GPRN data collection program.

HCN says all data provided through the network is automatically de-identified and encrypted at the GP's practice before sending, and that only nominated company personnel have access to the data. GPs have to give their written consent before participating, and patients can opt out at any time.

HCN research general manager Geoffrey Sayer says he is frustrated by the controversy around the initiative.

"It's a myth to believe you can just magically turn this stuff into squillions of dollars," he says.

"I'm not denying there's a lot of interest in information, but from day one we've made a commitment to protect the doctor's privacy and protect the patient's privacy and we take that very seriously.

"If we were exposed for Trojan horses in the middle of the night, as some have claimed, we would be absolutely slaughtered - and rightly so. The information is just not worth it."

Through GPRN, HCN is hoping to get a better understanding of how doctors use electronic systems, Sayer says.

"HCN has put a lot of investment into this process," he says.

"We have made data available to a number of organisations at our own expense, we are providing expertise and consultancies to groups that are not resourced to do this type of stuff."

These include collaborations with organisations such as the National Prescribing Service (NPS) and the University of Adelaide Department of General Practice. But HCN has refused to name private companies which may be purchasing information for commercial-in-confidence reasons.

NPS chair Dr Stephen Phillips says his organisation is trialling an electronic format for collection of clinical audit data with HCN, but this is entirely separate from the GPRN project.

"None of the information collected under our program is available for commercial use, none of it is available for use in any way except for the professional review of the doctor concerned," Phillips says. "We've gone out of our way to ensure proper privacy and confidentiality were in place before we started, because NPS was particularly concerned about the prospect of data associated with our programs somehow being available to the pharmaceutical industry."

In recent weeks, NPS has sought reassurances and clarifications of these issues, and "we're absolutely convinced the terms and conditions we sought for confidentiality have been adhered to", he says.

Dr Justin Beilby, of Adelaide University's department of general practice, says HCN owns the data, and the university is not involved in any commercial arrangements.

"We have a partnership in the sense of looking at how to use this information to improve the health of the community, but we're not running the process," Beilby says.

"HCN draws the data together and we contract with HCN to access that data for specific research questions."

The university has strict ethical guidelines in relation to its projects, he says, "and I'm comfortable that the process as outlined to us by HCN protects the privacy issues".

Macklin says she is concerned proper consent is not being sought by doctors supplying data to the GPRN. "A notice in the waiting room advising patients they can opt out is not patient

consent," she says. "Patients have to be actually asked and agree to participate before any information -- identified or de-identified -- is passed on, or on-sold."

The key issue for health consumers is how data will be used. Potentially, marketing to health consumers is far wider than mere pharmaceuticals.

How will people react if a visit to the GP for travel vaccinations results in a deluge of advertising from tour companies and travel insurance firms?

And will someone seeking advice on weight loss necessarily be thrilled to open a mailbox full of offers from diet clinics and slimming pill makers?

"The more data goes into detail, the easier it is to combine several databases and re-identify down to the individual level," says country GP Dr Horst Herb, who is writing his own Linux-based practice software.

"That's something neither doctors nor patients would ever want to happen."

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NATIONAL UNDERGRADUATE RURAL HEALTH CONFERENCE

The National Undergraduate Rural Health Conference is the annual conference of the National Rural Health Network (NRHN), the peak organisation representing the interests of undergraduate students in all health disciplines. It is concerned with rural health issues and education in rural, remote and Aboriginal Torres Strait Islander health at undergraduate and postgraduate level. NRHN is a member of the National Rural Health Alliance. The 2000 Conference was convened by TROHPIQ, Queensland's Rural Health Organisation for students. The location for the 2000 Conference was the University of Southern Queensland, Toowoomba, Qld and was held between 9 - 13 September 2000. The Conference was attended by approximately 200 student and 40 academic and profession delegates.

The conference theme "Bringing it all Together" represented the need to draw together the diverse aspects of rural health care and to act on them through taking stock, looking ahead, and moving forward. Through the hard work of the delegates and the quality of the presentations of the speakers at the conference, some of the objectives are currently well progressed.

All of the Conference Proceedings can be found at <http://www.nrhn.org/reports/5th-NURHC> which contains all available presentations plus summaries of discussions and supporting papers.

NURHC 2001
6th National Undergraduate Rural Health Conference
22 – 26 September 2001
Tasman Peninsula, Tasmania

Website: <http://www.ruralhealth.utas.edu.au/nurhc-2001>

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INTERNATIONAL RURAL AND REMOTE ALLIED HEALTH PROFESSIONALS CONFERENCE

The International Rural & Remote Allied Health Professionals Conference is to be held in Cairns from 30 August to 1 September 2001.

This conference is a collaboration between Services for Australian Rural and Remote Allied Health (SARRAH), and the North Queensland Rural Health Training Unit (NQRHTU), Queensland Health. The conference will run over three days with additional pre and post conference workshops. The program will feature lecture style presentations, discussion forums, discipline specific and multidisciplinary clinical workshops, and exhibits of products relevant to various allied health professions.

For details, contact the Alliance at:
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CONTRIBUTION AND SUBSCRIPTION INFORMATION AND DISCLAIMER

The NRHA e-forum is a forum for the expression of YOUR views. Contributions are sought on any topic relevant to rural health concerns. Please send contributions to the moderator, Jim Groves, at grovesc@winshop.com.au.

The NRHA e-forum is edited by a third party moderator, Jim Groves. As such, the Alliance does not control postings and the contents do not necessarily reflect the opinions of the Alliance. Nor do postings necessarily reflect the view of Jim Groves or any organisation he is associated with. Jim Groves can be contacted at grovesc@winshop.com.au.

The e-forum is sent to a mailing list of the Alliance and those have indicated interest through the subscription box at the NRHA Web site (http://www.ruralhealth.org.au). This issue is going to 1,166 recipients. Please forward a copy to any colleague you think may be interested.

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