

Best of the fest

An Oscar-winning animation and stirring documentaries about wheelchair rugby and children learning ballroom dancing have taken the 52nd Sydney Film Festival to a promising start – despite a rash of technical glitches.

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Jumb and Dumber

Australians are making a big mark overseas, but for all the wrong reasons. Criminal feats of etulence, cupidty and just plain evil are quickly overwhelming triumphant seeds of skill on the international sporting field and generosity in humanitarian aid. And we're not just talking about Schapelle, Russell and Renae.

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Unich Confidential

Just Sedgwick Hanfstaengl knew more about Hitler than most – that he liked dangerous circus acts, for example, and was paranoid about being seen. It was a closeness that only the Fuehrer's personal shadow player could experience.

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COMMENT

Don't exactly Kodak moment, I realise. Somehow graduation, and farewell to the 18 to 34 demographic that the globalised world has so desperately tried to reach and blitz with products the past decades feels more tenuous than my 21st birthday was... come my next birthday, even the Nikes, Noks and Pepsis of the world will slide silently off the radar."

on Castles – Page 19



"Electronic Schemes"

Ruth Pollard

SMH 11/6/03 pp 15-16

YOU won't believe what I've found," the young woman's friend wrote in an email. "Check out this weblink." She clicked on the address.

It took her straight to a publicly accessible part of the St Vincent's Hospital website, where her personal medical file had been posted along with the files of 12 others.

Containing information she had disclosed to no one other than the hospital – involving self-harm, mental illness and gender identity – the inadvertent revelation of such personal details was devastating. The hospital quickly removed the files but, for her, the damage was done.

Most of us are seduced by the convenience of technology, and often live a life connected by mobiles, email and the internet. But it is only a matter of time, some say, before "function creep" takes us to places we thought we would never go. Where the possible becomes the inevitable, where governments, business and industry will do it just because they can.

The changes will seem minor at first. But experts warn the barriers to accessing personal medical information will soon be broken down, and the privacy we had once taken for granted will soon disappear.

And it seems the battle over electronic records is being fought between two seemingly irreconcilable issues – a desire for safety and convenience versus the value of privacy.

It is true that many people – particularly those with chronic diseases or the elderly – will benefit from the creation of an electronic health record that follows them from specialist to GP, from hospital to pharmacy.

Their need to have easily accessible health records, to ensure they don't have to rely on memory or unwieldy paper records whenever they see a new clinician, often outweighs any concerns they may have about the privacy of that information.

Not only are electronic records expected to be cost-effective, they can be used to reduce the duplication of diagnostic testing, imaging and history taking and increase the adoption of screening programs and preventive health measures.

Privacy advocates who have criticised a centralised database of medical records, collated and stored without consumer consent, are the first to acknowledge the value of these electronic files.

But they and others, including people who rarely use the public health system, warn that removing the right of consumers to choose whether they have an electronic health record – as NSW Health did last week – is the first step towards the loss of control of personal medical information.

And they say safeguards, already watered down by exemptions in health privacy legislation, will provide little protection.

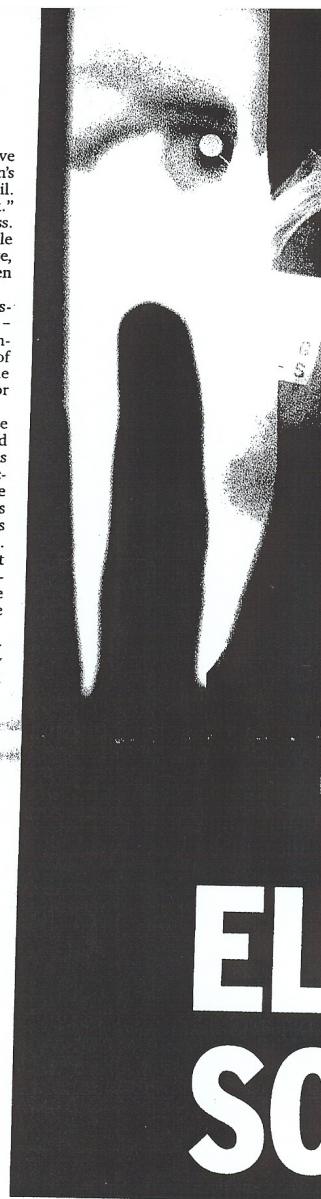
The first problem, says the former privacy commissioner Chris Puplick, is the amount of information held on these records, much of which will add little to the clinical details a doctor will need to diagnose an illness or decide on treatment.

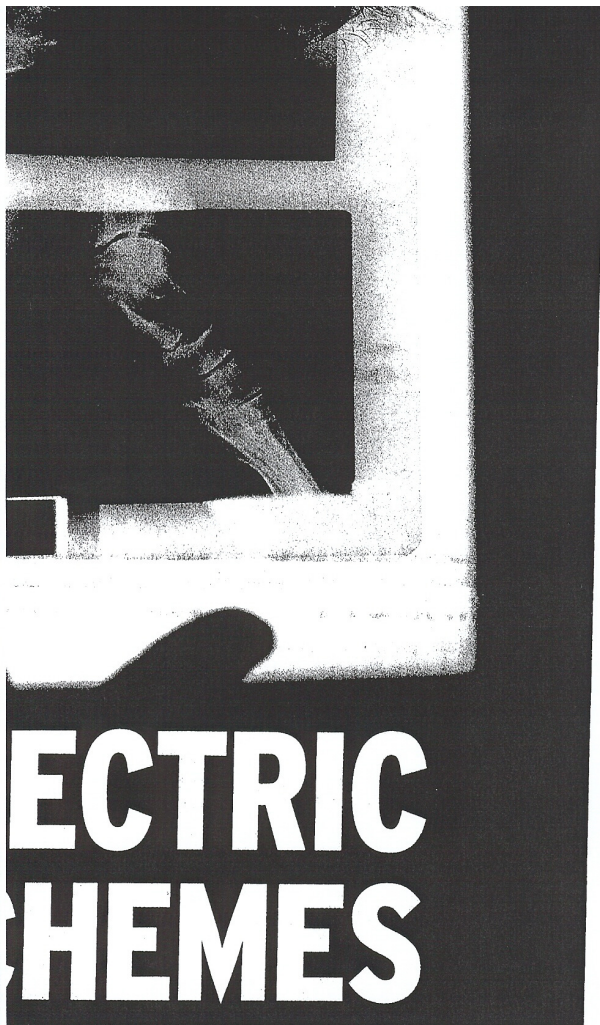
"There is information... which is sensitive and not relevant for everybody to have access to, such as a young man who might have had sexually transmissible diseases when he was younger, or a woman who may have had

a termination of pregnancy," says Puplick, now executive officer at the Centre for Advancement of International Health at the University of Wollongong.

Even the revelation of where a person received medical treatment can tell a story. A medical record might note treatment was received at Justice Health, meaning the patient was in jail, or Bloomfield hospital, a mental institution.

Puplick says there is no medical reason for a doctor to know a patient was in jail, and





very reason for the patient to worry he or she might be judged because of it.

"A new treating practitioner may in fact only have to know blood group, allergies, current medication - the idea that everybody's record is simply available to anybody without those privacy protections is quite horrent," he says.

Puplick notes there are provisions in the Health Administration Act that require the state's health department to provide a medical record to the premier on request. "If, for

example, during the course of an election campaign, an unscrupulous premier decided to have a look at the health records of the leader of the opposition or ... a pesky journalist ... there is absolutely no protection," he warns.

Even before a system of linked electronic medical records exists, there have been enormous problems maintaining the privacy of a patient's records.

When St Vincent's Hospital inadvertently posted the private medical records of at least

13 patients on its website in 2003, it sounded an alarm over the scale of privacy breaches possible in the age of technology. Some of the patients were HIV-positive, so their status was disclosed, while the young woman who contacted the *Herald* said details of her physical condition and her mental illness were posted.

The 26-year-old, who does not want to be identified, says the experience almost destroyed her, and has left her extremely distrustful of hospitals, doctors and computers. It means she is unlikely to seek medical help when she needs it (see breakout over page).

Last week, the *Herald* revealed that NSW Health had quietly changed its position on whether consumers should have the right to consent to a health record being created. No, it decided, they should not.

Asked what led to the change of heart, the assistant director architecture and standards, information management for NSW Health, Joanna Kelly, said giving consumers a choice was too costly, and that patients had approved the change.

NSW Health estimates the cost of adopting an "opt in" model, where consumers would be asked to consent to a record being created, would be \$350 million.

So how much less expensive would it be to establish an "opt out" model - where an electronic health record would be created for everyone and consumers would then be able to say who could have access to it?

NSW Health hasn't done any costings on that, Kelly says. She just knows it's less expensive. Puplick and other privacy advocates were outraged.

"It is part and parcel of a general attitude that this Government takes towards privacy, which is that it is a nuisance, it gets in the way of the Roads and Traffic Authority, the health department, the police, the education department," he says.

The former deputy privacy commissioner Anna Johnston, who now chairs the Australian Privacy Foundation, accuses NSW Health of not consulting widely enough on the issue.

"They were very much focusing on the people who have the most to gain out of electronic health records, such as those with a chronic disease, rather than a broad cross-section of people who may not be frequent users of the health systems," Johnston says.

Of most concern to Johnston is the so-called "honey pot" effect, where as long as it is known that an electronic file exists, organisations will be tempted to try to gain access. Even if an insurance company, for example, cannot pressure the health department into releasing a file, it can pressure an individual to provide the file on demand, she says.

They could say "Show us the file or we will refuse you insurance", Johnston says. And because it exists in a neat, electronic format, it could be difficult for a consumer to say no.

Under the proposed NSW system, even those people who decide not to share their information will be unable to prevent the Government from continuing to collect and store it.

"One of the reasons I think the Australian Card was rejected in the '80s was that people started to see function creep in the making. Continued Page 16

xy to make family
o says. "It's an enor-
flect our lives and our voices,
O'Mahony says.

by Anthony...
Opens mid-September.

ELECTRIC SCHEMES

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first it was supposed to be for tax fraud, then welfare fraud," Johnston says.

The same kind of "function creep" occurred with the tax file number, which was only meant to be about tax. Then it was extended to welfare benefits, and now banks require one. It is not hard to see a pattern emerging, she says.

Others fear it is just a small leap from having electronic health records linked to Medicare data, and then a small jump again to having all interactions with the health system monitored by either the federal or state government. There is also the danger that many people will simply not go to the doctor because of fears their medical condition might be used against them, Johnston says.

"When people ... do not use a health service because of their fear that someone may get access to that record, it is the point at which all the public health benefits are lost," she says.

Doctors also have grave concerns about the direction NSW has taken on electronic medical records. The NSW president of the Australian Medical Association, John

Gullotta, says there are concerns about who has access to the files and how patient privacy - particularly in relation to mental illness and sexually transmitted illnesses - could be protected.

He says the association is pushing for the model in which a patient would have to provide consent before a medical record is created.

The Doctors Reform Society agrees. Its president, Tim Woodruff, says even though there are important benefits from such a scheme, these privacy concerns are crucial to the patient, and to the future of the doctor-patient relationship.

The director of the NSW Council of Social Service, Gary Moore, has reservations but is prepared to give NSW Health the benefit of the doubt. While acknowledging there is a "divergence of views among consumer groups" on the issue - contrary to NSW Health's assertion that consumers were overwhelmingly positive about the policy shift - the organisation will support the new model being trialled in two area health services.

"It is true that older people and people with chronic conditions in general have less opposition to an opt-out

model, but it is also true that some of the groups [representing] hepatitis C, HIV and younger people's consumer groups have more concerns about privacy," Moore says.

NSW Health's Joanna Kelly says consumers at focus groups described the model that would require obtaining consent before an electronic record was created as "overkill".

"The reason that we have designed this the way we have is largely driven by consumers," she says. "We believe this is a right approach but it will go to Privacy NSW and a decision will be made."

The proposed system is the best option for patients and should be implemented as soon as possible, says Geoff Spitzkowsky, the former chairman of the Lower Hunter Consumers Council and member of the NSW Health electronic health records steering committee.

"I am convinced that it is as secure as current information technology can make it," he says. "We believe the introduction of an electronic health record system in Australia is probably the greatest non-clinical advancement in the health system in 50 years."

A matter of trust: sickened by a hospital's ill-treatment

In her own words, a 26-year-old woman



A matter of trust: sickened by a hospital's ill-treatment

In her own words, a 26-year-old woman speaks out about the breach of her privacy.

MY PERSONAL and health information was accidentally posted on the internet, accessible to anyone. You didn't even need a security password to access it.

This breach of privacy occurred when my "management plan" was backed up overnight by the hospital's server. Instead of backing it up on the internal intranet, it was posted onto the internet. There were other management plans in the same folder mine was in.

When I found out about the breach, I felt numb. I was in shock. I also felt angry – personal information that I had disclosed to the hospital was on the internet.

The management plan included information that identified me: my name, my date of birth. It also included a medical history, diagnosis and an outline of the treatment I should receive when I attended the hospital.

At the time of this privacy breach, I had been attending the hospital's emergency department frequently for the treatment of self-mutilation.

As I write this, it still hurts to know the most private information about myself was posted onto the World Wide Web. I still feel angry.

When I walk down the road, when I sit on a bus, no one knows I used to physically hurt myself. I cover the scars.

The hospital took away from me my right to tell people what I have been through, how much I want them to know and when it feels right to tell them about myself.



I did not ever consent to my personal health information being stored electronically and the hospital failed to adequately protect my file.

It was created and uploaded onto the hospital's server by a clinical nurse consultant, not a qualified IT professional.

Before any trials go ahead, more research should be done. The Government must invest more in IT to ensure that what happened to me never happens to others. Standards and security processes must be in place.

In principle, I support the idea of sharing important health information – such as allergies, previous heart conditions – between doctors and hospitals, electronically.

However, I strongly feel that the patient's permission should always be sought whenever someone seeks to store or share this information.

We should have the right not to participate in any trial or eventual electronic health record. We should also have the right to choose who can have access to the information.

I had placed my trust in the hospital to help me – it was a safe place for me when I felt vulnerable.

Now I am not as vulnerable and I have found other ways of coping, but what is lost – probably forever – is my trust in the health system and the doctors and nurses who work in it.