

Media Release, June 3 2021

APF: Aussies show the way for Brits to grab patient data

“If you haven’t heard about this it’s because they haven’t told you”, say Phil Booth and Sam Smith of medConfidential.org.(1)

The Australian Department of Health’s Primary Health Insights (PHI) project commenced in mid-2019. Every time Aussies see their GP, 400 types of medical information are sent to PHI data bases. The PHI have stored up to 25 million patients’ sensitive and confidential medical records from doctors’ computers so far.

The kinds of extraordinarily private data that are expropriated include prescription and medical benefit identifiers, IVF treatment, medications – such as opioids and antidepressants; alcohol consumption; smoking; and diagnoses such as cancer, chlamydia and anxiety.

The dates are included in the data points, and so are Medical and Pharmaceutical Benefits Scheme PINs (identifiers), pathology results, and even the information that patients confidentially share with their General Practitioners to receive health care.

Theoretically, patients can opt out of the scheme with every individual GP practice they see. But they make that hard to do, and very few achieve it. (2)

Now the British government is raising the ghost of its defunct data.care scheme to do the same thing. The UK scheme will re-use people’s sensitive health records for research and administrative purposes beyond their own medical care.(3-4)

Juanita Fernando, of the Australian Privacy Foundation, said, “It’s like having a journalist hidden in your GP’s consulting rooms, reporting on every confidential thing you discuss with your doctor”.

But British patients enjoy a better privacy regime than Australian patients. The British have until 20 June 2021 to formally opt out of the scheme nation-wide. Fernando summed the situation up: “At least in Britain, unlike Australia, the government plans to tell patients about this latest grab for general practitioner data, and how to opt out”.

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References

1. medConfidential; Keep our secrets. *medConfidential*, 17 May 2021. Available from <https://medconfidential.org/>
2. Fernando, J. (2021) Federal Government quietly reward GPs for patient health data without getting informed consent, March. *Australian Privacy Foundation*. Available from <https://privacy.org.au/wp-content/uploads/2021/04/MBGovtGPsPatientData-210401.pdf>
3. Murgia, M. England’s NHS plans to share patient records with third parties. *The Financial Times Ltd*. May 26 2021. Available from <https://www.ft.com/content/9fee812f-6975-49ce-915c-aeb25d3dd748>
4. Crouch, H. New data collection service could ‘destroy’ patient trust. *digitalhealth*, 26 May 2021. Available from <https://www.digitalhealth.net/2021/05/data-collection-service-destroy-patient-trust/>

Background Information

The Australian Privacy Foundation (APF) is the primary national association dedicated to protecting the privacy rights of Australians. The Foundation aims to focus public attention on emerging issues that pose a threat to the freedom and privacy of Australians. The Foundation has led the fight to defend the right of individuals to control their personal information and to be free of excessive intrusions.

The APF's primary activity is analysis of the privacy impact of systems and proposals for new systems. It makes frequent submissions to parliamentary committees and government agencies. It publishes information on privacy laws and privacy issues. It provides continual background briefings to the media on privacy-related matters.

Where possible, the APF cooperates with and supports privacy oversight agencies, but it is entirely independent of the agencies that administer privacy legislation, and regrettably often finds it necessary to be critical of their performance.

When necessary, the APF conducts campaigns for or against specific proposals. It works with civil liberties councils, consumer organisations, professional associations and other community groups as appropriate to the circumstances. The Privacy Foundation is also an active participant in Privacy International, the world-wide privacy protection network.

The APF is open to membership by individuals and organisations who support the APF's Objects. Funding that is provided by members and donors is used to run the Foundation and to support its activities including research, campaigns and awards events.

The APF does not claim any right to formally represent the public as a whole, nor to formally represent any particular population segment, and it accordingly makes no public declarations about its membership-base. The APF's contributions to policy are based on the expertise of the members of its Board, Committees and Reference Groups, and its impact reflects the quality of the evidence, analysis and arguments that its contributions contain.

The APF's Board, Committees and Reference Groups comprise professionals who bring to their work deep experience in privacy, information technology and the law.

The Board is supported by Patrons The Hon Michael Kirby AC CMG and The Hon Elizabeth Evatt AC, and an Advisory Panel of eminent citizens, including former judges, former Ministers of the Crown, and a former Prime Minister.

The following pages provide access to information about the APF:

- Policies <https://privacy.org.au/publications/by-date/>
- Media <https://privacy.org.au/home/updates/>
- Current Board Members <https://privacy.org.au/about/contacts/>
- Patron and Advisory Panel <https://privacy.org.au/about/contacts/advisorypanel/>

The following pages provide outlines of some of the campaigns that the APF has conducted:

- The Australia Card (1985-87) <https://privacy.org.au/About/Formation.html>
- Credit Reporting (1988-90) <https://privacy.org.au/campaigns/consumer-credit-reporting/>
- The Census (2006) <https://privacy.org.au/campaigns/census2006/>
- The Access Card (2006-07) <https://privacy.org.au/campaigns/id-cards/hsac/>
- The Media (2007-) <https://privacy.org.au/campaigns/privacy-media/>
- The MyHR (2012-) <https://privacy.org.au/campaigns/myhr/>
- The Census (2016) <https://privacy.org.au/campaigns/census2016/>