



**Australian Privacy
Foundation**

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MEDIA RELEASE

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APF:

Every 3 minutes Australian health services collect 400 data points of up to 25m patients' medical records

Primary Health Networks (PHNs) have been collecting 400 data points of up to 25 million Australian patient health records since August 2019. The records are apparently deidentified, but as science has long demonstrated, can be later identified so that criminal agents may collect 400 pieces of information about you from this information.⁽¹⁻²⁾

Your General Practice asks for your consent to do this by bundling the authority into imprecise packages of tick-box styled general statements. By consenting to be treated by your usual doctor, patients also consent to link information from their confidential medical consult to information stored by health authorities (see Figure 1, below).

Juanita Fernando, Chair of the Australian Privacy Foundation (APF) Health Committee was “...*annoyed to discover the consent mechanism. I [sic] didn't realise I [sic] was sharing all that private and sensitive health information with my doctor, PHNs and the government to store*”.

Patients lose control over the way their data is used as it flows from health authorities to researchers in a cascade from one study to the next.

The APF has traced the uncontrolled consent mechanism to the Australian Institute of Health and Welfare (AIHW), who evidence suggests are designated by the Federal Government as our National Data Custodian. Sadly, when we reached out to the AIHW to ask some questions, we were referred to the Department of Health for answers. Fernando continues, “*Around and around we go, ping-pong backwards and forwards between and betwixt government departments and health authorities for answers, but our questions remain*”.

Our key questions ask -

1. How can people withdraw or refuse consent for the PHN data collection?
2. Who or what are the positions and bodies that hold the data collected by the PHNs?

So we request that federal health authorities and PHNs to share their data collection plans with Australians and advise how people may withdraw or refuse consent.

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Medical Centre

CONSENT FORM

We require your consent to collect personal information about you. Please read this consent form carefully and sign where indicated below.

This medical practice collects information from you for the primary purpose of providing quality health care. We require you to provide us with your personal details and a full medical history so that we may properly assess, diagnose, treat and be pro-active in your health care needs. This means we will use the information you provide us in the following ways.

- o Administrative purposes in running our medical practice.
 - o Billing purposes including compliance with Medicare and Health Insurance Commission requirements.
 - o Disclosure to others involved in your healthcare including treating doctors and specialists outside this medical practice. This may occur through the referral to other doctors, or for medical tests and in the reports or results returned to us following referrals.
 - o Disclosure to other doctors in the practice, locums etc. attached to the practice for the purpose of patient care and teaching. Please let us know if you do not want your records accessed for these purposes and we note in your record accordingly.
 - o Disclosure for research and quality assurance activities to improve individual and community health care and practice management, all information in these instances is un-identified. These activities are ongoing within the practice. I have read the information above and understand the reasons why any information must be collected. I am also aware that this practice has a privacy policy on handling information.

/ understand that / am not obliged to provide any information requested of me, but failure to do so may compromise the quality of healthcare and treatment given to me. I understand that if any information is to be used for any other purpose other than set out above, my further consent will be obtained.

/ consent to the handling of my information by the practice for the purposes set out above, subject to any limitations on access or disclosure that I notify this practice of.

(Please tick if agree) / am happy to receive Appointment and/or Recall SMS text reminder messages.

Signed.....

Name.....Date.....

Signed as Guardian of child.....

Name.....

Figure 1: Sample general practice consent paperwork attached to patient enrolment paperwork

References

1. Sugarman, J. & Carrithers, J.(2021) Certificates of confidentiality and unexpected complications for pragmatic clinical trials. Learn Health Sys; 5(2). Available from <https://onlinelibrary.wiley.com/doi/10.1002/lrh2.10238>
<https://doi.org/10.1002/lrh2.10238>
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/MB-GovtGPsPatientData-210401.pdf>