



an Education Across the Nation (EdXN) presentation

Privacy is your Problem

- how to become empowered, not enslaved

learn the critical risks and how you can protect personal information

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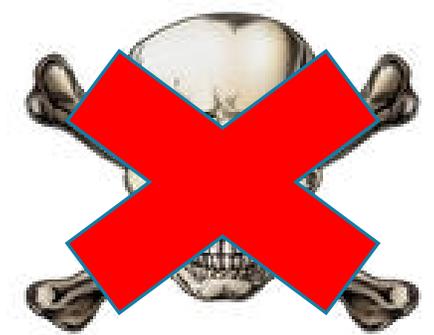
to prevent any confusion

Privacy Protection



a bit about me

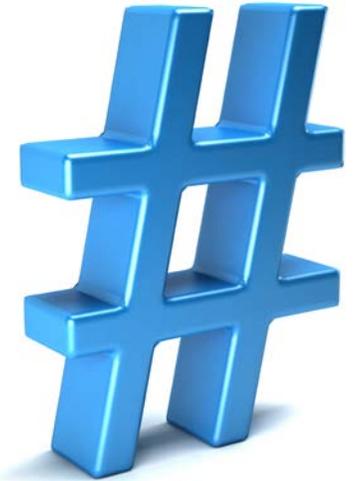
- 30 years+ experience in IT - I've always worked in risk / risk minimization
- Firstly in machine and aircraft control systems - last 15 years focus on Health IT
- Chair of Australian and the International workgroups on Health Privacy and Security
- Australian Law Reform technical committee, Standards committee IT14
- Many submissions to government changes to legislation and policy
- Now work as a Cyber Security and Privacy consultant –industry, gov. and professional societies
- I publish 'How-To' eBooks to assist practitioners, particularly SMEs





topics

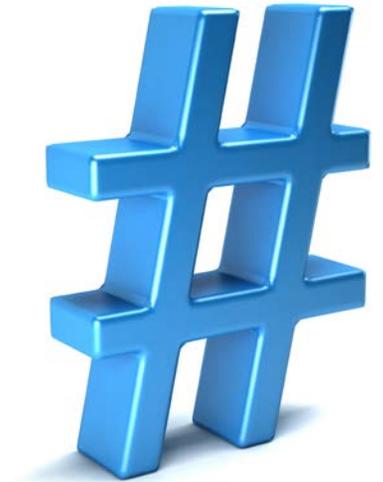
- **is privacy dead?**
- **privacy law changes**
- **holistic view of privacy**
- **calculating privacy risks**
- **privacy analysis – case study**
- **privacy-by-design**
- **‘My Health Record’**
- **social networking**
- **the way forward?**





topics

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- the way forward?





is privacy dead?

“You have zero privacy anyway. Get over it.”

Scott McNealy (Co-founder, Sun Microsystems) 1999



is privacy dead?

“If you have something that you don’t want anyone to know, maybe you shouldn’t be doing it in the first place”

Eric Schmidt (CEO, Google) 2009



is privacy dead?

“Arguing that you don't care about the right to privacy because you have nothing to hide is no different than saying you don't care about free speech because you have nothing to say”

Edward Snowden, 2015



is privacy dead?

“We believe that people have a fundamental right to privacy. The American people demand it, the constitution demands it, morality demands it”

Tim Cook (CEO, Apple) 2015



is privacy dead?

“Digital surveillance is worse than anything George Orwell could have foreseen”

Joseph Cannataci (UN Privacy Chief) 2015



SMH thinks Privacy is dead!



Ben Grubb and Telstra Corporation Limited **[2015] AICmr 35 (1 May 2015)**

Determination and reasons for determination of Privacy Commissioner, Timothy Pilgrim

“On 13 Oct this country's entire communications industry will be turned into a surveillance and monitoring arm of at least 21 agencies of executive government”

“The electronically logged data of mobile, landline voice (including missed and failed) calls and text messages, all Aus emails, download volumes and location information”

“Mandatorily retained by Australian telcos and ISPs or face a \$2 Million fine”

Complainant:	Ben Grubb
Respondent:	Telstra Corporation Limited
Determination date:	1 May 2015
Application number:	CP13/01119
Catchwords:	Privacy — Privacy Act — National Privacy Principles — (CTH) Privacy Act 1988 — s 52 — NPP6.1 — Access



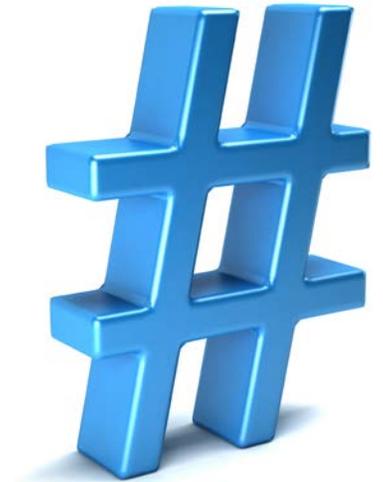
We published ABC reporter Will Ockenden's metadata in full and asked you to analyse it. Here's what you got right — and wrong.

Ashley Madison or 'jihadi' content sites, may in effect be discoverable without the need for a warrant. ”



topics

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new laws

- Privacy Act - Updated 12 March 2014 - after major review
Now contains 13 new Australian Privacy Principles (APPs)
- Telecommunications (Interception and Access) Amendment (Data Retention) - Act 2015
- Personally Controlled Electronic Health Act
Centralised government health record for all Australians
- Health Identifiers Act
Every Australian assigned a unique 16 digit ID



Healthcare Identifiers Act 2010

No. 72, 2010

Compilation No. 8

Compilation date: 5 December 2014
Includes amendments up to: Act No. 126, 2014
Registered: 11 December 2014

Prepared by the Office of Parliamentary Counsel, Canberra



Privacy law changes – Australian Privacy Principles

APP 1 – open and transparent management of personal information

- more prescriptive requirements for privacy policies

APP 2 – anonymity and pseudonymity

- Provide individuals ,where practical, with the option of dealing with entities anonymously (e.g. pseudonym)

APP 3 – collection of solicited personal information

- Collect from Individual and only collect 'Sensitive' with consent

APP 7 – direct marketing

- When individual consents or would expect this and if they can opt-out easily

13 APPs now (previously 10 NPPs or 11 IPPs)

APP 8 – cross-border disclosures

- Agency must take reasonable steps to ensure overseas recipients comply with APPs

APP 11 – security of personal information

- Steps to destroy/de-identified when no longer needed

APP 12 – access to personal information

- Process for individuals to access and correct their personal information

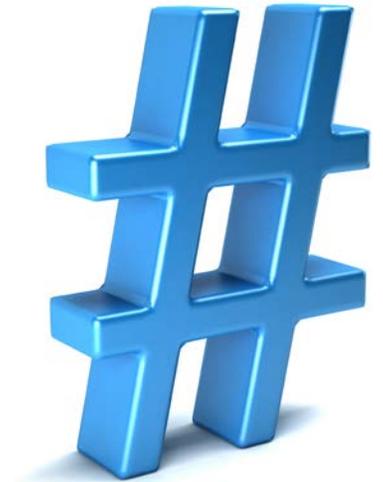
APP 13 – correction of personal information

- Correct so that its up-to-date, complete, relevant, accurate and not misleading



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holistic view of privacy



Good **SECURITY** is essential but far from the whole story

PRIVACY protection goes much further - it requires a holistic view

What if **SECURITY** is breached but the information disclosed can not identifying you?

What if personal information is disclosed by other means? - e.g. an overseas organizations hassling you to buy the latest insulin pumps since they were informed that you are a diabetic.

What if authorized users look up your personal information when they have no moral right to do so? - e.g. your sensitive information is not part of their case load?

That is, they were authorized by the system since they work at the organization concerned. They might be your relatives or acquaintances!

Your **PRIVACY** is breached (although the **SECURITY** may not have been)



confidentiality and trust

CONFIDENTIALITY is about not disclosing secret information

Patient **CONFIDENTIALITY** is about the healthcare practitioners keeping personal sensitive health information 'secret' from anyone who doesn't 'need-to-know'

In business, 'commercial in confidence' relates to **CONFIDENTIALITY** of company secrets

TRUST is the confidence you place in others to keep secrets and protect you

What if you provide your contact list to an organization (or an app) and they later use this in ways you would never had agreed to when you originally provided it?

They may use your contact list to sell services and claim it was from your recommendation

A breach of organizational **TRUST**



safety



What if the personal (possibly sensitive) information that is breached causes you or an acquaintance harm?

SAFETY is about taking measures to minimize harm

What if a **SECURITY** breach causes important information to be:

- corrupted (poor integrity) or
- really slows the system down (poor availability) or
- makes it impossible to retrieve (inaccessible)?

This might cause harm to either 'you' or the 'system' – which in turn may cause harm to the business.

harm

HARM to be concerned about with regard to IT systems:

Harm to:

- the individual (embarrassment, loss of finance, social status, job or respect);
- the system (integrity, availability or accessibility);
- the business (trust, financial);
- the community and environment (confidence, respect, financial and damage).





risks

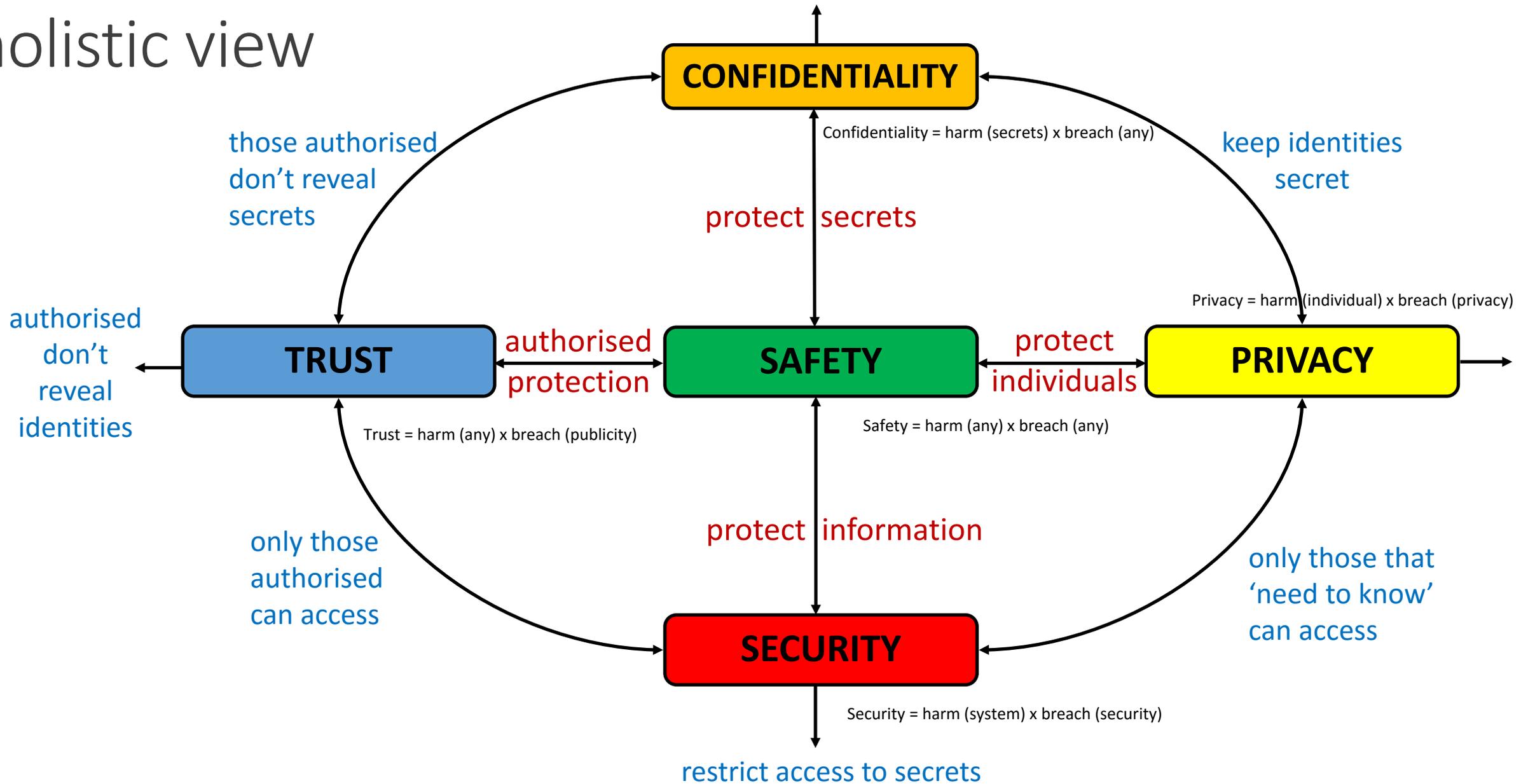
Minimising the IT RISKS of:

- unauthorised access (**SECURITY**)
- inappropriate disclosure regarding identifiable individuals (**PRIVACY**)
- inappropriate disclosure of secret/protected information (**CONFIDENTIALITY**)
- unexpected organisational behaviour (**TRUST**)
- harm to individual, system or secrets (**SAFETY**)

*“exposure to the chance of injury or loss;
a hazard or dangerous chance”*

[‘Risk’ definition: Macquarie Dictionary]

holistic view



recent example

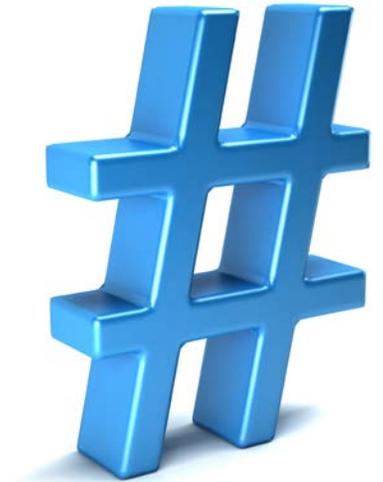
- **breach (security)** from disclosure of 33 million accounts to unauthorised hackers
- **breach (publicity)** occurred when criminals threatened to expose accounts on the Internet
- **breach (privacy)** resulted when personal data was published for all to download
- 'significant' **harm (individual)** and **harm (business)** as a consequence
- **SECURITY** and **PRIVACY** risks may have now been minimised by the company
- **TRUST**, **CONFIDENTIALITY** and **SAFETY** risk levels remain 'Very High'





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calculating privacy risks



To calculate privacy risk levels:

You need to know the chance of a breach occurring

this can be measured in likelihood (i.e. frequency) of a breach occurrence per annum

You also need to know the impact (consequences) once a breach has occurred

this can be measured in 'number of records' or 'cost to business', etc.

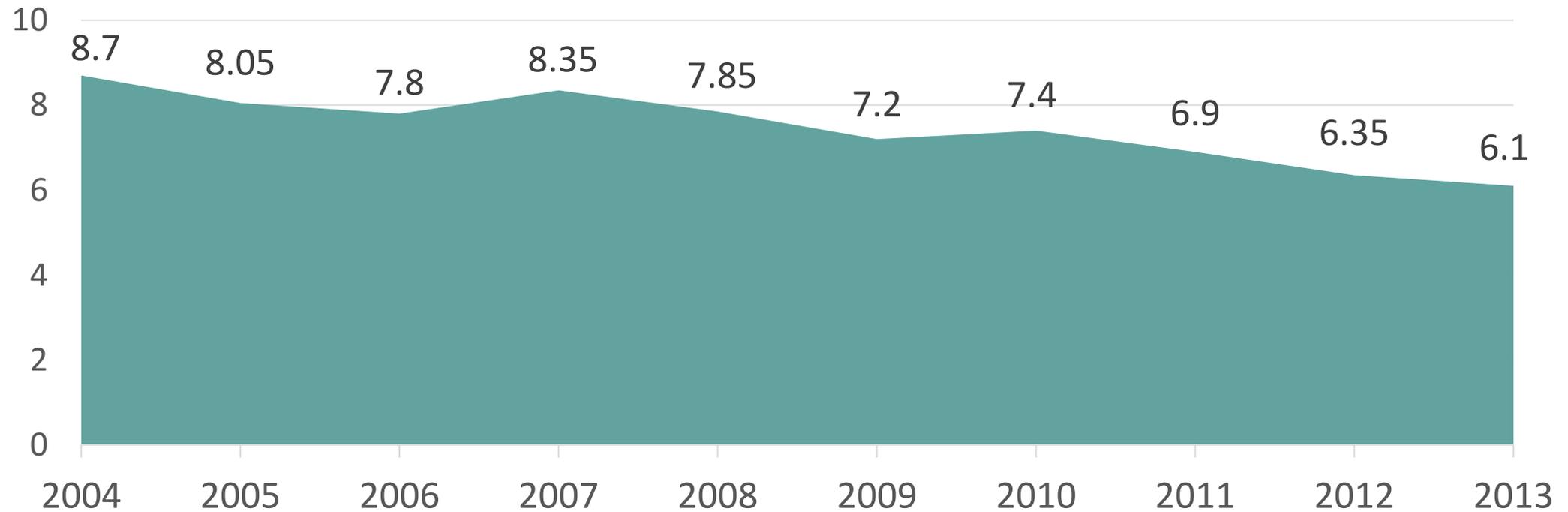
These factors are much easier to estimate when you have a reliable history of occurrences and you are dealing with well understood technologies, e.g.:

EASIER – risks from Australian postal services misdelivering personal letters

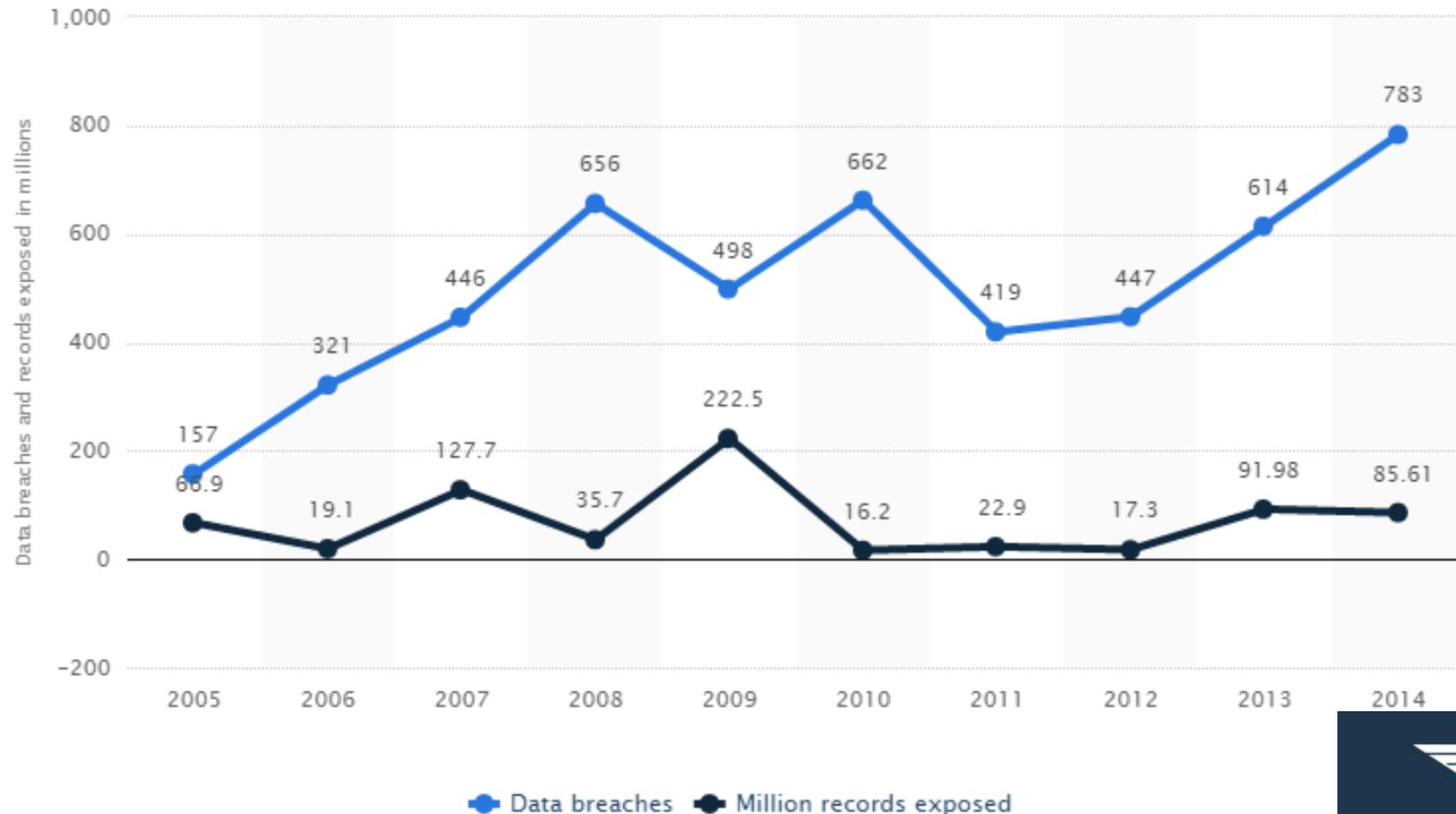
HARDER – risks from new mobile APP to access your personal details from a company database

example risk history

Motor Vehicle Fatalities per 100,000 population (ABS)



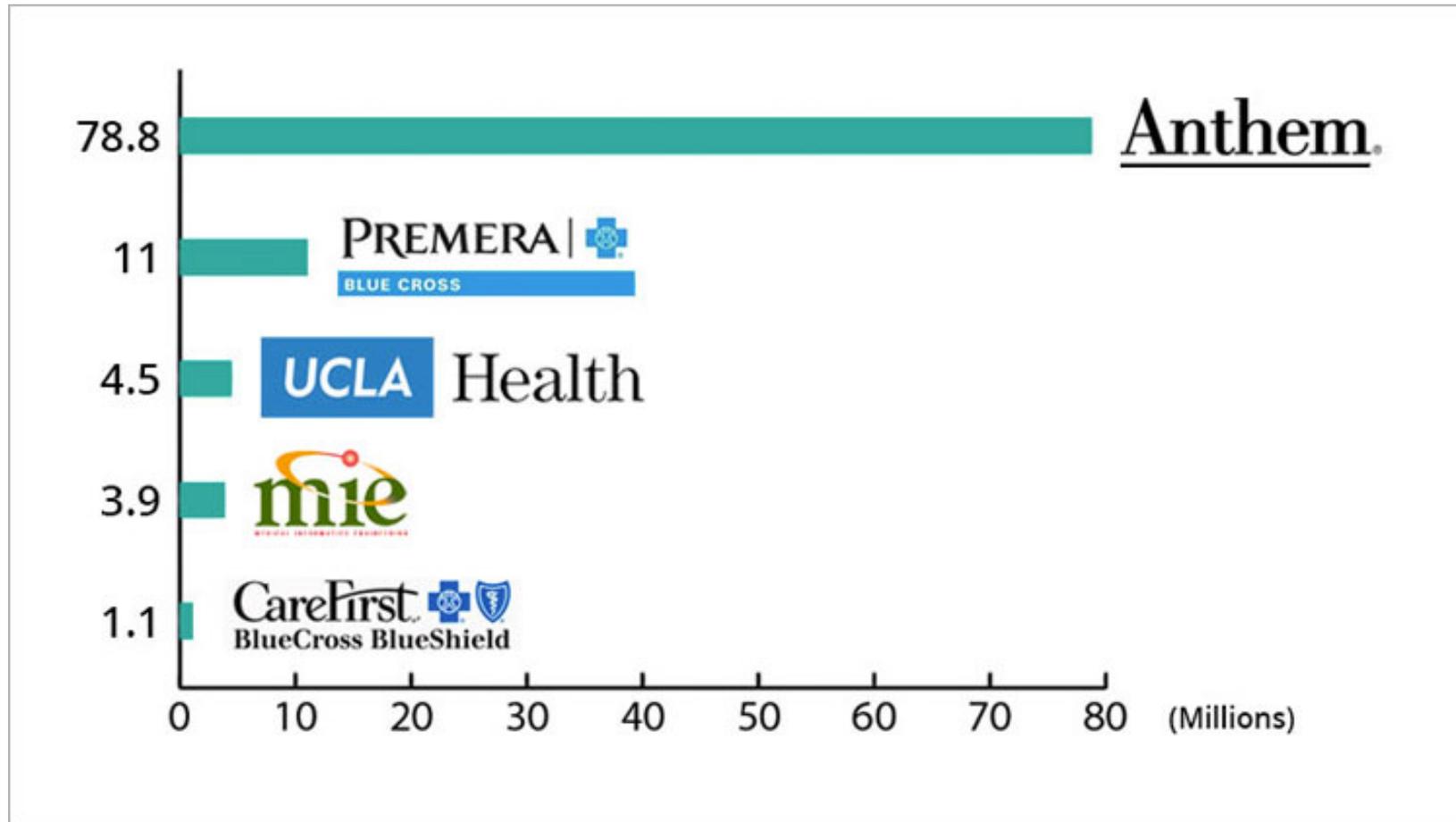
Annual number of data breaches and exposed records in the United States 2005-2014



offers some predictability?



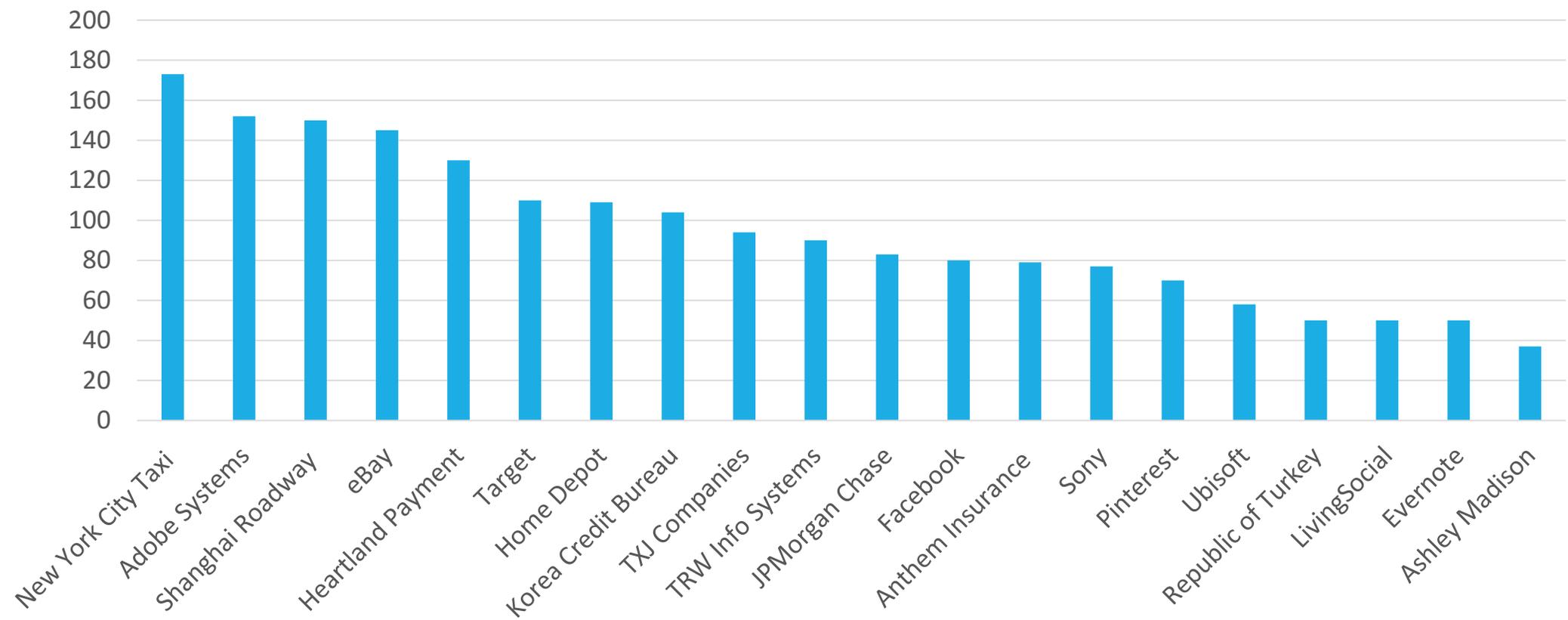
Over 100 Million Affected in 2015 Healthcare Data Breaches





Largest Reported Data Breaches

Records Breached (in millions)

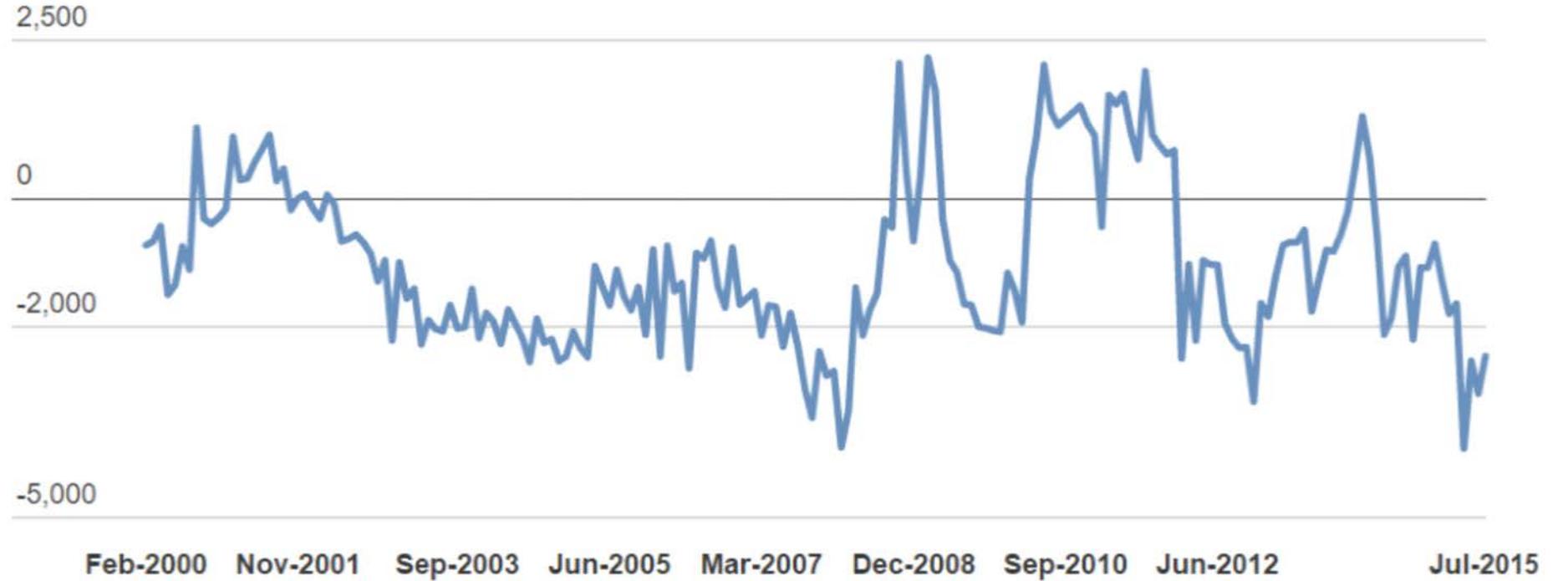




consider highly volatile?

International Trade in Goods and Services

Monthly balance of trade data since 2000 (\$ millions) seasonally adjusted



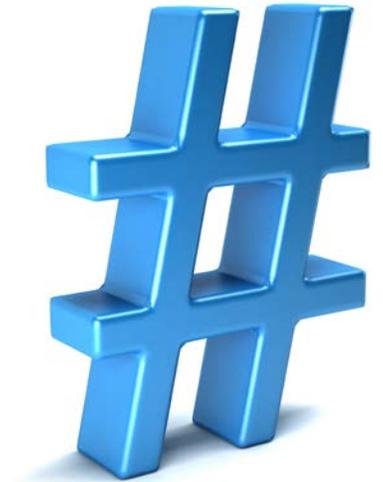
Source: ABS / ABC News
[Get the data](#) [Embed](#)





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privacy analysis - case study



Privacy Impact Assessment (PIA)

“Online Information Management for Members”

YourOnlineFriends.com is an Internet-based service to assist parents or guardians of children with special medical needs.

They plan on extending their services to allow online applications for new members and information updates by existing members.

This will include entry of personal information, some of which is highly sensitive.

This PIA considers the impact on privacy through the addition of these new services.



areas of concern



The main concerns:

- lack of system documentation from third party IT service providers
- use of shared resources (e.g. USB drive, Dropbox, shared network drives, etc.)
- a necessity to strengthen network security measures

Other concerns:

- unnecessary collection of some personal information
- not providing an opt-out from direct marketing
- the focus on information security rather than privacy at the annual audits

areas of concern (2)

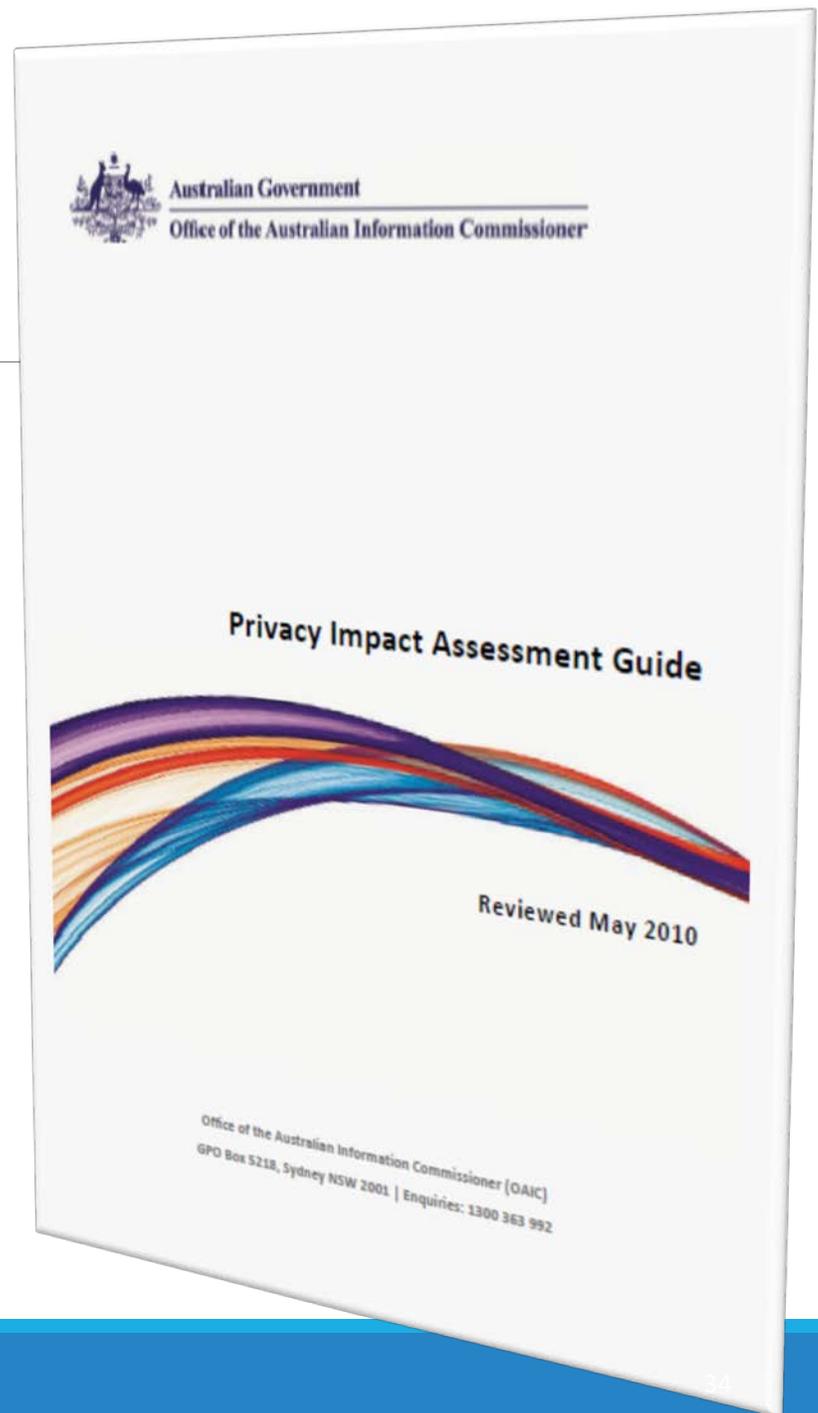


Recommendations:

- some practices by staff members resulting in unintentionally violation of the Australian Privacy Principles
- introduction of staff privacy training
- **YourOnlineFriends.com** makes use of third party service providers yet it is still responsible for the privacy of its customers
- the inclusion of privacy compliance in third-party service agreements
- maintaining ongoing compliance and the publication of an abridged PIA

PIA

- The Australian government recommends undertaking a PIA
- This case study identified twenty potential privacy impacts.
- Privacy impact was estimated ranging from High-level to Medium to Low-level risks.
- Report provided recommended actions to mitigate these risks down to an acceptable level.
- Actioned as soon as reasonably practicable





PIA Steps

- ❑ 12 steps that lead up to a executive management report and presentation
- ❑ Not a trivial process but only really requires common sense

- 1. Check Compliance with the Privacy Act**
- 2. Threshold Assessment**
- 3. Plan and Scope the PIA**
- 4. Information Gathering**
- 5. Information Flow Map Diagram**
- 6. Determine the Risks**
- 7. Analyse the Risks**
- 8. Check Legal Compliance**
- 9. Formulate Recommendations**
- 10. Prepare the PIA Report**
- 11. Present your Results**
- 12. Follow up the PIA, document and secure**



Complete Questionnaire:
Does your business need to comply with the Privacy Act?

Do you need to comply with the Privacy Act?

Steps to the PIA report (forms and documentation)

YES

Is a PIA necessary for this project?

Complete Threshold Assessment Checklist



YES planning to proceed

Plan the PIA—what is in-scope and out-of-scope?

List of essential documents

More documents identified



Commence Steps for the PIA Checklist

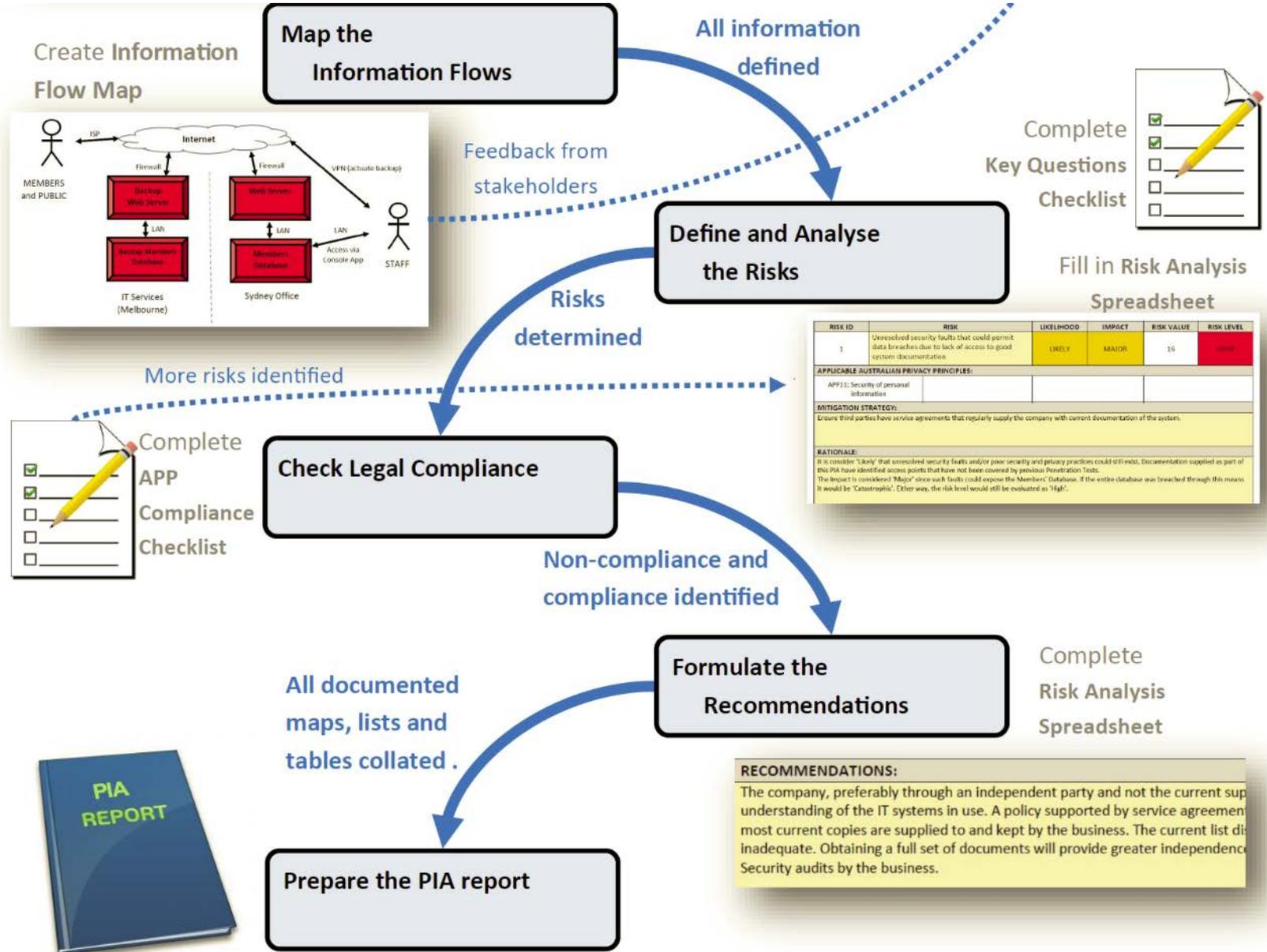
What information do I need?

Complete Information needed for the PIA Checklist



Required information identified





Executive Summary, Project Description, Maps, Checklists, Risk Tables, Compliance and Recommendations.

RISK ID	RISK	LIKELIHOOD	IMPACT	RISK VALUE	RISK LEVEL
1	Unresolved security faults that could permit data breaches due to lack of access to good system documentation.	LIKELY	MAJOR	16	High
APPLICABLE AUSTRALIAN PRIVACY PRINCIPLES:					
APP1: Security of personal information					
MITIGATION STRATEGY:					
Ensure third parties have service agreements that regularly supply the company with current documentation of the system.					
RATIONALE:					
It is considered 'likely' that unresolved security faults and/or poor security and privacy practices could still exist. Documentation supplied as part of this PIA have identified access points that have not been covered by previous Penetration Tests. The impact is considered 'Major' since such faults could expose the Members' Database. If the entire database was breached through this means it would be 'Catastrophic'. Other way, the risk level would still be evaluated as 'High'.					

RECOMMENDATIONS:

The company, preferably through an independent party and not the current support understanding of the IT systems in use. A policy supported by service agreements most current copies are supplied to and kept by the business. The current list of documents is inadequate. Obtaining a full set of documents will provide greater independence Security audits by the business.

steps checklist

No.	STEP	Examples and Explanations	Requirements	In Progress	Completed
1	Check Compliance with the Privacy Act	Read WHO needs to comply with the Privacy Act? Complete Questionnaire: 'Does your business need to comply with the Privacy Act?'	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
2	Threshold Assessment	Read WHO needs to do a PIA? Complete the 'Threshold Assessment checklist' (10 questions)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
3	Plan and Scope the PIA	Read WHAT do I need to do to plan and scope my PIA? Estimate the size of your PIA then generate Scope Lists	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
4	Information Gathering	Read WHAT information will I need? Complete: 'Information needed for the PIA Checklist' (65 questions)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
5	Information Flow Map Diagram	Read HOW do I generate an Information Flow Map diagram? Generate your own information maps	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>



step 2 - PIA threshold assessment

threshold outcome

Q9: Who will be involved in the PIA if it goes ahead?

The CEO, two members of the board (one who specializes in IT), the membership manager and a small focus group of volunteer members.

The PIA will be undertaken by the membership manager who currently handles any privacy inquiries.

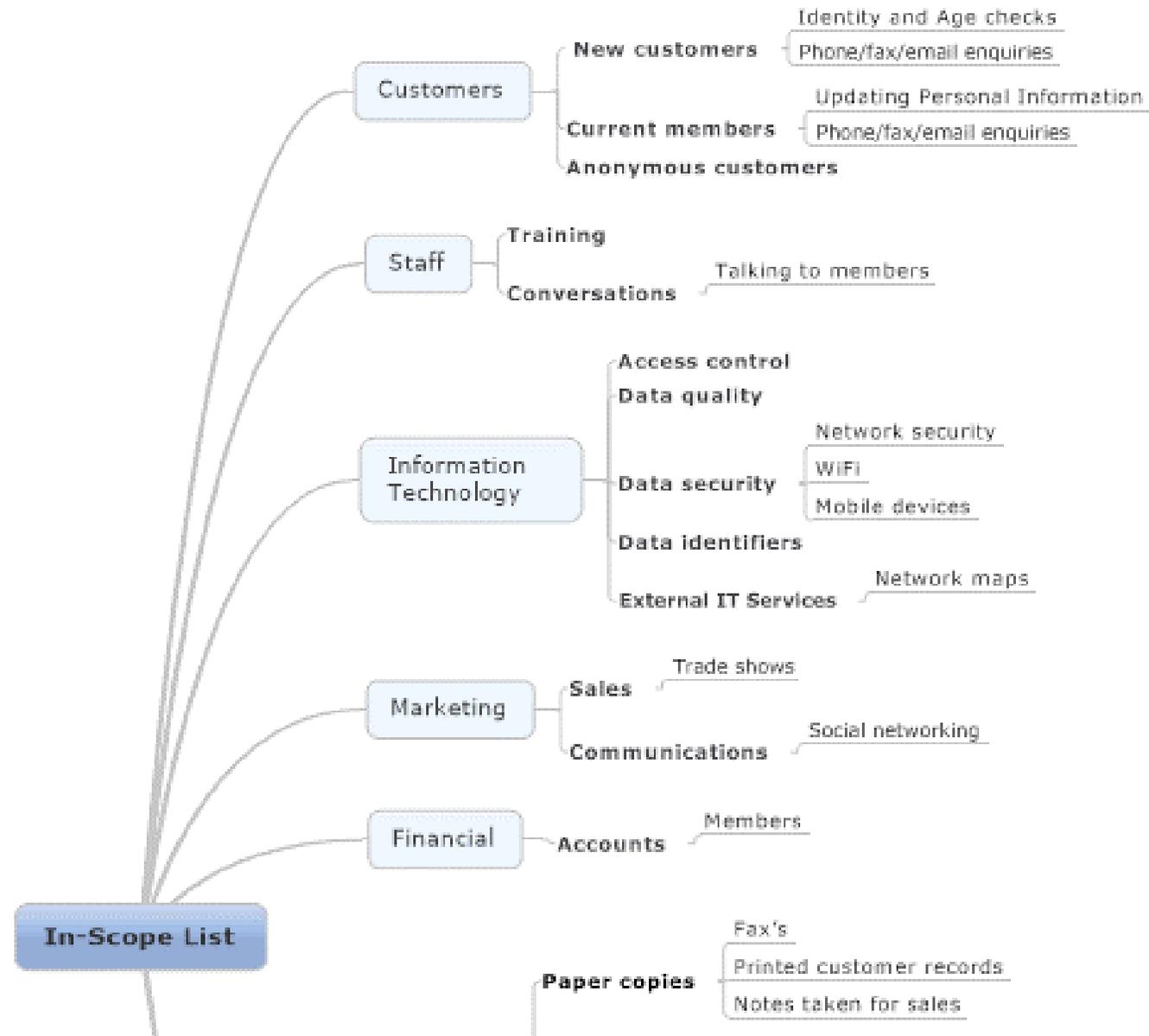
All staff, including sub-contractors will be available for interviews.

Q10: Based on the above answers are you going to proceed to undertake a PIA?

- NO
- YES
- UNSURE

- Sensitive information is involved.
- New risks will result from adopting on-line access of personal information.
- Concerns have already been raised by the board of directors and by the current members once this project allows connectivity via the Internet.
- The service has a high public interest profile that demands high privacy protections.
- The cost of undertaking the PIA will be offset by reduced liability insurance costs.

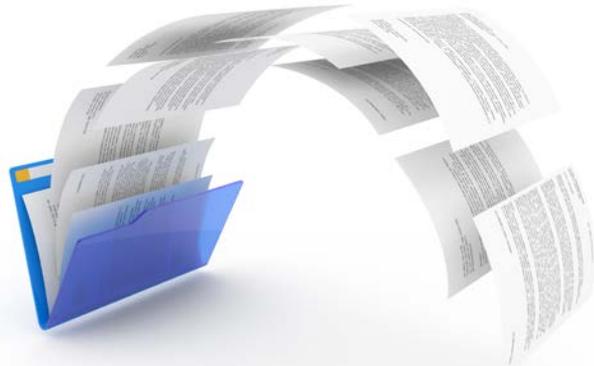
step 3 – scope



scope (2)

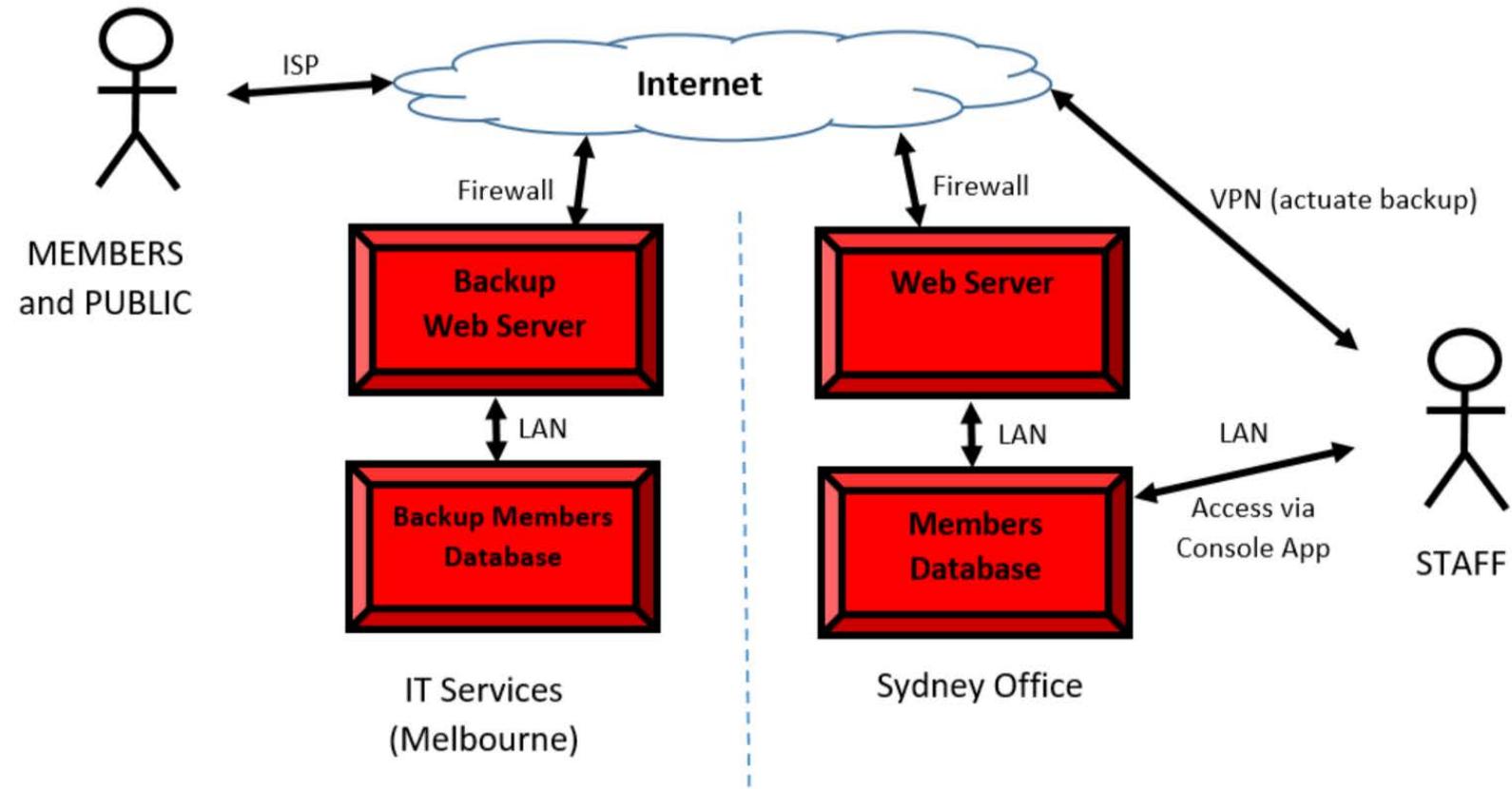


step 4 - info needed checklist



No.	1) NECESSITY OF IDENTIFIED VERIFICATION	YES - INFO REQUIRED	NO - NOT APPLICABLE	DONE
1	Can the project can proceed using anonymous or de-identified data, if so to what extent?	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="checkbox"/>
<p>YES partly. This project requires personal information for initial identification and verification of claimed health conditions.</p> <p>Members are encouraged to use suitable pseudonyms when adding comments to the forums.</p>				
2	Is necessary to verify the identity of an individual and, if so, to what degree of confidence is needed?	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="checkbox"/>
<p>YES. To ensure members are responsible for children with specific health concerns it is necessary to verify their identity with a high degree of confidence.</p> <p>Refer to: 'Members Application Form'</p>				
3	Can you describe the process by which the identity of individuals will be verified ?	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="checkbox"/>
<p>YES. This will be done using confirmation from a GP or Hospital</p> <p>Refer to: Medical Practitioner's Confirmation Form'</p>				
4	Will new identification numbers need to be issued to individuals, and if so, can you describe the purpose of using new IDs and any protections from misuse by others?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="checkbox"/>
<p>NO. Only internal account names.</p>				

step 5 – information mapping



step 6 – determine risks

10 key questions checklist

No.	Key Questions	YES	NO	NOT SURE
1	Do individuals have to give up control of their personal information?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
NO. Members can modify their information and request that all their personal information is deleted if they leave the service.				
2	Will the project change the way individuals interact with your business, such as through more frequent identity checks, costs, or impacts on individuals or groups who do not have identity documents?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
YES. They will now have to use the on-line forms for supplying personal information and updating it. Since the service is already an on-line provision this should not be a problem. Costs will be lower than current postal services. Nothing else changes as individuals must supply identity and health information that is verified by a GP/Hospital.				
3	Will decisions that have consequences for individuals be made as a result of the way personal information is handled in the project (such as decisions about services or benefits)?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
NO. The decision process on who gets access to the service will be the same.				



step 6 – determine risks

summary of risks table

RISK ID	RISK	LIKELIHOOD	IMPACT	RISK VALUE	RISK LEVEL
1	Unresolved security faults that could permit data breaches due to lack of access to good system documentation	LIKELY	MAJOR	16	HIGH
2	Not updating application software to the latest versions	LIKELY	MAJOR	16	HIGH
3	Staff passwords compromised since they are not strong enough or changed regularly	LIKELY	MAJOR	16	HIGH
4	User allowed to connect own devices (e.g. USB drives)	LIKELY	MAJOR	16	HIGH
5	Disclosure of personal and sensitive information held on shared drives	POSSIBLE	MAJOR	12	MEDIUM
6	System compromised due to web surfing by staff (including temps) while simultaneously having access to database	POSSIBLE	MAJOR	12	MEDIUM
7	Privacy Breach from inadequate incident reporting procedure	POSSIBLE	MAJOR	12	MEDIUM
8	Personal information collected that has no purpose	LIKELY	MODERATE	12	MEDIUM
9	Business identifiers using individual's names	LIKELY	MODERATE	12	MEDIUM

‘Australian Government Protective Security Governance Guidelines’
i.e. business impact levels when determining risk rating

LIKELIHOOD	CONSEQUENCES				
	Insignificant	Negligible	Moderate	Major	Extreme
Remote	VERY LOW	VERY LOW	LOW	MEDIUM	HIGH
Unlikely	VERY LOW	LOW	MEDIUM	MEDIUM	HIGH
Possible	VERY LOW	LOW	MEDIUM	HIGH	VERY HIGH
Likely	VERY LOW	LOW	MEDIUM	HIGH	VERY HIGH
Almost certain	LOW	LOW	MEDIUM	HIGH	VERY HIGH

Australian Government publication – ‘Information Security Management Guidelines
Risk management of outsourced ICT arrangements (including Cloud)’

likelihood

The following table shows how to determine the **Likelihood** of an event in a one year period*.

ATTRIBUTE	LIKELIHOOD	EXAMPLE RATIOS
Rare	not expected to ever happen	less than 1 in a 1000 chance
Unlikely	not expected to happen	up to 1 in 100 chance
Possible	could happen	up to 1 in 10 chance
Likely	expected to happen	up to 1 in 1 chance
Almost Certain	will happen	more than a 1 in 1 chance

*(Not that, one year is recommended as the maximum period to coincide with your privacy reviews).

impact

The following table shows how you might determine the **Impact** if the event occurred.

ATTRIBUTE	IMPACT	EXAMPLE COSTS (for SMEs)	EXAMPLE Records Breached
Insignificant	negligible harm to the business	less than \$1,000	0
Minor	some harm to the business	up to \$5,000	1-4
Moderate	harm the business	up to \$25,000	5-99
Major	serious harm to the business	up to \$1 million	100-999 [!]
Catastrophic	ruin the business	greater than \$3M	1,000+ [!]

[!]For more sensitive data these numbers could be significantly lower (i.e. use as a guide only)



step 7 – analyse risks

RISK ID	RISK	LIKELIHOOD	IMPACT	RISK VALUE	RISK LEVEL
2	Not updating application software to the latest versions	LIKELY	MAJOR	16	HIGH
APPLICABLE AUSTRALIAN PRIVACY PRINCIPLES:					
APP11: Security of personal information					
MITIGATION STRATEGY:					
Ensure all application software is upgraded to include the latest security patches.					
RATIONALE:					
Adversaries are always looking to exploit vulnerabilities. Security patching is essential to help minimise these risk. Evidence from the PIA showed that such updates only occur following an annual security audits. It is therefore considered 'Likely' that such risks will be exploited and the impact is considered to be 'Major' if not 'Catastrophic' - either will result in an unnecessarily High risk.					
RECOMMENDATIONS:					
Consult with the IT service providers on more regular updates with patches and the benefits of upgrading to new safer versions when they are made available.					



	A	B	C	D	E	G	I	J
1	RISK ID	RISK			LIKELIHOOD	IMPACT	RISK VALUE	RISK LEVEL
2	1						0	
3	APPLICABLE AUSTRALIAN PRIVACY PRINCIPLES:							
4								
5	MITIGATION STRATEGY:							
6								
7	RATIONALE:							
8								
9	RECOMMENDATIONS:							
10								

step 8 – APP compliance

No.	APP1 - open and transparent management of personal information	Examples and Explanations	YES	NEEDS IMPROVING	NOT APPLICABLE
1.1	Does your business have an appropriate APP compliant Privacy Policy ?	Privacy policy(s) must be clearly expressed, up-to-date, covers the important privacy matters in APP 1.4 and freely available (e.g. on your website).	<input checked="" type="radio"/>	<input type="radio"/>	
			Privacy Policy available on the website		
1.2	Have reasonable steps been taken that will ensure compliance with the APPs ?	Evidence the business exercises good practices, procedures and systems for ongoing privacy protection (include APP codes such as credit reporting).	<input type="radio"/>	<input checked="" type="radio"/>	
			Identified Risks #7, 18		
1.3	Have reasonable steps been taken for handling privacy inquiries and complaints ?	Evidence the business has in place appropriate complaint procedures and systems	<input checked="" type="radio"/>	<input type="radio"/>	
			as per Privacy Policy		

*Note, the eBook: "Privacy Policy Essentials for Australian Businesses" covers these requirements in detail.

No.	APP2 - anonymity and pseudonymity	Examples and Explanations	YES	NEEDS IMPROVING	NOT APPLICABLE
2.1	Will individuals participating in the project have the option of not identifying themselves?	E.g. when circumstances permit, they will be allowed to remain anonymous OR use a pseudonym (another name)	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
			They must identify themselves to join		

step 9 & 10 – Generate Management Recommendations and Report



The PIA should contain two types of recommendations:

- How to mitigate against each identified risk
- What actions should be taken to progress this project

REPORT:

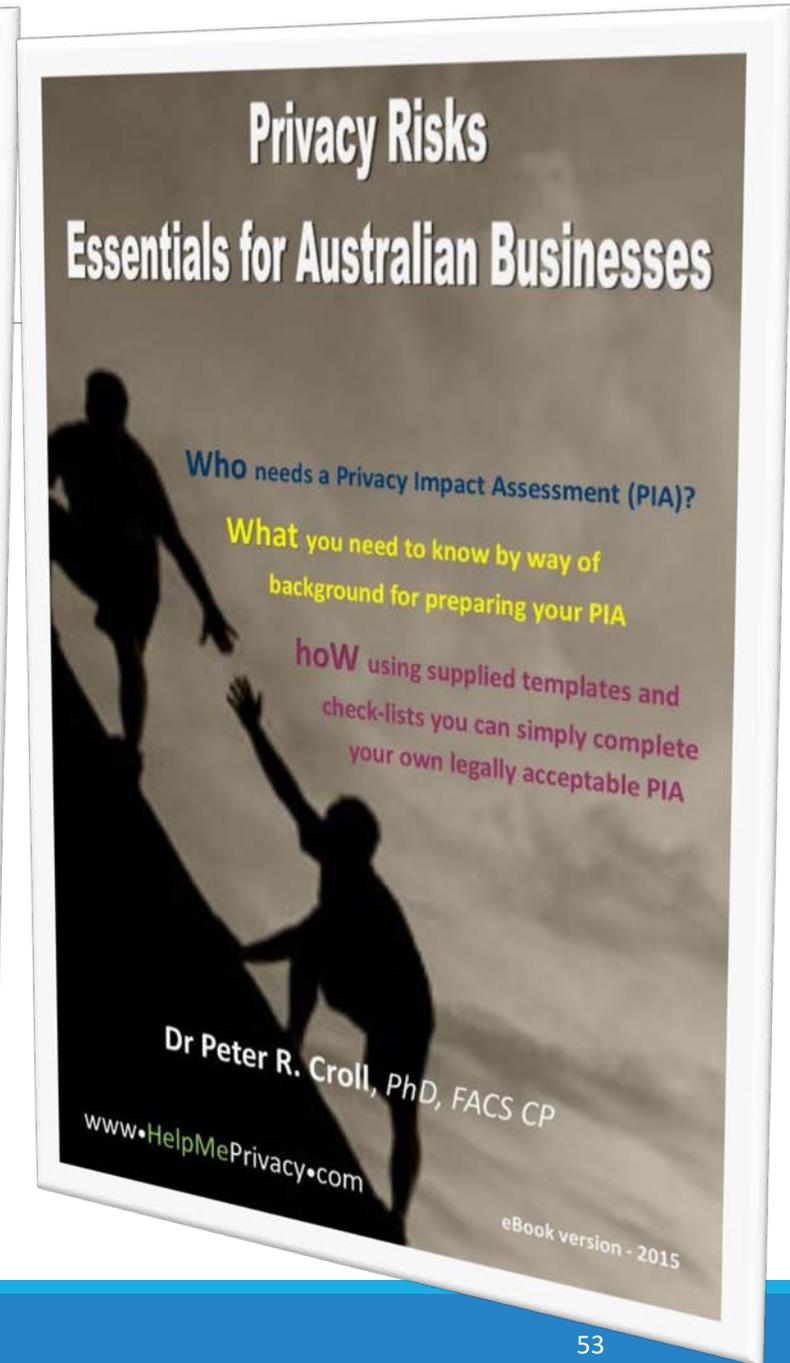
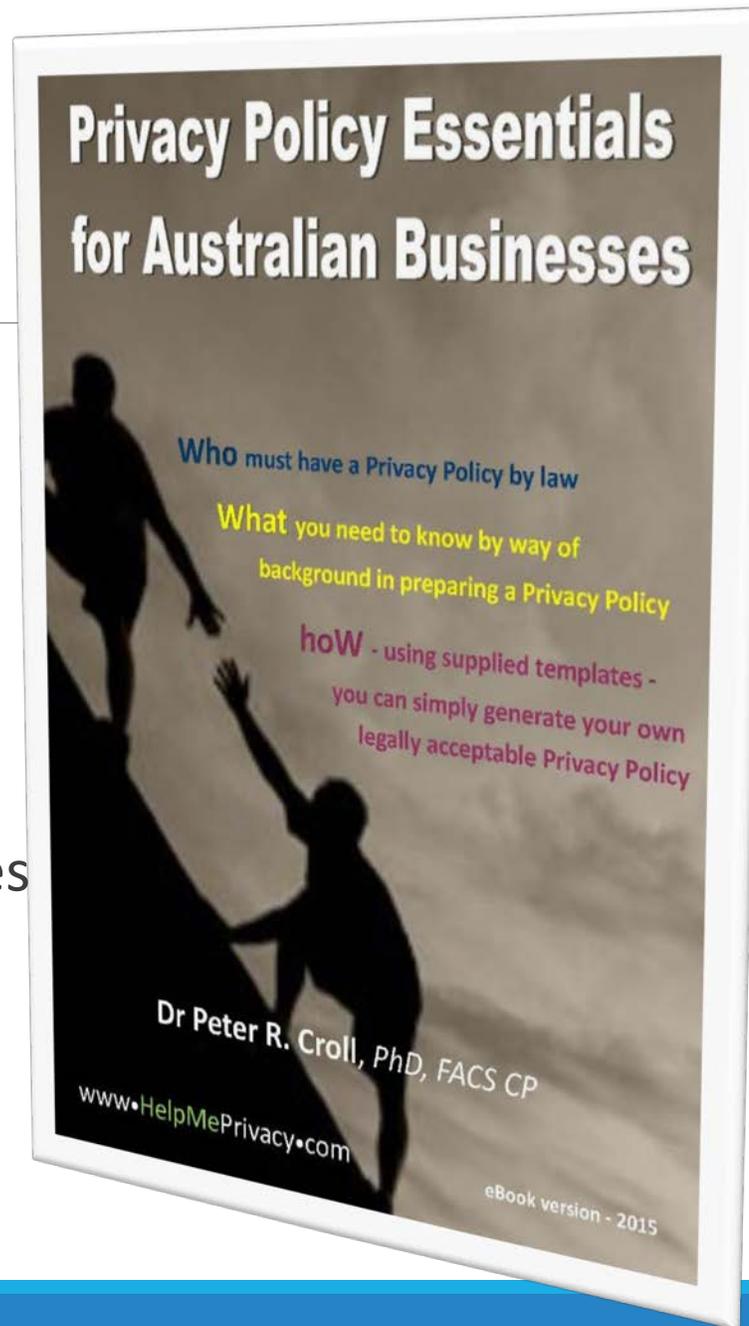
- Title Pages
- Executive Summary
- Approach
- Project Description
- Analysis
- Compliance Check
- Conclusions
- Appendix

Length	Type
2-3 Pages	Threshold Assessment Only
3-15 pages	Brief PIA
15-30 pages	Concise PIA
30-75 pages	Comprehensive PIA
75-150 pages	Detailed PIA
150 pages + (excluding appendices)	Very detailed PIA



- Free samples available
- Contains all the checklists
- Non technical jargon
- Aimed at Australian businesses

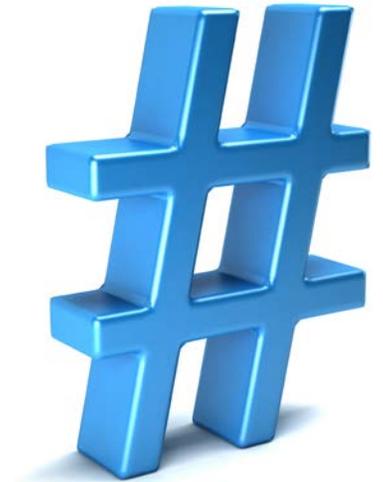
www.HelpMePrivacy.com





topics

- is privacy dead?
- privacy law changes
- holistic view of privacy
- calculating privacy risks
- privacy analysis – case study
- **privacy-by-design**
 - ‘My Health Record’
 - social networking
 - the way forward?





privacy by design

An approach when developing a new product or service to ensure that privacy protections have been embedded into all the design stages rather than being added on as an afterthought

The company wanted to comply with APP 10 (Quality) and APP 13 (Correction)

They distributed annually (by post) a copy of the information held on each registered customer

As they grew they found it necessary to use a third party printer who used a mailing company

Following a publicised breach they acted to reduce the risks

To meet monthly deadlines the printer required a CSV file to be sent by FTP

PROBLEM – how could they separate the sensitive information from the customer's name and mailing address if it was being printed?

SOLUTION – ask customers to log-in with password and check/modify their information online.



new problems



Not all customers were comfortable with online access

Most had not previously set up online accounts and – reluctant, just for supplying updates.

Many customers ended up phoning the company - very resource intensive.

Others asked for their details to be posted to them

The company ended up with a hybrid solution – new software specifically developed for:

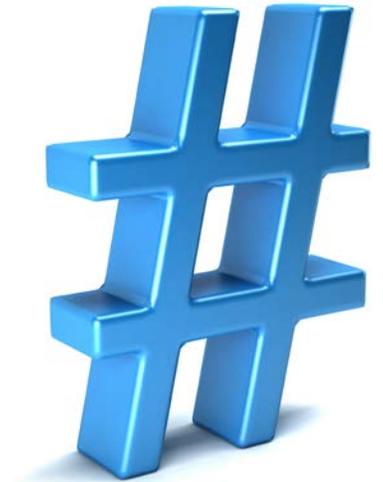
- customers' online access
- separately printing names and addresses labels
- separately printing sensitive information
- auto encryption of the CSV files
- plus extensions to their CRM software

If these privacy concern had been identified and addressed at the design stage their risks and costs would have been significantly reduced.



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'my Gov' Services

- Medicare
- Centrelink
- Australia Tax Office
- Dept. Veterans Affairs
- My Aged Care
- Child Support
- Nat Disability Ins Service
- Australian Job Search

The screenshot shows the myGov website interface. At the top, there is a navigation bar with the Australian Government logo, the myGov logo, and a 'sign out' button. Below this, a 'Welcome' message displays the user's last sign-in time: 'Last sign in: 04/09/2015, 09:43am Australian Eastern Standard Time (AEST)'. The main dashboard features five large, colorful icons for 'Inbox', 'Profile', 'Update Details', 'Services', and 'Settings'. To the right of these icons, a sidebar contains the text 'All in one place' and 'A fast, simple way to access government online services. One login. One password. One destination.' Below this text is a green 'Service Finder' button. At the bottom of the dashboard, there is a 'Current notices' section with three bullet points: 'Australian Taxation Office', 'Tax Time Documents Available', and 'Australian Organ Donor Register Registration'.

**Personally Controlled
Electronic Health Record**

'My Health Record'

(formally: Personally Controlled Electronic Health Record)



The screenshot shows the 'My Health Record' web interface. At the top left, there are logos for the Australian Government Department of Health, eHealth, and The National eHealth Record System. On the top right, a user is logged in as 'PETER RONALD CROLL' with a 'Log out' button and a message indicating the last login time: 'You last logged in on 01-Sep-2014 at 06:28:49 PM (AEST)'. Below the header, there is a navigation bar with 'My Home', 'My Details', and 'Help'. The main content area displays the user's name 'CROLL, PETER RONALD (PROF)', their date of birth (redacted), and sex 'Male'. A sidebar on the left contains a menu with options: 'Health Record Overview' (selected), 'Clinical Documents', 'Medicine Records', 'Personal', 'Child Development', 'Medicare Records', 'Settings', and 'Who accessed my record?'. The main content area is titled 'Health Record Overview' and includes a warning: 'Advance Care Directive Custodian details are not available on this record'. Below this, there is an information box stating: 'This is not a complete view of your health information. For more information about your health record or data please consult your healthcare professional. Note that all date and time information shown on this page and the left hand side menu are converted to the Australian Eastern Standard Time Zone (or Australian Eastern Daylight Time Zone when applicable)'. A yellow box highlights the section 'Documents available on the PCEHR since the last Shared Health Summary', which contains an information box stating: 'There are no Documents available on the PCEHR since the last Shared Health Summary.' Below this, another information box states: 'No Shared Health Summary available.' At the bottom, the 'Indigenous Status' is listed as 'Not stated'.

My Home | My Details | Help

CROLL, PETER RONALD (PROF) DOB 1[REDACTED] yrs) SEX Male CLOSE

Print | Show History | Manage Access | Remove

Showing All

Health Record Overview

Clinical Documents

- ▼ Diagnostic Imaging Report
Diagnostic Imaging Report View
- ▶ Pathology Report
Shared Health Summary

Medicine Records

- ▼ eHealth Prescription Record
[01-Jul-2014 eHealth Prescription](#)
Prescription and Dispense View

Personal

Child Development

Medicare Records

Settings

Who accessed my record?

eHealth Prescription Record

1 Jul 2014

Dr Peter **CROLL** DoB [REDACTED] (y*) SEX Male IHI [REDACTED]

START OF DOCUMENT

Family Practice
[REDACTED] (Medical Practitioners nfd)
Author [REDACTED]
Phone [REDACTED]

Prescription Item

THERAPEUTIC GOOD	
Medicine	[REDACTED]
Generic Name	[REDACTED] en
Strength	0.025 mg;160 ELISA units
Form	Syringe
Route	Intramuscular
Directions	1 For doctor's use
DISPENSING	
Quantity	1
Maximum Number of Repeats	0
Minimum Interval Between Repeats	0 days
Brand Substitute Allowed	Yes

Showing All

- 1 g-2012 Medicare/DVA B
- 2 -2012 Medicare/DVA B
- 1 -2012 Medicare/DVA B
- 1 -2012 Medicare/DVA B
- 0 r-2012 Medicare/DVA B
- 0 g-2011 Medicare/DVA B
- 1 r-2011 Medicare/DVA B
- 0 r-2011 Medicare/DVA B
- 1 -2010 Medicare/DVA B

Pharmaceutical Benefits Report

[Medicare Overview](#)

Settings

Who accessed my record?

i No information available

Medicare Services - MBS & DVA items

Date	Number	Description	Service Provider	In Hospital?
24-Feb-2015	00023	CONSULTATION AT CONSULTING ROOMS - LEVEL 'B'.	DR [REDACTED]	No
19-Feb-2015	65070	[REDACTED] it	DR [REDACTED]	No
19-Feb-2015	66536	HDL	DR [REDACTED]	No
19-Feb-2015	66512	General chemistry x 5 or more.	DR [REDACTED]	No
18-Feb-2015	00023	CONSULTATION AT CONSULTING ROOMS - LEVEL 'B'.	DR [REDACTED]	No
14-Jul-2014	00023	CONSULTATION AT CONSULTING ROOMS - LEVEL 'B'.	DR [REDACTED]	No
09-Jul-2014	23041	Anaesthesia, 46 minutes to 50 minutes (4 units)	DR [REDACTED]	Yes
09-Jul-2014	17610	Pre-anaesthesia brief consultation	DR [REDACTED]	Yes
09-Jul-2014	20810	Initiation of management of Anaesthesia for [REDACTED] procedures.	DR [REDACTED]	Yes
09-Jul-2014	72824	[REDACTED] specimens	DR [REDACTED]	Yes

record set to 'RESTRICTED ACCESS' with a PIN

[My Home](#) | [My Details](#) | [Help](#)

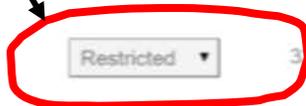
CROLL, PETER RONALD (PROF) DOB 1 [REDACTED] (s) SEX Male [CLOSE](#)

Showing All

Health Record Overview

- Clinical Documents
- Medicine Records
- Personal
- Child Development
- Medicare Records
- Settings
 - Personal Controls
 - Medicare Information Settings
 - Manage Access to this Record
 - Manage Document Access**
 - Restricted Settings
- Who accessed my record?
 - Access History
 - Notification Settings

Medicare/DVA Benefits Report	2 [REDACTED] 2013	Medicare/DVA Benefits Report	DHS	General	31 months ago	Remove
Medicare/DVA Benefits Report	1 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	Restricted	31 months ago	Remove
Medicare/DVA Benefits Report	2 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	General	33 months ago	Remove
Medicare/DVA Benefits Report	2 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	General	33 months ago	Remove
Medicare/DVA Benefits Report	3 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	General	34 months ago	Remove
Medicare/DVA Benefits Report	0 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	General	35 months ago	Remove
Medicare/DVA Benefits Report	0 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	General	35 months ago	Remove
Medicare/DVA Benefits Report	2 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	General	35 months ago	Remove
Medicare/DVA Benefits Report	2 [REDACTED] 2012	Medicare/DVA Benefits Report	DHS	General	35 months ago	Remove
Pharmaceutical Benefits Report	2 [REDACTED] 2012	Pharmaceutical Benefits Report	DHS	General	35 months ago	Remove



Showing All

Health Record Overview

- Clinical Documents
- Medicine Records
- Personal
- Child Development
- Medicare Records
- Settings
- Who accessed my record?
- Access History
- Notification Settings

04 Sep 2015 09:47:57	Self	Retrieve Document	Read	Link to Document
04 Sep 2015 09:47:39	Self	Retrieve Diagnostic Imaging Report View	Read	
04 Sep 2015 09:45:16	Self	Retrieve Health Overview	Read	
04 Sep 2015 09:44:59	Self	Open Record	Read	
26 Feb 2015 01:14:28	External Provider (DHS Medicare)	Add Document	Create	Link to Document
26 Feb 2015 01:14:27	External Provider (DHS Medicare)	Add Document	Create	Link to Document
26 Feb 2015 01:14:25	External Provider (DHS Medicare)	Add Document	Create	Link to Document
25 Feb 2015 01:12:05	External Provider (DHS Medicare)	Add Document	Create	Link to Document
19 Feb 2015 01:01:47	External Provider (DHS Medicare)	Add Document	Create	Link to Document

Showing All

Health Record Overview

Clinical Documents

Medicine Records

Personal

Child Development

Medicare Records

Settings

Personal Controls

Medicare Information Settings

Manage Access to this Record

Manage Document Access

Restricted Settings

Who accessed my record?

Access History

Notification Settings

How do I manage healthcare provider organisation access to my eHealth Record?

The National eHealth Record System maintains a list of healthcare provider organisations that have accessed your eHealth Record, this is called your Access List. You can view or change the type of access these healthcare providers have to your eHealth Record on the Manage Healthcare Provider Organisation Access screen.

General Access Restricted Access Revoked Access

Edit Settings

How do I cancel my registration in the eHealth Record System?

You can choose to cancel your eHealth record at any time. If you choose to do this, healthcare providers involved in your care will no longer be able to access and upload information to your eHealth record and your information will no longer be available in a medical emergency.

The System Operator is required to retain the information in your eHealth record and will only use or disclose this information if authorised by law. Documents in a cancelled eHealth record will continue to be held in the National eHealth Record System but will not be available for viewing by anyone. Documents passed on to Healthcare Provider Organisations will continue to be held by them in accordance with the organisation's rules and practices.

You can choose to register again at any time.

Cancel eHealth Record



How do I limit access to my eHealth Record?

You may control which healthcare provider organisations access your eHealth Record.

If you wish to specify access for each healthcare provider organisation, you should create a Record Access Code (RAC).

This code will need to be provided to new healthcare providers you want to have access to your eHealth Record.

Even if you have a Record Access Code, all information in your record will be available in a medical emergency.

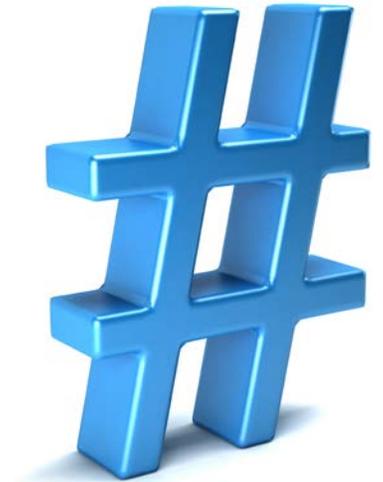
To gain emergency access a healthcare providers must declare that there is a serious threat to your life, health or safety.

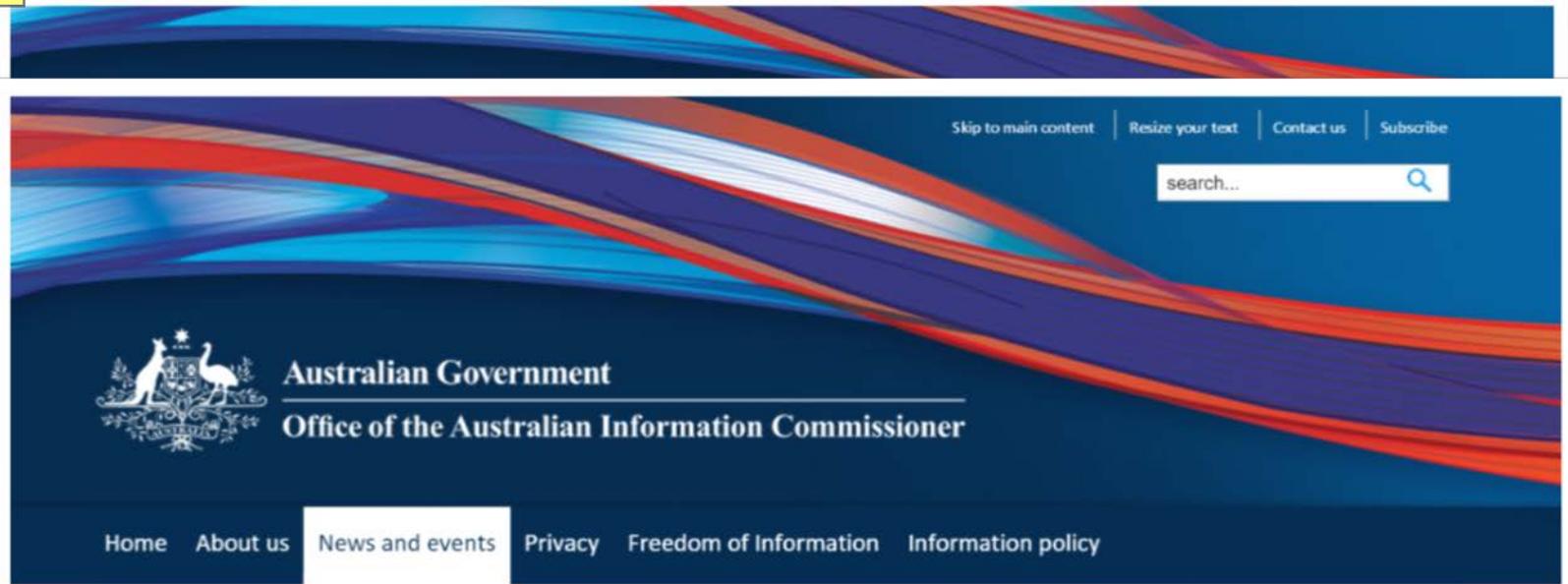
If you do not have a Record Access Code, any healthcare providers involved in your care can access your Record.



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Records stored in cloud

No encryption was used

Prior to the new APPs

News

OAIC events

Media releases

Statements

Privacy statements

FOI statements

Information policy statements

Operational statements

Australian Government's Budget decision to disband OAIC

Speeches

Video and audio

[Home](#) [News and events](#) [Statements](#) [Privacy statements](#) [Ashley Madison data breach](#) [Ashley Madison data breach — investigation commenced](#)

Ashley Madison data breach — investigation commenced

Tuesday, 25 August 2015

The Acting Australian Information Commissioner Timothy Pilgrim has opened an investigation into a data breach of the dating website Ashley Madison.

Avid Life Media Inc, the company that operates the Ashley Madison website, is based in Canada and, recognising the global nature of this incident, the Commissioner's investigation will be conducted jointly with the Office of the Privacy Commissioner of Canada.

All organisations that carry on business in Australia and are covered by the *Privacy Act 1988* (Privacy Act) have obligations in relation to the personal information that they hold. This includes taking reasonable steps to ensure that personal information is held securely. The Office of the Australian Information Commissioner's (OAIC) investigation will focus on this issue.



consider privacy of other Aus dating sites

choice the consumer advocate and product review organisation
(www.choice.com.au)

their investigation into popular online dating sites, including RSVP, eHarmony, Oasis Active, Plenty of Fish, Zoosk and OkCupid, and the popular app Tinder

they found that scams are rife, and some privacy policies and terms and conditions are riddled with disturbing provisions



RSVP

Signing up to an RSVP account and agreeing to its privacy terms and conditions in effect grants permission for your personal information, including photos and email addresses, to be used for "any purpose" , which may include advertising or transmission to a third party.

While all sites we looked at track your activities using cookies, RSVP even shows other users how often you're on the site and who you're looking at.



eHarmony

By posting information and photos on a profile page or any public area of the eHarmony website, users automatically agree to have that information perpetually owned and used by eHarmony for purposes such as advertising.

Users' contact details may be shared with third parties for advertising, but opting out is possible by changing certain settings or notifying eHarmony of your request in writing.



Oasis Active

By signing up, users agree that all profile information – including photos – is public, and so automatically grant an irrevocable and ongoing licence for the company to use and distribute any information posted or transmitted on the site.

In effect, this means users' photos, aliases and other personal details can be used in advertising, online and off, although it's possible to opt out of this by updating privacy options in the account settings portal on the website.

Email addresses, photos and information may also be shared with third parties for marketing purposes on behalf of Oasis Active.



OkCupid

OkCupid may use contact information for advertising purposes and compiling its OkTrends blog, which tracks and charts user behaviour.

They may also share this information with third parties.

OkCupid allows information posted on its site to appear in search engine results.



Plenty of Fish (PoF)

PoF says it may share your personal information with affiliates and third parties acting on their behalf in the "normal course of business", though they do say they won't sell it to others.



Tinder

Privacy is a significant concern when it comes to Tinder, as users sign up with their Facebook profile, meaning the company has access to a large amount of personal information, including your email address, likes, birthday, education history, interests, current city, personal description, your friends list, and photos of you and your Facebook friends who might be common with other users.

Tinder also gives itself access to the content of your chats when you're using the app, and uses this information to market itself and third party products or services.

You can't delete your Tinder account, only the app. This means your virtual Tinder footprint could exist in perpetuity.



Zoosk

If you sign up to Zoosk and give the site access to one of your social media profiles, such as Twitter or Facebook, they may make posts on your behalf on that platform.

Think twice about giving Zoosk access to your address book – they keep your contacts on file and may later use your information to suggest friends and connections to other members.

By signing up to Zoosk, you grant permission for all your user content to be used for purposes including advertising or transmission to a third party.



spotify

SORRY.

A blog post by Spotify CEO, Daniel Ek, August 21st, 2015 10:02

We are in the middle of rolling out new terms and conditions and privacy policy and they've caused a lot of confusion about what kind of information we access and what we do with it. We apologize for that. We should have done a better job in communicating what these policies mean and how any information you choose to share will – and will not – be used.

We understand people's concerns about their personal information and are 100 percent committed to protecting our users' privacy and ensuring that you have control over the information you share.

So let me try and clear things up.

In our new privacy policy, we indicated that we may ask your permission to access new types of information, including photos, mobile device location, voice controls, and your contacts. **Let me be crystal clear here: If you don't want to share this kind of information, you don't have to.** We will ask for your express permission before accessing any of this data – and we will only use it for specific purposes that will allow you to customize your Spotify experience.



what you grant to spotify (terms)

You grant Spotify a non-exclusive, transferable, sub-licensable, royalty-free, perpetual (or, in jurisdictions where this is not permitted, for a term equal to the duration of the Agreements plus twenty (20) years), irrevocable, fully paid, worldwide licence to use, reproduce, make available to the public (e.g. perform or display), publish, translate, modify, create derivative works from, and distribute any of your User Content in connection with the Service through any medium, whether alone or in combination with other content or materials, in any manner and by any means, method or technology, whether now known or hereafter created.

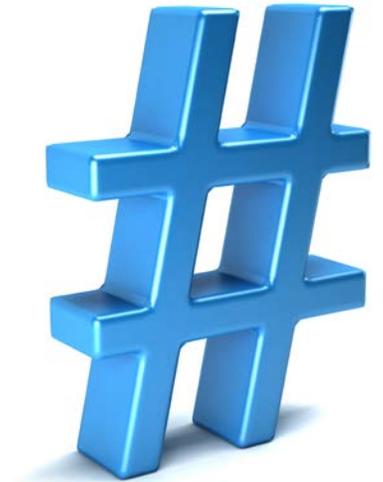
.....you also agree to waive any “moral rights” and your right to object to derogatory treatment

This is not under their Privacy Policy but under their Terms and Conditions of Use – a link from the full Privacy Policy – total of 24 pages – over 8,000 words.



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- **the way forward?**



IMIA's WG 4

'security in health information systems'

- ❑ SiHIS seeking to address global inadequacies for many years
- ❑ proposals on minimum standards, guidelines, legislative frameworks, voluntary codes, etc.
- ❑ have been widely debated and published
- ❑ health information protection has previously relied on regulated models that are somewhat static.
- ❑ patients seeking '**confidentiality**' place trust in the health professionals who they regard as in control.
- ❑ yet, today's connected world is not adequately controlled.
- ❑ with digital data, significant measures are required to implement '**Privacy**' protection.





the way forward?

- ❑ #1 ensure your organisation is privacy compliant (APPs)
- ❑ #2 take a holistic view on privacy
- ❑ #3 do a Privacy Impact Assessment (PIA) with all new projects
- ❑ #4 follow a 'Privacy-by-Design' approach
- ❑ #5 report breaches and act promptly to prevent them reoccurring
- ❑ #6 don't sign up to social networks without checking what you're committing to
- ❑ #7 don't give out any personal information you don't need to, or want to
- ❑ #8 take control of your personal information, whenever possible



www.HelpMePrivacy.com

Thank You!

w: www.PeterCroll.com

e: help@petercroll.com