

COGS IN THE MACHINE: TWO COUNTRIES ATTEMPT TO BALANCE INDIVIDUALIZED CONCERNS IN THE PURSUIT OF PUBLIC HEALTH

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Just like an online video going viral,¹ healthcare can now be crowdsourced, providing a new method for public health officials to follow and analyze trends in a community's health.² Indeed, by following the public's online searches, researchers can determine an individual's likelihood of developing an eating disorder, the effectiveness of flu vaccinations, or conduct post-surveillance of a drug's side effects.³ With Big Tech and Big Data promising to disrupt the healthcare sector, the possibilities for public health seem endless. For example, data that might have been impossible to collect, sort, and analyze, may now be assembled and processed in large sets. Doing so can help researchers, policymakers, and public health officials make better decisions on critical interventions to improve health across entire communities.

Such advances, however, will require the free flow of information, not just between clinicians and other healthcare providers—but also other sources of information relevant to public health. For instance, stakeholders in the healthcare community have noted that having information about a patient's access to housing, transportation, food, and other social determinants of health⁴ could in turn improve the patient's health status by helping him with social services.⁵ Similarly, healthcare professionals serving

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¹ Jeff Howe, *The Rise of Crowdsourcing*, WIRED (June 1, 2006), <https://www.wired.com/2006/06/crowds/>.

² Elad Yom-Tov, *Researchers are Studying Your Google Searches to Improve Public Health*, STAT (Apr. 8, 2016), <https://www.statnews.com/2016/04/08/online-searches-public-health/>.

³ *Id.*

⁴ Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, *Social Determinants of Health*, HEALTHY PEOPLE 2020 (Aug. 2, 2019), <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health/>.

⁵ Loel S. Solomon & Michael H. Kanter, *Health Care Steps Up to Social Determinants of Health: Current Context*, THE PERMANENTE JOURNAL (Oct. 22, 2018), www.thepermanentejournal.org/issues/2018/volume-22-suppl-issue/6882-social-determinants.html (discussing “the development of models using both clinical and nonclinical data to predict patients who may benefit from social

older patients have noted that if they could exchange information with providers of long-term care services and support, their patients could age in a manner that preserves their dignity and autonomy.⁶ If our healthcare system and policymakers can crack the nut of interoperability—among healthcare providers themselves and then with other nonclinical providers of services and support—the open exchange of health information could provide even greater dividends for public health.⁷

These advances could lead to not only healthier individuals but also healthier communities as health information—both clinical and nonclinical—becomes available to public health authorities through technological advances and disruptions. The growing amount of data available can enable even more effective public health surveillance efforts, or “the ongoing systematic collection, analysis, and interpretation of data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease and injury.”⁸ Such efforts, in turn, can provide the evidence that public officials need to determine whether and how to intervene in a community in order to protect the public health.⁹

But having vast amounts of information about individuals and their health status freely flowing may raise alarm if health information gathered by clinicians and medical researchers is used for unauthorized non-clinical purposes.¹⁰ Public health surveillance necessitates a greater use of individuals’ health information—the collection of such information, its exchange across jurisdictions and agencies, and the ability to use data

needs interventions, thereby allowing health systems to better target their screening and intervention resources”).

⁶ National Association of Area Agencies on Aging, *Information Technology in Area Agencies on Aging: Report from the 2015 National AAA Survey*, 14-17, <https://www.n4a.org/Files/UPDATE%20Information%20Technology%20in%20AAAs%20Report%20from%202015%20National%20Survey.pdf> (noting that aging-service providers often collect consumer information that would be useful to share with healthcare providers and plans to partner in order to provide for better care).

⁷ Association of State and Territorial Health Officials, *Improving Public Health Surveillance Through Interoperability, Data Standards, and Legislation*, ASTHO EXPERTS BLOG (Jan. 24, 2019), <http://www.astho.org/StatePublicHealth/Improving-Public-Health-Surveillance-Through-Interoperability-Data-Standards-Legislation/01-24-19/> [hereinafter *ASTHO*] (“Interoperability... would ensure that the right information can be shared between public health agencies and healthcare providers in a timely manner to address public health crises and epidemics.”)

⁸ Peter Nsubuga et al., *Public Health Surveillance: A Tool for Targeting and Monitoring Interventions*, DISEASE CONTROL PRIORITIES IN DEVELOPING COUNTRIES 997, 997 (Dean Jamison et al. eds. 2d ed. 2006) (citing S.B. Thacker & R.L. Berkelman, *Public Health Surveillance in the United States*, EPIDEMIOLOG. REV. (1998)).

⁹ *Id.*

¹⁰ David Carter, *HIV Transmission, Public Health Detention and the Recalcitrant Subject of Discipline: Kuoth, Lam V R and the Co-Constitution of Public Health and Criminal Law*, 25 GRIFFITH L. REV. 172 (2017).

analytics to review such information for multiple purposes.¹¹ While the greater availability of health data can make public health surveillance more effective, others fear that the same data could be used for law enforcement purposes. Consequently, patients may fear utilizing public health resources due to the threat of criminal sanctions.¹² As our government contemplates ways to share data, not only across the healthcare sector but potentially also across other sectors, to address social determinants of health, we need to consider ways to address the cultural, historical, and ethical issues that pose barriers to the free exchange of this information.

Of course, these concerns are not unique to the American political, legal, and healthcare systems, and this symposium piece provides an opportunity to explore public health surveillance around a specific public health issue from a comparative legal and policy perspective between the United States and Australia.¹³ Both countries have engaged in massive initiatives to encourage the digitization and exchange of health information.¹⁴ Similar to the United States, Australia has experienced an increase in deaths related to opioid misuse;¹⁵ however, while the United States has already declared this epidemic a public health emergency, Australia can introduce policies to curb opioid misuse before it reaches the nightmarish levels seen here. Moreover, Australia could learn from the American example on how to utilize health information technology (HIT) to address the opioid crisis, but in ways that address both universal and national concerns about the scope of public health surveillance.¹⁶

This article analyzes the tension and provides a legal and policy comparison between the two countries. First, the article will provide a general overview of the public policy promises made when both countries embarked

¹¹ ASTHO, *supra* note 7 (noting “it is crucial to have laws and policies to encourage common practices and data standards to maintain the public’s trust. Public health agency leaders have a major role to play in assuring this trust through the adoption of legislation, adherence to internationally recognized data standards, and the creation of policies or processes.”).

¹² Oliver Kim, *Slightly Hazy: Transparency and the Costs of Too Much Information*, TRANSPARENCY IN HEALTH AND HEALTH CARE IN THE UNITED STATES 58, 65-66 (Holly Fernandez Lynch et al eds., 2019).

¹³ See Oliver Kim, *Is the Grass the Same Colour? Reflections on National Governments Implementing Health Care Initiatives*, HEALTH AFFAIRS GRANTWATCH (Nov. 8, 2018), <https://www.healthaffairs.org/doi/10.1377/hblog20181106.371884/full/>.

¹⁴ *Infra* Section I.B-C.

¹⁵ Dan Lubman & Samantha Lulic, *America’s Opioid Epidemic is Starting to Hit Australia’s Shores*, MONASH UNIVERSITY LENS (Feb. 12, 2019), <https://lens.monash.edu/@medicine-health/2019/02/12/1371034/opioid-crisis-headed-for-australia>.

¹⁶ American research into reducing the damage caused by the opioid epidemic has been influential in other areas of Australian public policy. Brittany Flaherty, *Legalizing Medical Cannabis Reduces Opioid Overdose Deaths? Not So Fast, New Study Says*, STAT (June 10, 2019), <https://www.statnews.com/2019/06/10/legalizing-medical-marijuana-opioid-overdose-deaths/> (quoting an Australian researcher on substance misuse that a 2014 American study on whether the legalization of marijuana for medical use reduces opioid-related deaths “[has] been cited in my own country as compelling evidence [in support of] medical cannabis”).

on significant campaigns to digitize health information. The second section examines the disconnect between policymakers' proposals seeking to free health information and the distrust both from the public generally and from certain specific segments of society. While this section is not exhaustive, it will look at some of the historic injustices caused by the healthcare sector with the acquiescence of the government. The third section discusses the public health challenge of opioid misuse facing both countries, and the fourth section explains how HIT is being utilized to address this challenge and some of the concerns that have been raised about this type of surveillance. The final section offers policy recommendations for Australia as it contemplates how to best utilize HIT to address its opioid crisis based on the American experience. Hopefully, such recommendations will produce collaborations that will not only lead to political, legal, and ethical changes to improve public health surveillance but also to a better system that will save lives and improve individuals' health and well-being as well.

I. USING HEALTH INFORMATION TECHNOLOGY FOR PUBLIC HEALTH SURVEILLANCE

Both the United States and Australia have engaged in large scale efforts to digitize health information, with the "selling points" for these initiatives being more efficient, effective care for the individual patient and improved health for the public overall. In trying to promote the public's overall health instead of focusing on each individual's health, it is axiomatic that having access to large amounts of information is key to being effective.¹⁷ The promise of HIT is that it should allow data to be culled from different sources in a way that is actionable for officials to provide effective interventions:

to assess the health and risk status of a population, data must be obtained from multiple disparate sources (e.g., hospitals, social service agencies, police, departments of labor and industry, population surveys, and on-site inspections). Data about particular individuals from these sources must be accurately combined, then individual-level data must be compiled into usable, aggregate forms at the population level. This information must be presented in clear and compelling ways to legislators and other policymakers, scientists, advocacy groups, and the public while ensuring the confidentiality of the health information of specific individuals.¹⁸

¹⁷ Denise Koo et al., *Public Health 101 for Informaticians*, 8 J. AM. MED. INFORMATICS ASS'N 585, 587 (2001).

¹⁸ *Id.* at 593-95.

The following section discusses how HIT fits in with public health surveillance specifically, and how each country's HIT efforts claim to support this policy goal.

A. An overview of public health uses of health information technology

The World Health Organization defines public health surveillance as the “ongoing, systematic collection, analysis and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice.”¹⁹ Public health surveillance relies on gathering data from the local, state, and regional or national level in order “to inform policy changes, guide new program interventions, sharpen public communications, and help agencies assess research investments.”²⁰ By necessity, public health surveillance relies on a “cooperative federalism” model, where each level of government plays a role and shares responsibilities in surveilling and responding to public health concerns.²¹ But in a nod to limited resources and individuals' privacy,²² “the reason for collecting, analyzing, and disseminating information on a disease is to control that disease. Collection and analysis should not be allowed to consume resources if action does not follow.”²³ In other words, public health agencies should narrowly tailor their activities to address the health concern.

Ideally, electronic health records (EHRs) provide a searchable mechanism for researchers to survey important public health trends such as disease trends, medication adherence and utilization, and other actions or inactions that can lead to disease.²⁴ Moreover, using electronic health

¹⁹ *Public Health Surveillance: Immunization, Vaccines and Biologicals*, WORLD HEALTH ORGANIZATION, https://www.who.int/immunization/monitoring_surveillance/burden/vpd/en/.

²⁰ *Public Health Surveillance: Preparing for the Future*, CENTERS FOR DISEASE CONTROL AND PREVENTION 10 (Sept. 2018), <https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf>; see also *Surveillance Systems Reported in Communicable Diseases Intelligence*, AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH, (last updated Apr. 11, 2016) (noting that “surveillance in Australia operates at the national, state and local levels”).

²¹ *Surveillance Systems Reported in Communicable Diseases Intelligence*, AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH, (last updated Apr. 11, 2016) (indicating the “[p]rimary responsibility for public health action lies with the state and territory health departments. The role of communicable disease surveillance at a national level includes: detecting outbreaks and identifying national trends; providing guidance for policy development and resource allocation at the national level; monitoring the need for and impact of national disease control programs; coordinating a response to national or multi-jurisdictional outbreaks; describing the epidemiology of rare diseases that occur infrequently at state and territory levels; meeting various international reporting requirements, such as providing disease statistics to the World Health Organization; and supporting quarantine activities, which are the responsibility of the Australian government.”).

²² LAWRENCE GOSTIN, *PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT* 115 (2000).

²³ Nsubuga et al., *supra* note 8, at 999 (quoting William Foege et al., *Surveillance Projects for Selected Diseases*, 5 INT'L J. OF EPIDEMIOLOGY 29 (1976)).

²⁴ Gostin, *supra* note 22, at 117; see also Nicolas Terry & Leslie Francis, *Ensuring the Privacy and Confidentiality of Electronic Health Records*, U. ILL. L. REV. 681, 683 (2007).

information would make public health data more accessible across jurisdictions, both domestically²⁵ and even globally.²⁶ Given this wealth of information, the Association of State and Territorial Health Organizations declared that “information from electronic health records... *must* be available and understandable to help public health agencies identify threats to the health and safety of the population, as well as individuals.”²⁷ Indeed, American law has recognized that federally protected health information does not require individuals’ authorization in order for it to be used for public health purposes.²⁸

Although public health was not necessarily the primary rationale for justifying wide scale efforts to promote EHRs,²⁹ both Australia and the United States did stress the communitarian benefits of EHRs and information exchange.

B. The American HITECH law and public health promises

As part of the 2009 stimulus act,³⁰ the federal government committed to invest billions of dollars into EHR systems as a foundation for patients to be able to access and share information with their providers. The stimulus act contained the Health Information Technology for Economic and Clinical Health (HITECH) Act,³¹ which authorized Medicare and Medicaid incentives for certain providers—mainly physicians and hospitals—to adopt and “meaningfully use” EHR systems that were certified to meet federal standards.³² What counted as meaningful use of EHRs was supposed to

²⁵ Noam Artz, *A Public Health Perspective on Interoperability*, PUBLIC HEALTH INFORMATICS INSTITUTE (Apr. 20, 2017), <https://www.phii.org/blog/public-health-perspective-interoperability> (noting “[t]here are more than 2,500 public health agencies in the U.S. at the federal, state, local, territorial and tribal levels,” which makes interoperability difficult across agencies); *see also* ASTHO, *supra* note 7 (echoing the digital diversity within the public health community resulting in “public health agencies and healthcare providers... not us[ing] the same information systems, data formats, or even data standards”).

²⁶ Oliver Kim, *Ebbs and Flows: Issues in Cross-Border Exchange and Regulation of Health Information*, 26 ANNALS OF HEALTH L. 39, 51-53 (2017) (discussing how information exchange between countries helps prepare public health agencies with situations across borders).

²⁷ ASTHO, *supra* note 7 (emphasis added).

²⁸ 45 C.F.R. § 164.512(b) (exempting protected health information from certain public health activities as requested by public health authorities).

²⁹ Fred Schulte & Erika Fry, *Death By 1,000 Clicks: Where Electronic Health Records Went Wrong*, KAISER HEALTH NEWS (Mar. 18, 2019), www.khn.org/news/death-by-a-thousand-clicks/ (noting that EHRs were supposed to “make medicine safer, bring higher-quality care, empower patients, and... save money” in the healthcare system through reduced tests and more effective care).

³⁰ American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, 123 Stat. 115.

³¹ *Id.* at § 13001, 123 Stat. 126.

³² While former FDA Commissioner Scott Gottlieb called for some type of regulatory authority within FDA as he was leaving the agency (as explained in, Fred Schulte & Erika Fry, *FDA Chief Calls for Stricter Scrutiny of Electronic Health Records*, KAISER HEALTH NEWS (Mar. 21, 2019), khn.org/news/fda-chief-calls-for-stricter-scrutiny-of-electronic-health-records/), Congress has

become progressively more challenging under three stages of regulations, some of which later were folded into a new payment system when Congress reformed Medicare's payment system for physicians and other clinicians.³³

The first two meaningful use stages required EHRs to be able to perform certain public health functions in order to receive federal certification: to share data with immunization registries, cancer registries, and other specialized registries, and to be able to share syndromic surveillance data and clinical laboratory results.³⁴ The third and final stage of meaningful use consolidated different aspects of "public health reporting," elevating the number of specific measures that eligible practitioners and hospitals needed to report on.³⁵

While there is hope that efforts required by the 21st Century Cures Act³⁶ will provide greater interoperability by empowering patients to adopt a third-party app to access and compile their health data, there is still great skepticism about the ability of EHR systems' ability to connect disparate, sometimes competing portions of the healthcare system.³⁷ Some critics have declared that the strain and stress that EHR utilization causes on healthcare providers is a public health emergency in and of itself.³⁸ Indeed, even President Barack Obama called HITECH the most disappointing health policy of his administration.³⁹

limited the federal government's ability to regulate many types of software as medical devices; see e.g., 21st Century Cures Act, Pub. L. No. 114 – 255, 130 Stat. 1130 (2016).

³³ Office of the National Coordinator for Health Information Technology, *Meaningful Use and MACRA*, HEALTHIT.GOV, www.healthit.gov/topic/meaningful-use-and-macra/meaningful-use-and-macra (last reviewed Feb. 12, 2019).

³⁴ Daniel Friedman et al., *Electronic Health Records and US Public Health: Current Realities and Future Promise*, 103 AM. J. OF PUB. HEALTH 1560 (2013).

³⁵ Medicare and Medicaid Programs: Electronic Health Record Incentive Program—Stage 3 and Modifications to Meaningful Use in 2015 Through 2017, 80 Fed. Reg. 62762, 62787 (Oct. 16, 2015) (codified as 42 C.F.R. pts. 412 & 495). Eventually Congress folded meaningful use into a new payment system for practitioners; see Medicare Access and CHIP Reauthorization Act, Pub. L. No. 114-10 (2015), 129 Stat. 87 (2015). The Centers for Medicare and Medicaid Services reduced the public health reporting requirement for participating hospitals, Centers for Medicare and Medicaid Services, *Stage 3 Program Requirements for Eligible Hospitals, CAHs and Dual-Eligible Hospitals Attesting to CMS*, CMS.GOV (Apr. 25, 2018), www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Stage3_RequieEH.html.

³⁶ 21st Century Cures Act, Pub. L. No. 114 – 255 § 4001, 130 Stat. 1157 (2016)

³⁷ See Noam Arzt, *The Interoperability of Things*, 29 J. OF HEALTHCARE INFO. MGMT. 6 (2015).

³⁸ Schulte & Fry, *supra* note 29.

³⁹ Sarah Kliff, *Obama's Surprising Answer on Which Part of Obamacare Has Disappointed Him the Most*, VOX (Jan. 9, 2017), <https://www.vox.com/2017/1/9/14211778/obama-electronic-medical-records>; see also Roger Maduro, *Obama and Biden Blast EHR Vendors for Data Blocking*, OPEN HEALTH NEWS (Jan. 19, 2017) (noting that both President Obama and then-Vice President Joe Biden criticized EHR vendors as hurting information exchange).

C. Australia's My Health Record and public health promises

In 2018, the Australian government launched a nationwide initiative, My Health Record,⁴⁰ to provide all Australians with an EHR unless they opted out.⁴¹ My Health Record was actually the Australian government's second attempt at creating a national EHR: in 2012, the government offered Australians the option of a "Personally Controlled Electronic Health Record" (PCEHR), but they needed to opt into the PCEHR; consequently, the take-up rate among patients was poor, and providers saw little reason to review PCEHRs if patients weren't utilizing them.⁴² Proponents of My Health Record claimed that it would "save lives and deliver economic benefits" through greater information sharing, reduction of medical errors, and the ability to see public health trends in data.⁴³

Although many of the arguments that proponents made related to individualized benefits, there was a greater emphasis on meaningful public health benefits under My Health Record than were made in promoting HITECH.⁴⁴ Recognizing the value of holding millions of individuals' health data, the Australian Department of Health issued a framework on how "secondary use" research could be conducted utilizing data stored within the cumulative My Health Record EHRs.⁴⁵ By 2021, the Australian government projected sufficient data would be collected through My Health Record "for research, policy and planning purposes [to] improve the Australian health system by making it more efficient, effective and sustainable."⁴⁶ In addition to being able to opt out of My Health Record altogether, Australians may remain in My Health Record but opt out of having their data utilized for

⁴⁰ Australian Digital Health Agency, MY HEALTH RECORD (last visited Apr. 30, 2019), www.myhealthrecord.gov.au/.

⁴¹ *Health Legislation Amendment (eHealth) Act 2015* (Cth) reg 157 (Austl.).

⁴² Suman Reddy, *My Health Record: The Resuscitation of E-Health, Or a Data Placebo?* KING & WOOD MALLESONS (Mar. 28, 2017) (noting that over \$1 billion AUD was spent on PCEHR).

⁴³ Lynne Minion, *AMA Calls for Improvements to My Health Record For It to Reach Potential*, HEALTHCARE IT NEWS (Dec. 15, 2017), <https://www.healthcareit.com.au/article/ama-calls-improvements-my-health-record-it-reach-potential>.

⁴⁴ See, e.g., Australian Digital Health Agency, *The Potential of My Health Record for Australia's Future Health Needs*, MY HEALTH RECORD (Oct. 9, 2018), www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/potential-for-australias-future-health (noting that "the bigger picture" would result in "My Health Record helping to helping health researchers and public health experts ensure patients receive evidence-based care and that future health investment is directed at those who need it most" and "how we can improve the Australian health system"). This distinction is likely because the data held by My Health Record was centralized within the Australian government, whereas HITECH's data was diffused among a disparate group of private practitioners and hospitals that often lacked the ability to exchange them with each other, let alone public health agencies.

⁴⁵ AUSTRALIAN DEPARTMENT OF HEALTH, FRAMEWORK TO GUIDE THE SECONDARY USE OF MY HEALTH RECORD SYSTEM DATA (May 2018).

⁴⁶ AUSTRALIA DIGITAL HEALTH AGENCY, SECURE USE OF MY HEALTH RECORD DATA, MY HEALTH RECORD (last visited Aug. 10, 2018), conversation.digitalhealth.gov.au/1-my-health-record.

research purposes.⁴⁷ Critics, however, noted that My Health Record would be a basic summary with much of the data being uploaded as PDFs, limiting the ability to search and use data contained in My Health Record.⁴⁸ Being able to cull through the data of 25 million people could someday have an impact on public health but perhaps would not be as useful at this initial stage.

II. CHALLENGES TO UTILIZING HIT FOR PUBLIC HEALTH SURVEILLANCE

As noted, HIT proponents offered a host of reasons for freeing up the use of our data to improve both individual health and the public health, but there are also a host of reasons that make individuals reluctant to turn over their data, even to benefit the community at large. The following is a broad overview that attempts to describe some of the major shared, as well as specific, policy concerns that have come up in each country.

A. Societal privacy concerns

The bedrock of the provider-patient relationship is trust, and that same level of trust must exist in EHRs, shared databases, and other digital tools if they are going to be welcomed—or at least tolerated—by patients and consumers. However, there is a growing “trust gap”: the narrative is not good for digital health’s trustworthiness due to “a steady drip-drip-drip of articles documenting how health apps are sharing data with third parties.”⁴⁹ Moreover, observers have raised concerns about how digital technologies

⁴⁷ *Id.* at 2, 4 (noting that Australians can opt-out of secondary use of their de-identified data and must opt in or consent for the use of identifiable data); Charis Chang, *My Health Record: Should you opt out?*, NEWS.COM.AU (Jan. 9, 2019), www.news.com.au/lifestyle/health/my-health-record-should-you-opt-out/news-story/d31d492dfaf3788ba9851e73073f482.

⁴⁸ Katharine Kemp et al., *My Health Record: The Case For Opting Out*, THE CONVERSATION (July 16, 2018), theconversation.com/my-health-record-the-case-for-opting-out-99302 (noting an online poll of the Australian Medical Association found that 76% of respondents believed that My Health Record would not improve patient outcomes); Bernard Robertson-Dunn, *My Health Record: On A Path To Nowhere?*, MJA INSIGHT (July 2, 2018), insightplus.mja.com.au/2018/25/my-health-record-on-a-path-to-nowhere/ (noting that “My Health Record is a simple document database[,] based primarily on pdf files, which are simply aggregated without being integrated or managed from a clinical perspective”).

⁴⁹ Susannah Fox, *Trust Gap: Health Apps and Data Sharing*, SUSANNAH FOX (Apr. 29, 2019), <https://susannahfox.com/2019/04/29/trust-gap-health-apps-and-data-sharing/>.

affect women,⁵⁰ people of color,⁵¹ and those of limited means⁵² in areas such as privacy, security, and criminal justice. For example, many questions about privacy arose when police were able to use a private company's DNA ancestry tool to identify the Golden State Killer through partial matches from relatives' genetic data.⁵³ Some law enforcement agencies are building up their own DNA databases, and while they may have obtained DNA samples consensually, the individuals surveyed may not realize that their DNA could be used beyond just individual matches.⁵⁴

In Australia, privacy concerns⁵⁵ and political backlash⁵⁶ against My Health Record did result in statutory changes to the national EHR's authorization. In addition to an extension of the opt-out period through

⁵⁰ Emily Chang, *What Women Know About the Internet*, NEW YORK TIMES (Apr. 10, 2019), <https://www.nytimes.com/2019/04/10/opinion/privacy-feminism.html>.

⁵¹ Cat Zakrzewski, *Advocate Urges Congress to Protect Digital Rights of People of Color as It Crafts Privacy Bill*, WASHINGTON POST – THE TECHNOLOGY 202 (Feb. 26, 2019), https://www.washingtonpost.com/news/powerpost/paloma/the-technology-202/2019/02/26/the-technology-202-advocate-urges-congress-to-protect-digital-rights-of-people-of-color-as-it-crafts-privacy-bill/5c744bc31b326b71858c6c3a/?utm_term=.f2eb7c9b242b.

⁵² Mary Madden, *The Devastating Consequences of Being Poor in the Digital Age*, NEW YORK TIMES (Apr. 25, 2019), <https://www.nytimes.com/2019/04/25/opinion/privacy-poverty.html>.

⁵³ Avi Selk, *The Ingenious and 'Dystopian' DNA Technique Police Used to Hunt the 'Golden State Killer' Suspect*, WASHINGTON POST (Apr. 28, 2018), www.washingtonpost.com/news/true-crime/wp/2018/04/27/golden-state-killer-dna-website-gedmatch-was-used-to-identify-joseph-deangelo-as-suspect-police-say/?utm_term=.be98027f7f68 (noting that states have moved to regulate or even ban familial DNA searches using DNA samples submitted to ancestry websites); Clare Wilson, *Serial Killer Suspect Identified Using DNA Family Tree Website*, NEW SCIENTIST (Apr. 27, 2018), www.newscientist.com/article/2167554-serial-killer-suspect-identified-using-dna-family-tree-website/.

⁵⁴ Jay Stanley, *The Police Want Your DNA to Prove You're Innocent. Do You Give it to Them?*, ACLU BLOG (Sept. 16, 2016), <https://www.aclu.org/blog/privacy-technology/medical-and-genetic-privacy/police-want-your-dna-prove-youre-innocent-do-you>; see also Lauren Kirchner, *DNA Dragnet: In Some Cities, Police Go From Stop-and-Frisk to Stop-and-Spit*, PROPUBLICA (Sept. 12, 2016), <https://www.propublica.org/article/dna-dragnet-in-some-cities-police-go-from-stop-and-frisk-to-stop-and-spit> (explaining one physician's concern after police swabbed his son, "My concern... is that it's not just Adam's DNA... It's my DNA, it's my wife's DNA, and our parents. Not to sound bad, but you just get nervous."). Note that public health surveillance does contemplate the use of data obtained from law enforcement agencies, but that is different than using data gathered for public health purposes then being used for policing. Koo et al., *supra* note 17.

⁵⁵ Kemp et al., *supra* note 48.

⁵⁶ Lynne Minion, *Federal Government Announces My Health Record Opt Out Period as Public Concerns About Data Security Grow*, HEALTHCARE IT NEWS (May 15, 2018), www.healthcareit.com.au/article/federal-government-announces-my-health-record-opt-out-period-public-concerns-about-data. The political backlash was swift as Australians feared both the possibility of public (state surveillance) and private (hackers) use of their data, and critics argued the Australian Digital Health Agency was failing to educate the public about their option to opt out. Kemp et al., *supra* note 48; see also Joseph Brookes, *Every Australian Could Have a Digital Health Record by October 15: But Critics Question the Value*, WHICH-50 (May 28, 2018), <https://which-50.com/cover-story-every-australian-could-have-a-digital-health-record-by-october-15-but-critics-question-the-value/> (discussing how the agency CEO Tim Kelsey was asked why he announced the beginning of the opt-out period "under the cover of the royal wedding... almost guaranteeing that it got no media coverage" and therefore stoking conspiracy rumors).

January 31, 2018,⁵⁷ these legislative amendments included safeguards on the use of secondary-utilization of data, the requirement of a warrant to review patient data, and the ability for individuals to destroy their record permanently.⁵⁸

B. Historical concerns related to specific segments of the population

In addition to general concerns about privacy, both countries also share a sad history of mistreating certain communities that have resulted in specific segments of the populace having distrust in the medical community.

1. *Examples from the United States*

The United States has many horrific examples of medical experiments conducted on vulnerable, low-income individuals, particularly among the African-American and Native American communities, and these events have far-reaching effects on the practice of medicine even today.⁵⁹ Current political trends also may make patients—particularly those seeking care that is either stigmatized or at odds with federal policy—fearful of sharing data or even accessing care.⁶⁰ Collecting information that may identify patients' immigration status can be a barrier to undocumented immigrants seeking healthcare services.⁶¹ Despite healthcare facilities being seen as “sensitive locations,” threats of deportation have caused individuals to forego care for fear of revealing their immigration status.⁶²

Again, these consequences are two-fold: minorities have some of the worst health outcomes, but because of barriers and challenges to their use of

⁵⁷ Stilgherrian, *Hunt Finally Submits to My Health Record Arm-Twists as Opt-Out Window Extended*, ZDNET (Nov. 14, 2018), www.zdnet.com/article/hunt-finally-submits-to-my-health-record-arm-twists-as-opt-out-window-extended/.

⁵⁸ *My Health Records Amendment (Strengthening Privacy) Act 2018* (Cth) reg 154 (Austl.).

⁵⁹ HARRIET WASHINGTON, *MEDICAL APARTHEID THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* 386 (2006) (noting that “[m]ainstream medical scientists, journals, and even some news media fail to evaluate these fears in the light of historical and scientific fact and tend instead to dismiss all such doubts and fears as antiscience.”). These concerns resonate even today in various aspects of care: for example, in a community study of attitudes related to advance care planning in Washtenaw County, Michigan, African-American participants in a focus group revealed they were concerned about sharing information related to their end-of-life wishes because they were concerned that it could be used against them to ration their care. Oliver Kim et al., *Advance Care Planning: Tying a Community Perspective to the National Conversation*, CTR FOR HEALTHCARE RESEARCH & TRANSFORMATION (Aug. 22, 2016).

⁶⁰ See, e.g., Ike Swetlitz, *Immigrants, Fearing Trump's Deportation Policies, Avoid Doctor Visits*, PBS NEWSHOUR (Feb. 25, 2017), www.pbs.org/newshour/rundown/immigrants-trump-deportation-doctor/ [<https://perma.cc/S5V9-HJV5>].

⁶¹ Karen Hacker et al., *Barriers to Health Care for Undocumented Immigrants: A Literature Review*, RISK MGMT. AND HEALTHCARE POL'Y 175, 178 (2015).

⁶² Swetlitz, *supra* note 60.

healthcare resources, we do not have all the data necessary to determine how to address these disparities. For instance, an analysis of genomic studies found that while this data is becoming less exclusively based on people of European descent, “[t]he degree to which people of African and Latin American ancestry, Hispanic people and indigenous peoples are represented in [such studies] has barely shifted” in nearly a decade.⁶³ Is it because researchers are failing to recruit patients from these racial and ethnic groups, or because they do not want to participate, or both?⁶⁴

2. *Examples from Australia*

In comparison to the United States, Australia is much more homogenous: the majority of Australians trace their backgrounds to white European countries with the vast preponderance being British (67%), followed by Irish (8.7%), Italian (3.8%), and German (3.7%).⁶⁵ Australia is seeing a growing Asian population, and the Indigenous Australian population, or the Aboriginal and Torres Strait Islander communities, make up less than 3% of the population.⁶⁶

In addition to the aforementioned privacy concerns noted in the general public, Australian law and policy has had negative effects on minority populations. Only since the 1970s has Australia liberalized its immigration policies, which were informally called the “White Australia” policy in an effort to keep Australia predominantly “white and British.”⁶⁷ Gradual shifts in immigration policy allowed non-Europeans to enter based on needed skills and eventually resulted in a series of immigration reforms and civil rights laws passed in the late 1960s and early 1970s.⁶⁸

Australia’s Indigenous population shares tragic parallels to the African American and Native American communities.⁶⁹ This community is one of

⁶³ Alice B. Popejoy & Stephanie M. Fullerton, *Geonomics is Failing on Diversity*, 538 NATURE 161 (Oct. 12, 2016).

⁶⁴ Travonia Hughes et al., *African Americans and Clinical Research: Evidence Concerning Barriers and Facilitators to Participation and Recruitment Recommendations*, 57 THE GERONTOLOGIST 348, 353-354 (Nov. 9, 2015).

⁶⁵ *Demographics and Ethnic Groups of Australia*, WORLD ATLAS (June 13, 2018), www.worldatlas.com/articles/ethnic-background-of-australians.html; see also *Australia-Oceania: People and Society*, CIA WORLD FACTBOOK (2018), www.cia.gov/library/publications/the-world-factbook/geos/as.html (with greatest predominance being English-Australian-Scottish).

⁶⁶ Emil Jeyaratnam, *Twelve Charts on Race and Racism in Australia*, THE CONVERSATION (Nov. 27, 2018), theconversation.com/twelve-charts-on-race-and-racism-in-australia-105961; see also *Demographics and Ethnic Groups of Australia*, *supra* note 65.

⁶⁷ Benjamin Jones, *Australian Politics Explainer: The White Australia Policy*, THE CONVERSATION (Apr. 9, 2017), <http://theconversation.com/australian-politics-explainer-the-white-australia-policy-74084>.

⁶⁸ *Id.*

⁶⁹ Ben Doherty, *Common Struggle: Black Lives Matter Leader Talks of Painful Parallels with Indigenous Australia*, THE GUARDIAN (July 15, 2018), <https://www.theguardian.com/us>

the most economically disadvantaged groups in Australia, largely due to “the legacy of more than 200 years of dispossession, social injustice, and discriminatory government policies that brought about the near annihilation of the country’s first peoples.”⁷⁰ For example, while the Indigenous population is less than 3% of the total population, it represents over a quarter of the prison population.⁷¹ Similarly in healthcare, many researchers have noted that despite Australia’s increase in funding for programs aimed at the Aboriginal and Torres Strait Islander communities, they continue to experience tremendous health disparities.⁷² Many reports have attributed systemic racism within the healthcare system as a major driver of such disparities.⁷³ One report noted that a common and pervasive reason for Indigenous patients delaying or failing to seek out healthcare services was due to a lack of trust in the healthcare system.⁷⁴

III. UTILIZING HEALTH INFORMATION TECHNOLOGY TO RESPOND TO THE PUBLIC HEALTH THREAT OF OPIOID MISUSE

As discussed, HIT can be utilized for public health purposes, and both the American and Australian investments into EHRs had this purpose as one of their public policy goals. While there are substantial hurdles—both from

news/2018/jul/15/common-struggle-black-lives-matter-leader-talks-of-painful-parallels-with-indigenous-australia; Katie Saulnier, *Aboriginal Self-Determination: A Comparative Study of New Zealand, Australia, and the United States of America*, INSTITUTE FOR THE STUDY OF INTERNATIONAL DEVELOPMENT ABORIGINAL POLICY STUDY PAPERS (2014), https://mcgill.ca/isid/files/isid/pb_2014_02_saulnier_0.pdf; see also David Wilkins, *African Americans and Aboriginal Peoples: Similarities and Differences in Historical Experiences*, 90 CORNELL L. REV. 515, 516-23 (2005) (discussing parallels between the American government’s treatment of Native Americans and African Americans).

⁷⁰ Jeff Wallenfeldt, *The Quality of Life for Indigenous Australians in the 21st Century*, ENCYCLOPAEDIA BRITANNICA (Oct. 3, 2107), <https://www.britannica.com/topic/The-quality-of-life-for-Indigenous-Australians-in-the-21st-century-2109242>.

⁷¹ Jeyaratnam, *supra* note 66.

⁷² S.M. van Holst Pellekaan & L. Clague, *Toward Health and Wellbeing for Indigenous Australians*, 81 POSTGRAD. MED. J. 618-19 (2005).

⁷³ *Achieving Aboriginal and Torres Strait Islander Health Equality within a Generation - A Human Rights based Approach*, AUSTRALIAN HUMAN RIGHTS COMMISSION, <https://www.humanrights.gov.au/our-work/publications/achieving-aboriginal-and-torres-strait-islander-health-equality-within> (recognizing “that the inequality in health status endured by Aboriginal and Torres Strait Islander peoples is linked to systemic discrimination”); Stephen Duckett, *Let’s Call Out Unconscious Racism in the Treatment of Indigenous Australians*, GRATTAN INSTITUTE (Aug. 14, 2018), grattan.edu.au/news/time-to-name-and-call-out-unconscious-racism-in-the-treatment-of-indigenous-australians.

⁷⁴ Deborah Askew et al., *To Your Door: Factors that Influence Aboriginal and Torres Strait Islander Peoples Seeking Care*, KANYINI QUALITATIVE STUDY MONOGRAPH SERIES: NO. 1 11, 15 (2014), www.georgeinstitute.org/publications/to-your-door-factors-that-influence-aboriginal-and-torres-strait-islander-peoples (noting that health centers need to communicate a welcoming presence as many Indigenous patients expressed “experiences of racism and expectations about life being worse after a diagnosis discouraged Aboriginal and Torres Strait Islander peoples from seeking care”).

a technological perspective in terms of interoperability as well as individual concerns about the utilization of personal, private health data—it would seem that HIT should be an asset to public health agencies.

Responding to opioid misuse seems to be tailor-made for HIT utilization: having data on patients' opioid utilization, where opioids seem to be overprescribed, and being able to track where opioid overdoses are occurring would enable health officials and policymakers to better pinpoint resources to respond to this growing epidemic. The increase in opioid misuse and the resulting increase in overdoses and deaths in Australia, the United States, and other countries has been linked to several factors such as changes in prescribing patterns, greater recognition of chronic pain, an aging population, and aggressive pharmaceutical marketing.⁷⁵ In response, Australia and the United States are taking a number of steps—including how to use HIT—in addressing this increasingly-global public health crisis.

A. Uptick of opioid misuse in Australia

Since the 1990s, Australians' use of opioids has increased dramatically. One study noted that between 1991 and 2010, the population increased by 29%, but the supply by weight of opioid prescriptions increased 228%; another study found the number of opioid prescriptions subsidized by the Australian prescription drug scheme increased by 15 times in nearly the same period.⁷⁶ With such exponential increases comes the possibility of misuse, whether intentional or not. After peaking in the late 1990s mainly due to heroin, the death rate—1,808 individuals in 2016, or 7.5 per 100,000 people—has surged to nearly those record levels; however, those at risk are now more likely to be middle aged, living outside the large cities, and misusing prescription drugs.⁷⁷

B. Opioid crisis in the United States

Americans' use of opioids has increased dramatically: the sales of prescription opioids nearly quadrupled since 1999 due to several potential causes.⁷⁸ At the same time, the death rate due to overdoses tripled to 19.8 per 100,000 individuals, with nearly two-thirds of deaths involving either

⁷⁵ Tom Kovitwanichkanont & Carolyn Day, *Prescription Opioid Misuse and Public Health Approach in Australia*, 53 *SUBSTANCE USE & MISUSE* 200, 200-205 (2018).

⁷⁶ *Id.*; see also *National Pharmaceutical Drug Misuse Framework for Action (2012-2015)*, AUSTRALIAN GOVERNMENT, (2013).

⁷⁷ 3303.0 - *Causes of Death, Australia, 2016*, AUSTRALIAN BUREAU OF STATISTICS (2018), <https://www.abs.gov.au/ausstats/abs@.nsf/mf/3303.0>.

⁷⁸ Claire Felter, *The U.S. Opioid Epidemic*, COUNCIL ON FOREIGN RELATIONS (2017), https://www.cfr.org/backgrounder/us-opioid-epidemic?gclid=Cj0KCQjwjrvpBRC0ARIsAFrFuV9q18QVmo9U03Pa7jQAz6HUTRZwbFDNRotsevt-y1MMpnTzTGwY6toaAuF_EALw_wcB.

prescription or illegal opioids.⁷⁹ The opioid epidemic has had other public health consequences: nearly two million Americans have a prescription opioid use disorder, leading to an increase in illicit opioid use and diseases such as hepatitis C and HIV.⁸⁰ Deaths due to opioid overdoses exceed automobile accidents in the United States.⁸¹ The opioid epidemic's toll on the American public's health is so extensive that it is linked to a decline in the country's life expectancy.⁸²

Both the American government and the states have initiated numerous efforts to grapple with the opioid epidemic such as implementing prescription drug monitoring programs (PDMPs), limiting opioid prescriptions and production, and educating prescribers on appropriate opioid use.⁸³ However, the United States is seeing increases in the use of heroin, cocaine, methamphetamines, and synthetic opioids such as fentanyl.⁸⁴ Much of this increase in the use of illicit substances is tied to the opioid epidemic: nearly 80% of new heroin users had initially misused prescription opioids,⁸⁵ and nearly half of those who used heroin were also addicted to prescription opioids.⁸⁶

IV. UTILIZATION OF HEALTH INFORMATION TECHNOLOGY RESPONSES TO THE OPIOID CRISIS

One response to the opioid crisis is the increasing use of HIT to establish PDMPs to aid clinical decision-making in prescribing and dispensing opioids. Australia is seeking to establish its own PDMP policy, and in designing this digital response, Australia should look at the American PDMPs for lessons learned.

⁷⁹ H. Hedegaard, M. Warner, & A. Minino, *Drug Overdose Deaths in the United States, 1999-2016*, NCHS CTRS. FOR DISEASE PREVENTIONS AND CONTROL (2017).

⁸⁰ Office of the National Coordinator for Health Information Technology, *Health IT Playbook*, HEALTHIT.GOV (2018), <https://www.healthit.gov/playbook/>.

⁸¹ Ken Kolosh, *Accidental Injury Becomes #3 Cause of Death in the U.S.*, NATIONAL SAFETY COUNCIL (2018), <https://www.nsc.org/safety-first-blog/accidental-injury-becomes-3-cause-of-death-in-the-us-1>.

⁸² Felter, *supra* note 78.

⁸³ *Id.*; German Lopez, *The States Taking the Opioid Epidemic Seriously (and Not)*, in *One Map*, VOX (Feb. 22, 2018), <https://www.vox.com/policy-and-politics/2018/2/22/17037346/opioid-epidemic-state-policy-map>.

⁸⁴ Felter, *supra* note 78; *see also* Hedegaard, *supra* note 79.

⁸⁵ Office of the National Coordinator for Health Information Technology, *supra* note 81.

⁸⁶ *Today's Heroin Epidemic*, CTRS. FOR DISEASE CONTROL AND PREVENTION (2015).

A. What is a prescription drug monitoring program?

A PDMP is an electronic database used to track prescriptions for controlled substances, typically within a state.⁸⁷ Research has found that PDMPs are an effective tool that can help change prescribing behaviors while reducing opioid misuse and patients' attempts to "shop" among multiple practitioners in an effort to obtain a prescription.⁸⁸ Although monitoring programs for prescription drug utilization date back to the 1930s, technology has helped improve their accessibility and effectiveness.⁸⁹ Using HIT for such a purpose seems like a relatively routine use; indeed, one of the "low hanging fruits" for HIT policy goals is to reduce medication errors and increase appropriate prescribing.⁹⁰

The Centers for Disease Control and Prevention (CDC) have made four basic recommendations for PDMP features to include. First, all prescribers should consult with the state PDMP prior to issuing a script for an opioid or other controlled substance.⁹¹ By checking with the PDMP, a healthcare provider can see a patient's prior prescription history, including dose, supply, and prescriber of scheduled drugs that the patient has previously filled.⁹² Although the CDC stops short of urging states to mandate that healthcare providers check the state PDMP before issuing a script, a majority of states have passed such a mandate.⁹³

Second, data should be available in real time so that healthcare providers and public health officials have accurate information on patient

⁸⁷ *What States Need to Know About PDMPs*, CNTRS. FOR DISEASE CONTROL AND PREVENTION (Oct. 3, 2017), www.cdc.gov/drugoverdose/pdmp/states.html.

⁸⁸ Lisa Sacco et al., *Prescription Drug Monitoring Programs*, CONG. RESEARCH SERV. 1, 10 (2018).

⁸⁹ Yuhua Bao et al., *Prescription Drug Monitoring Programs are Associated with Sustained Reductions in Opioid Prescribing by Physicians*, 35 HEALTH AFFAIRS 1045 (2016). In the United States, the federal government has provided several funding sources for states to adopt PDMPs. Sacco, *supra* note 88, at 15-21. Congress authorized additional grant programs as part of the Comprehensive Addiction and Recovery Act (CARA), P.L. 114-198, and the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment (SUPPORT) for Patients and Communities Act, P.L. 115-271.

⁹⁰ Australian Digital Health Agency, *supra* note 40. Indeed, Congress created an electronic prescribing incentive program in Medicare, Medicare Improvements for Patients and Providers Act, Pub. L. No. 110-275 §132 (2008), prior to the more ambitious HITECH program. The adoption of the federal e-prescribing incentive program has been less contentious and more successful than the adoption of EHRs. See Seth Joseph et al., *E-Prescribing Adoption and use Increased Substantially Following the Start of a Federal Incentive Program*, 32 HEALTH AFFAIRS 1221, 1225-27 (2013).

⁹¹ *Today's Heroin Epidemic*, *supra* note 86.

⁹² Rebecca Haffajee et al., *Mandatory use of Prescription Drug Monitoring Programs*, 313 J. AM. MED. ASS'N 891 (2015).

⁹³ Christine Vestal, *States Require Doctors to use Prescription Drug Monitoring Systems for Patients*, WASHINGTON POST (Jan. 15, 2018), www.washingtonpost.com/national/health-science/states-require-doctors-to-use-prescription-drug-monitoring-systems-for-patients/2018/01/12/c76807b8-f009-11e7-97bf-bba379b809ab_story.html?utm_term=.f32918c8bbfd.

utilization.⁹⁴ The CDC calls for addressing potential “lag time” when pharmacies fail to upload data in a timely fashion when prescriptions for opioids are actually filled by a pharmacist to state PDMPs.⁹⁵

Third, the CDC calls for PDMPs to be “actively managed” and not simply seen as a passive database.⁹⁶ For example, states can use PDMP data to issue reports on patients at the highest risk for opioid misuse or to identify inappropriate prescribing trends.⁹⁷ Such proactive reports can help change prescriber behavior.⁹⁸

Fourth, PDMPs should be accessible, user-friendly, and functional in order to encourage utilization and assuage provider resistance.⁹⁹ Many providers resisted and fought mandates to use PDMPs because of complaints that PDMPs are difficult to use.¹⁰⁰ In response, the CDC notes that states have adopted policies to make it easier to use and access PDMPs such as “integrating PDMPs into electronic health record (EHR) systems, permitting physicians to delegate PDMP access to other allied health professionals in their office (e.g., physician assistants and nurse practitioners), and streamlining the process for providers to register with the PDMP.”¹⁰¹

B. Utilization of prescription drug monitoring programs in the United States

PDMPs have been almost universally adopted across the United States, but how each PDMP operates varies widely from state to state.¹⁰² Due to the diversity in states’ approaches, there is inconsistency in how PDMPs operate: for instance, Texas and New York still allow the use of some paper forms,¹⁰³ and Missouri remains the only state that has not established a PDMP—rather a county-based PDMP has taken the place of a state-operated one.¹⁰⁴ Some states mandate that all prescribers must register with the PDMP and utilize it

⁹⁴ *Today’s Heroin Epidemic*, *supra* note 86.

⁹⁵ *Id.*; Sacco, *supra* note 87, at 14.

⁹⁶ *Today’s Heroin Epidemic*, *supra* note 86.

⁹⁷ *Id.*

⁹⁸ Sacco, *supra* note 88, at 10.

⁹⁹ *Today’s Heroin Epidemic*, *supra* note 86.

¹⁰⁰ Haffajee, *supra* note 92, at 891-92. “A survey of prescribers found that the most common reason given for not using a PDMP was the time required to access it (73%); two other reasons were difficulty navigating the web portal (29%) and forgetting the password (may contribute to the amount of time required to access PDMP information).” *See also*, Sacco, *supra* note 88, at 14.

¹⁰¹ *What States Need to Know about PDMPs*, *supra* note 87.

¹⁰² M. Mofizul Islam & Ian McRae, *An Inevitable Wave of Prescription Drug Monitoring Programs in the Context of Prescription Opioids: Pros, Cons, and Tensions*, 15 BMC PHARMACOLOGY AND TOXICOLOGY 46 (2014).

¹⁰³ Prescription Drug Monitoring Program Training and Technical Assistance Center, *History of Prescription Drug Monitoring Programs*, BRANDEIS UNIVERSITY 5 (March 2018), https://www.pdmpassist.org/pdf/PDMP_admin/TAG_History_PDMPs_final_20180314.pdf.

¹⁰⁴ Sacco, *supra* note 88, at 4.

before writing a script for a controlled substance.¹⁰⁵ Many prescribers have resisted such mandates as administratively burdensome,¹⁰⁶ but proponents argue that the mandate reduces potential misuse and changes prescribing patterns. Most states share data their PDMPs collect with other states, and some have integrated their PDMPs with other HIT initiatives such as health information exchanges.¹⁰⁷

Many stakeholders have offered recommendations to improve their operations while others have raised policy concerns about the effectiveness of certain PDMP policies as a means of addressing the opioid epidemic. For example, while PDMPs can identify overprescribing and target those practitioners, some analysts argue that prescribers may “simply decline to prescribe opioids, raise prescribing thresholds, refer patients elsewhere, or substitute . . . nonmonitored drugs.”¹⁰⁸ Further, prescribers and patients may be reluctant to pursue care—a “chilling effect”—for fear of potential reprisals from being recorded in a PDMP depending on its accessibility to law enforcement and licensing boards or if it is housed in a law enforcement agency.¹⁰⁹ Finally, despite efforts to integrate PDMPs into other HIT efforts, providers have resisted efforts to mandate integration of their EHR systems into PDMPs because of technical concerns regarding the “maturity” of PDMPs.¹¹⁰

C. Australia’s efforts at developing PDMPs

In 2010, Australia allocated initial funding for a real-time drug monitoring initiative, the Electronic Recording and Reporting of Controlled Drugs (ERRCD) system.¹¹¹ Subsequently, the “National Pharmaceutical Drug Misuse Framework for Action” called for creating “an online, real time medication management tool that would provide access to information on patients’ medication usage to prescribers, dispensers, and regulators.”¹¹² Yet

¹⁰⁵ Haffajee, *supra* note 92, at 891-92.

¹⁰⁶ *Id.* at 891.

¹⁰⁷ Sacco, *supra* note 88, at 5. Although the majority of states are in an existing data-sharing agreement for their PDMPs, the federal government is seeking to require states to utilize an alternative data-sharing platform as a condition for new federal grants. Darius Tahir, *Federal Mandate to use Opioid Data-Sharing Technology Angers States*, POLITICO (Apr. 12, 2019), <https://www.politico.com/story/2019/04/12/opioid-data-sharing-angers-states-1320532>.

¹⁰⁸ Haffajee, *supra* note 92, at 891-92.

¹⁰⁹ Islam, *supra* note 102.

¹¹⁰ Jessica Kim Cohen, *There’s a Push to Slow Down Required EHR-PDMP Integration*, MODERN HEALTHCARE (June 26, 2019), www.modernhealthcare.com/politics-policy/theres-push-slow-down-required-ehr-pdmp-integration.

¹¹¹ The Department of Health, *Overview of the Fifth Community Pharmacy Agreement*, AUSTRALIAN GOVERNMENT (2015), <https://www1.health.gov.au/internet/main/publishing.nsf/Content/fifth-community-pharmacy-agreement>.

¹¹² *National Pharmaceutical Drug Misuse Framework for Action (2012-2015)*, AUSTRALIAN GOVERNMENT (2013).

efforts to implement ERRCD nationally have been slow: currently, only Tasmania has a functioning PDMP with several states announcing their own PDMPs.¹¹³ Australia has committed to funding ERRCD at the same time that another significant HIT initiative is underway: the relaunch of a national EHR called My Health Record.¹¹⁴

Although Australian policymakers have identified establishing a PDMP as a national priority, the Australian government has yet to move beyond the Tasmanian demonstration. As envisioned, ERRCD would provide a secure means of communication for prescribers, pharmacists, and regulators to “make a decision on whether to prescribe or dispense or provide alternative healthcare support” to an individual patient.¹¹⁵ To realize this ideal, it will require careful thinking about establishing trust with patients and providers, creating consistent policies across jurisdictions, and ensuring harmony with other HIT public policy initiatives.

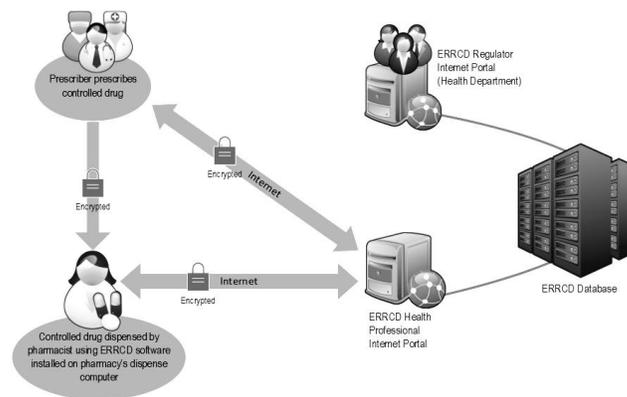


Figure 1. How ERRCD will operate (Pharmacy Guild of Australia)¹¹⁶

V. RECOMMENDATIONS FOR AUSTRALIA

Given its experience with My Health Record, Australia should consider carefully how to implement the next phase of its HIT deployment, using

¹¹³ Kate McDonald, *Real-time Prescription Monitoring Needs to get Real*, PULSE+IT (March 31, 2017), <https://www.pulseitmagazine.com.au/blog/3676-real-time-prescription-monitoring-needs-to-get-real>; see also Felter, *supra* note 78 (noting the lack of progress in expanding the pilot in Tasmania nationwide).

¹¹⁴ G. Hunt, *Media Release: National Approach to Prescription Drug Misuse*, MINISTRY FOR HEALTH (2017).

¹¹⁵ The Pharmacy Guild of Australia, *Electronic Recording and Reporting of Controlled Drugs (ERRCD)*, AUSTRALIAN GOVERNMENT (June 2015), https://www.guild.org.au/__data/assets/pdf_file/0011/6131/factsheet-electronic-recording-and-reporting-of-controlled-drugs-errcd.pdf.

¹¹⁶ *Id.*

PDMPs specifically for the purpose of monitoring and analyzing the prescribing and dispensing of opioids. The following are broad recommendations that Australia could learn from the American experience so far but tailor to its own political and culture environment.

A. Effect on harm reduction

Australian policymakers should carefully consider what type of agency will be responsible for hosting and monitoring the PDMP and the processes for alerting law enforcement or licensing boards in the case of suspicious activity. Australia generally has approached substance misuse policy from a “harm reduction” model in a bipartisan way while the United States has vacillated between public health and “law and order” approaches.¹¹⁷

Some observers have criticized PDMPs as being overly “legalistic” and capable of being used as a tool for law enforcement to monitor both patients and providers.¹¹⁸ As aforementioned, there are concerns that PDMPs in the United States have led to a “chilling effect” on physicians prescribing or patients seeking opioids because they believe that law enforcement agencies could use the PDMP data as part of a criminal investigation.¹¹⁹

B. Consistency across jurisdictions

Both the United States and Australia use a federal model of governance where power is divided between a national government and the states. As noted, American PDMPs vary in how they operate from state to state, including whether the state mandates prescribers to participate in a PDMP.¹²⁰ The Trump administration has called for transitioning from state PDMPs to “a nationally interoperable Prescription Drug Monitoring Program network.”¹²¹

Similarly, there could be inconsistency across Australia if the states cannot agree on uniform processes—how PDMP data is used, what agencies could use the data—for their PDMPs.¹²² One strategy to encourage uniformity would be for the Australian government to tie any financial

¹¹⁷ Kovitwanichkanont, *supra* note 75.

¹¹⁸ Islam, *supra* note 102.

¹¹⁹ *Id.* at 2-3.

¹²⁰ *Id.*

¹²¹ The White House, *President Donald J. Trump’s Initiative to Stop Opioid Abuse and Reduce Drug Supply and Demand* (2018), <https://www.whitehouse.gov/briefings-statements/president-donald-j-trumps-initiative-stop-opioid-abuse-reduce-drug-supply-demand/>. *But see* Darius Tahir, *Federal Mandate to use Opioid Data-Sharing Technology Angers States*, POLITICO (Apr. 12, 2019), <https://www.politico.com/story/2019/04/12/opioid-data-sharing-angers-states-1320532> (discussing a new requirement in the 2019 funding cycle to use a specific data-sharing technology).

¹²² *Supra* Section IV-B (discussing variation among state PDMPs in the United States).

support to the states and territories in exchange for their adoption of certain standard PDMP practices and policies.

C. An overabundance of HIT initiatives?

One final concern should be how PDMPs—whether national or state by state—will overlap with Australia’s already ambitious HIT agenda. The United States encouraged its healthcare sector to digitize through financial incentives for meaningfully using EMRs, and Australia plans to finalize a relaunch of its national EMR by the final quarter of 2018. One of the goals of My Health Record is to help identify and deal with public health emergencies by identifying trends in data, which ERRCD would do in a narrower capacity for controlled substances.

Whether My Health Record is effective remains to be seen, but the potential policy and political interactions between My Health Record and ERRCD should be carefully considered based on the American experience. First, American physicians have complained about the administrative burdens caused by using PDMPs¹²³ on top of existing concerns with EHR systems generally. To add two HIT systems—particularly if one system is run by the states and the other by the national government—could be administratively challenging for many healthcare practices. Given the seriousness of the opioid epidemic, policymakers should think through the appropriate processes for health professionals to comply with both My Health Record and ERRCD.¹²⁴

Second, some stakeholders are concerned that PDMPs may create a “chilling effect” on physicians scripting for opioids in appropriate circumstances, particularly when stakeholders fear law enforcement agencies’ use of PDMP data.¹²⁵ In Australia, there was concern and confusion whether law enforcement agencies could access My Health Record and search the electronic records without consent.¹²⁶ Although the government

¹²³ Vestal, *supra* note 93.

¹²⁴ Islam, *supra* note 102, at 4 (noting that “PDMP consultation may create additional time pressure on physicians” and thus may require “making the databases more convenient for physicians that include real-time data provision, easy recovery of forgotten passwords and easy navigation to the web portal”).

¹²⁵ Haffajee, *supra* note 92, at 891-92 (noting that as a way of avoiding use of a PDMP, providers could instead “simply decline to prescribe opioids, raise prescribing thresholds, refer patients elsewhere, or substitute to non-monitored drugs—all of which could compromise appropriate symptom management”).

¹²⁶ Paul Karp, *Police Can Access My Health Record Without Court Order, Parliamentary Library Warns*, THE GUARDIAN (July 24, 2018), <https://www.theguardian.com/australia-news/2018/jul/25/police-can-access-my-health-record-without-court-order-parliamentary-library-warns>; Stilgherrian, *Tens of Thousands opt out of My Health Record, but can Immigration and Local Councils View the Rest?*, ZDNet (July 17, 2018), <https://www.zdnet.com/article/tens-of-thousands-opt-out-of-my-health-record-but-can-immigration-and-local-councils-view-the-rest/> (theorizing

denied the possibility of such a situation,¹²⁷ this public outcry prompted the Australian health minister to amend the authorizing statute to clarify the need for a warrant.¹²⁸ Setting up another database with prescription drug information could prompt similar public outrage over patient privacy.

CONCLUSION

The use of information technology can be a boon for public health agencies in their surveillance work, but it is important for policymakers and health officials to recognize that it is just a tool, not the magic bullet, for public health improvement. Technology itself must be constantly monitored and updated because while public health surveillance can be aided by the use of technology, it certainly is not foolproof: as aforementioned, using Google searches helped to predict flu outbreaks,¹²⁹ but researchers discovered that the initial program had some design flaws that resulted in shuttering it and designing a new algorithm.¹³⁰ Further, it must be implemented in conjunction with other key considerations to encourage acceptance among the patient and provider community and allay fears about privacy and security.

Against these generalizations, countries can share lessons learned in the use of HIT for public health surveillance particularly in the critical area of reducing opioid misuse despite differences in health law and policy and political culture. Australia's nationwide effort to implement My Health Record demonstrated the legal, policy, and political challenges that can arise from the deployment of government-operated information technology used to collect, store, and analyze personal health data. The United States is unlikely to adopt a similar proposal as it is unlikely to be politically acceptable and could be legally challenging, and the fragmented nature of the American healthcare system makes it difficult to centralize health information. However, its experiences with PDMPs should be studied by Australia as it goes forward in developing its own state and national policies and laws in hopes of curbing its opioid challenges and preventing them from becoming as damaging as the American epidemic.

that potential agencies that could gain access could “encompass almost any government body, from senior ministers and their departments, down through state-level organisations [sic], to local governments”).

¹²⁷ Australian Digital Health Agency, *Fact Sheet: Police Access to My Health Record*, MY HEALTH RECORD (July 21, 2018), <https://www.myhealthrecord.gov.au/news-and-media/my-health-record-stories/fact-sheet-police-access-my-health-record>.

¹²⁸ *My Health Records Act 2012* (Cth) S 69A (Austl.); Cailyn Gribbin, *My Health Record: Greg Hunt Bows to Pressure, Announces Changes to Address Privacy Concerns*, ABC NEWS (July 31, 2018), <https://www.abc.net.au/news/2018-07-31/court-order-needed-for-my-health-record-greg-hunt-says/10058544>.

¹²⁹ Yom-Tov, *supra* note 2.

¹³⁰ David Lazer & Ryan Kennedy, *What We Can Learn from the Epic Failure of Google Flu Trends*, WIRED (Oct. 1, 2015), <https://www.wired.com/2015/10/can-learn-epic-failure-google-flu-trends/>.

