

Representation of marginalised populations in digital surveillance for notifiable conditions in Australia: a systematic review

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Abstract

Aim: This study aims to establish whether digital surveillance methods for notifiable diseases in Australia collect and report data in relation to marginalised populations.

Methods: The literature was systematically reviewed to identify primary research studies published between January 2005 and July 2023. Studies were included if they described an Australian digital surveillance system for notifiable conditions. The results were synthesised with a focus on evaluating the collection and reporting of data in relation to marginalised populations.

Results: A total of 13 articles reporting on seven surveillance systems were identified. Influenza and adverse events following immunisation were the two most common notifiable conditions monitored. A total of six surveillance systems encompassing 16 articles reported information on sub-populations. Of these, three surveillance systems (nine articles) included data on marginalised populations.

Conclusion: The data collected or reported in relation to sub-groups that characterise diversity in terms of health care needs, access, and marginalised populations are minimal. It is recommended that a set of equity and reporting principles is established for the future creation and use of any digital surveillance system.

INTRODUCTION

Infectious diseases create significant health and economic burden globally including Australia, as highlighted by the COVID-19 pandemic. As of July 2023, there have been over 11.5 million cases and over 20,000 deaths in Australia due to the novel coronavirus.¹ In addition to COVID-19, three other diseases accounted for the vast majority of Australia's notifiable disease reports in 2022: influenza with 233,369 notifications, respiratory syncytial virus with 95,776 notifications, and chlamydia with 94,222 notifications.² Prior to the pandemic, annual expenditure on all infectious diseases in Australia was reported as roughly \$7.52 billion.³ In 2021, the Australian government spent \$7.9 billion on specific COVID-19 health programmes alone.⁴

Timely and comprehensive surveillance of infectious diseases is essential for targeted public

health response and prevention efforts. Currently, infectious diseases are monitored in Australia via the National Notifiable Diseases Surveillance System (NNDSS).⁵ Over 70 conditions are legally required to be reported to this system by doctors and laboratories, encompassing gastrointestinal diseases, sexually transmissible infections and blood-borne viruses (BBVs), respiratory diseases, vaccine-preventable diseases, zoonoses, vector-borne diseases, and other diseases.^{2,5} There are also a number of other surveillance systems within Australia which collect additional data to enhance public health response, such as the New South Wales (NSW) Public Health Rapid, Emergency, Disease, and Syndromic Surveillance system which monitors unplanned visits to emergency departments and emergency triple zero calls (000), to detect any unusual emerging patterns in syndromes often related to infectious pathogens.⁶

Recently, novel methods of surveillance utilising digital technologies have emerged to complement existing methods of surveillance. This includes the use of monitoring social media data,⁷⁻⁹ and Google trends with machine learning methods,^{9,10} as well as the use of electronic medical records,¹¹ to predict disease outbreaks. Surveillance using these types of data provides benefits over traditional data sources in that they are generally publicly available and early work has shown they can provide timelier detection of some disease outbreaks.⁹

Analysis of global data has clearly linked poverty, inequality, marginalisation, and other barriers to healthcare with infectious disease burden.^{12,13} If implemented inequitably, digital health technologies can further increase health disparities in marginalised populations.^{14,15} This has been shown in Black communities across North America, UK, and Italy due to limited application of eHealth initiatives, and for those who live in rural areas due to limited access as a result of restricted Internet broadband coverage.¹⁵ Being an older adult (over the age of 40 years), having low income, and having low levels of education have also been identified as barriers to acquiring and understanding how to use digital health technologies.¹⁵ With the continuing adoption of digital health systems into Australian public health, the importance of limiting the disparity in marginalised populations such as Aboriginal and Torres Strait Islander people, elderly populations, and culturally and linguistically diverse (CALD) populations is evident. As there is very limited research on this in Australia, this study aims to establish whether digital surveillance methods for notifiable diseases in Australia collect and report data in relation to marginalised populations which will establish a benchmark and enable future assessment of whether these technologies improve health or create further marginalisation.

METHODS

Search strategy

The methods used in this review were developed in line with the Preferred

Reporting Items for Systematic Reviews and Meta-Analyses guidelines.¹⁶ The initial search of peer-reviewed published literature was conducted in PubMed (Medline), EMBASE, and CINAHL in January 2022. A secondary search of the literature was conducted on the 13th of June 2023 to identify additional studies published after January 2022. Initial search terms included digital health, surveillance, communicable diseases, and Australia. 'SARS-CoV-2'[Mesh] and 'COVID-19'[Mesh] were added to the secondary search. The full search strategy is available in Supplemental Appendix 1. All reference lists of all eligible studies were checked for additional studies for inclusion.

Inclusion and exclusion criteria

Studies were included if they met the following criteria:

- Described an Australian digital surveillance system, defined as systems which utilised data from social network sites (e.g. Facebook), content sharing websites (e.g. YouTube), search data (e.g. Google), blogs and forums (e.g. Reddit) and digital polls, or studies that utilised novel methods of digital analysis, specifically machine learning methods.
- Notifiable conditions were defined as any condition reportable to the NNDSS.⁵
- Full-text articles in English language.
- Were published between January 2005 and July 2023.

Studies were excluded if they met the following criteria:

- Surveillance was specific to a population group (i.e. healthcare workers).
- Described the methods of the system only, without reporting results.
- Compared the surveillance system to another system or evaluated the system without reporting results of the surveillance system.

Screening

The titles and abstracts of articles identified through the search were

extracted and uploaded to the systematic review software Covidence. Two authors (AD and ND) independently screened the titles and abstracts. The same authors reviewed full-text articles to assess their eligibility against the inclusion criteria. Reference lists from all included studies were examined to identify additional eligible studies. Any conflicts were resolved through discussion and consensus between the authors.

Data extraction and synthesis

Extraction of data was completed by one author (NDK) and cross-checked by a second author (AD) using a standard extraction form. Fields extracted included condition under surveillance, data used, study period, objective, location, sample size, overall results, study design, recruitment methods, and if any data were reported on subpopulation as well as marginalised populations specifically. Information regarding data or trends in marginalised populations was a key field for extraction to allow for an overall assessment of the equity of digital surveillance systems. Marginalised populations were defined as 'highly vulnerable populations that are systemically excluded from national or international policy making forums'.¹⁷ This includes, but is not limited to, Aboriginal and Torres Strait Islander people, elderly people, CALD populations, refugees, and sexual minorities.¹⁸

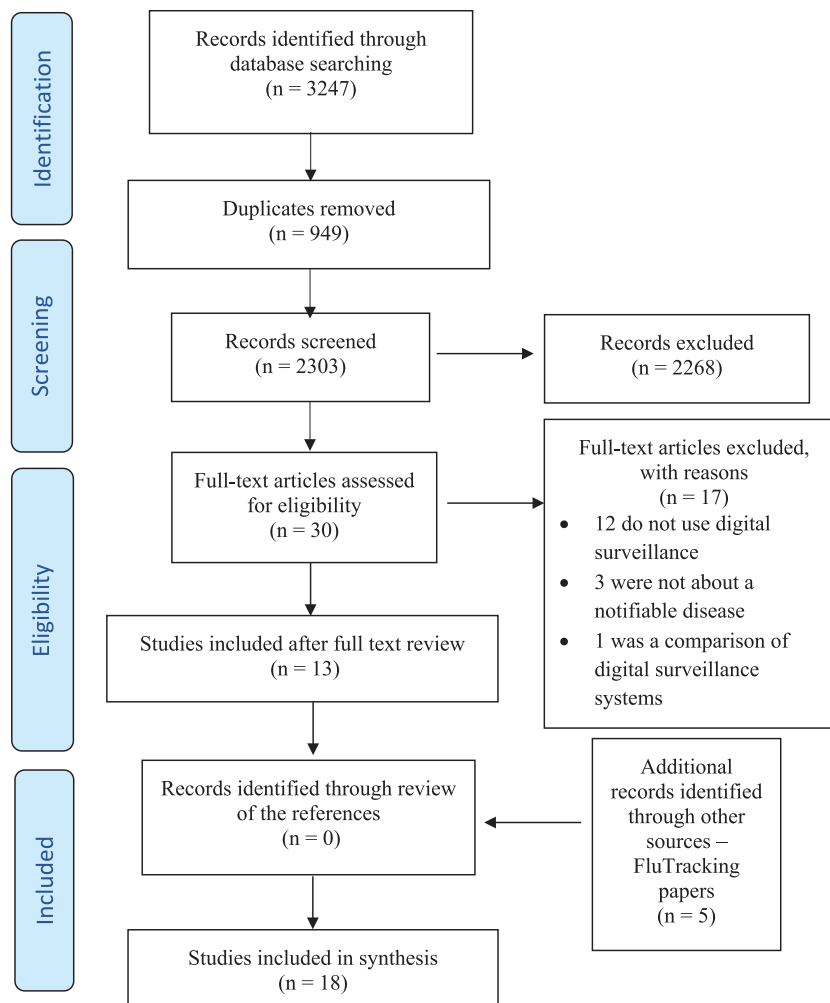
Data were formulated into tables to summarise and describe the study characteristics, as well details reported about marginalised populations within the surveillance systems.

RESULTS

A total of 3247 articles were identified from the initial search strategy, with 949 articles removed as duplicates. Screening of title and abstracts identified 35 articles for full-text review. Of these, 13 met the inclusion criteria, with 0 additional articles identified through a review of the reference lists of included articles (Figure 1). Only four of the nine available annual FluTracking reports were identified through the search. The

Figure 1.

PRISMA flowchart.



Note: PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

remaining five FluTracking articles were sourced from the Australian Government Communicable Disease Intelligence website,¹⁹ bringing the total number of included articles to 18.

The secondary search strategy including COVID-19-related documents yielded 792 articles, with 288 duplicates removed. Screening of title and abstracts identified eight articles for full-text review; however, none of these met the inclusion criteria.

A total of seven surveillance systems were studied across the 18 included articles. Nine articles correlate to the FluTracking system, with studies conducted from 2006 to 2018.^{20–28} One study correlates to the use of Twitter as a

potential surveillance system, conducted in 2015.²⁹ One study correlates to the SmartVax system and was conducted in 2013.³⁰ Two articles correlate to the FASTmum programme, both studies conducted in 2013.^{31,32} The VaxTracker system has two associated studies conducted in 2013 and 2017.^{33,34} Two studies conducted in 2015 correlate with the AusVaxSafety programme.^{35,36} The final surveillance system is the STARSS system which has one associated study conducted in 2017.³⁷ Overall, the time period for included articles ranged from 2006 to 2018, with the majority of studies conducted from 2013 onwards (72%). This is likely as a direct result of the creation of five of the seven

surveillance systems after the 2010 incident in which a particular brand of influenza vaccine caused an increase in febrile reactions (including febrile convulsions) in Australian children.^{30,32,33,35–37}

Data extraction identified influenza ($n = 10$)^{20–29} and adverse events following immunisation (AEFI; $n = 8$)^{30–37} as the two most common notifiable conditions monitored using digital methods for surveillance in Australia. A total of 16 of the 18 articles had influenza, influenza-like-illness, or response to the influenza vaccine as their surveillance topic.^{20–33,35,36} The two studies that were not associated with influenza included the VaxTracker study conducted in 2016

regarding AEFI from the pneumococcal polysaccharide vaccine in the elderly³⁴ and the STARSS study analysing AEFI from any vaccine.³⁷ Seven studies were conducted nationally,^{23–29} and of the remaining 11 studies conducted in individual states, most collected data from digital surveillance systems implemented in health practices located in NSW ($n=8$), Western Australia (WA; $n=6$), and South Australia (SA; $n=4$).^{20–22,30–37} The vast majority of included studies ($n=17$) collected data from participants via online surveys linked through Short Message Service (SMS) or email, or direct response to SMS.^{20–28,30–37} The one remaining study collected data from an algorithm monitoring geo-tagged tweets (see Table 1).²⁹

A total of six surveillance systems (all except Twitter) encompassing 16 studies reported information on sub-populations.^{20,22–28,30–37} Of these, three surveillance systems (FluTracking, FASTmum, and AusVaxSafety) encompassing nine studies included data on marginalised populations.^{23–28,32,35,36} The FluTracking annual surveillance reports initially stratified data according to age, state/territory, vaccination status, and whether participants worked with patients.^{20,22} From 2012 to the most recent report, other socio-demographic characteristics have been incorporated including sex, highest educational level attained, and Aboriginal and Torres Strait Islander identity.^{23–28} A separate FluTracking report specific to data collected from Indigenous Australian participants was published in 2019 analysing trends in fever and cough rates and vaccination rates since 2012.³⁸ This information was not included in the annual reports.

Of the five digital health surveillance systems monitoring AEFI, the FASTmum programme³² and the AusVaxSafety programme^{35,36} were the only ones to report and analyse data collected from Aboriginal and Torres Strait Islander participants. The initial FASTmum article did not collect socio-demographic characteristics apart from age.³¹ However, the following year an Aboriginal and Torres Strait Islander status question was added to the survey and data on

response rate to SMS versus phone interview were analysed and stratified according to ethnicity.³² The AusVaxSafety programme (which encompasses STARSS, VaxTracker, and SmartVax surveillance systems) also collected data on Aboriginal and Torres Strait Islander status; however, it did not further analyse or report this within the initial study.³⁵ The following AusVaxSafety study analysed fever rates in Aboriginal and Torres Strait Islander participants compared to non-Indigenous participants, but did not analyse these data in accordance with other sub-populations included, such as age, sex, underlying medical conditions, and whether or not medical attention was sought.³⁶ VaxTracker was the only subset of AusVaxSafety that reported including a question on Aboriginal and Torres Strait Islander identity on their survey, however, did not report any findings in their results (see Table 2).³⁴

Four of the nine studies, three of which are associated with FluTracking and one with AusVaxSafety, identified the percentage of participants with incomplete surveys.^{23,26,27,35} Of the FluTracking articles, approximately half (54.8%) of participants answered the question on Aboriginal and Torres Strait Islander status in 2012, when the question was first incorporated into the survey.²³ In 2016, 87.4% of participants had a complete survey,²⁶ rising to 92.3% in 2017.²⁷ Aboriginal and Torres Strait Islander representation by 2018 made up 1.6% of FluTracker's sample population.²⁹ The 2015 AusVaxSafety article reported that 24.5% of participants did not answer the ethnicity question; however, the percentage of participants who identified as Indigenous was 4.7%.³⁵ It is unclear if the 2015 AusVaxSafety study recorded responses of other ethnicities apart from 'Indigenous'. No other article included in this study recorded data on CALD populations.

DISCUSSION

This review identified that there are a number of surveillance systems within Australia for notifiable diseases utilising digital methods, which appears to be increasing over time. In our study, the

two main notifiable conditions currently monitored using these methods are influenza and AEFI.^{20–37} Half of the studies identified reported some information in relation to Aboriginal and Torres Strait Islander identity for the population.^{23–28,32,35,36} Almost all articles reported data in relation to some specific demographics including age, sex, and education.^{20,22–28,30–37} Despite this, the data collected or reported in relation to sub-groups that characterise diversity in terms of health care needs, access, and marginalised populations are minimal.

The majority of digital surveillance for notifiable conditions in Australia focuses on influenza and adverse events following the influenza vaccination.^{20–33,35,36} This is consistent with global literature with most digital surveillance systems for communicable diseases focusing on influenza.³⁹ Epidemics of influenza occur annually, with vaccination for some groups recommended each year. The constantly evolving nature of the spread of disease and vaccination uptake makes influenza a useful case study for this type of surveillance. This has also been the case with COVID-19, which is a constantly evolving public health situation requiring surveillance and occurred concurrently with the development of new methodologies in disease surveillance. While not captured in this review, a number of digital surveillance tools were utilised in the public health response to COVID-19 in Australia. The COVID-Safe App was implemented in Australia to assist with contact tracing,⁴⁰ and within Queensland a number of digital aspects were incorporated into the response including the Queensland response Digital Corona Virus Application and integrating data from both private and public pathology laboratories into a data lake.⁴¹ These types of examples used in the field were not included in this study as their descriptions and results are not recorded in published research articles. This is a significant limitation of our study as many developing systems that should meet our inclusion criteria may only be documented in grey literature as yet.

Approximately, half of the studies across this review, encompassing three

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Table 1.

Characteristics of included studies.						
Study ID – reference number	Time period	Surveillance topic	Sample size	Study design	Location	Data used
Dalton 2009 – 20	June–October 2006, June–October 2007, May–October 2008	FluTracker – Influenza	2006 – 394 2007 – 982 2008 – 4827	Surveillance system	2006-07 Hunter New England region of NSW 2008 – nation-wide	Weekly online questionnaires linked via email
Carlson 2009 – 21	June–October 2007	FluTracker – Influenza	982 participants according to FLU-1		NSW	Weekly online questionnaires compared to weekly counts of positive influenza A antigen tests from NSW Department of Health Notifiable Diseases Database
Dalton 2011 – 22	May 2009–October 2010	FluTracker – Influenza	12,603	Surveillance system	NSW, WA, SA, NT, ACT, Tasmania	Weekly online questionnaires linked via email
Carlson 2013 – 23	May–October 2011, May–October 2012	FluTracker – Influenza	2011 – 13,101 2012 – 16,046	Surveillance system	All states and territories in Australia	Weekly online questionnaires linked via email
Dalton 2015 – 24	April–October 2013, May–October 2014	FluTracker – Influenza	2013 – 18,440 2014 – 20,087	Surveillance system	All states and territories in Australia	Weekly online questionnaires linked via email
Dalton 2016 – 25	April–October 2015	FluTracker – Influenza	27,828	Surveillance system	All states and territories in Australia	Weekly online questionnaires linked via email
Carlson 2019 – 26	May–October 2016	FluTracker – Influenza	30,998	Surveillance system	All states and territories in Australia	Weekly online questionnaires linked via email
Moberley 2019 – 27	April–October 2017	FluTracker – Influenza	33,947	Surveillance system	All states and territories in Australia	Weekly online questionnaires linked via email
Howard 2022 – 28	April–October 2018	FluTracker – Influenza	45,532	Surveillance system	All states and territories in Australia	Weekly online questionnaires linked via email
Zhang 2017 – 29	2015	Geo-tagged tweets – Influenza	N/A		Australia	Tweets geo-tagged for Australia found through authors' algorithm to be ILI-related
Leeb 2014 – 30	11 November 2011–10 June 2013	SmartVax – AEFI from any vaccine	2432		Perth, WA	Response to SMS or email

(Continued)

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Table 1. (Continued)

Characteristics of included studies.						
Study ID – reference number	Time period	Surveillance topic	Sample size	Study design	Location	Data used
Regan 2014 – 31	March–July 2013	FASTmum – AEFI from influenza vaccine	3173		WA	Response to SMS compared to phone calls
Regan 2015 – 32	16 March–22 May 2013	FASTmum – AEFI from influenza vaccine	2011	RCT	WA – metropolitan and rural areas	Response rate to SMS compared to phone calls, and data collected from link to online survey via SMS
Cashman 2014 – 33	21 March–30 June 2013	VaxTracker – AEFI from influenza vaccine	290	Surveillance system	Northern NSW – Newcastle metropolitan and Tamworth rural populations	Survey data linked via email or text message
Pillsbury 2015 – 34	1 April–31 August 2015	AusVaxSafety – AEFI from influenza vaccine in children	3340		NSW, VIC, SA, and WA	Data collected from SMS or email with link to smartphone survey (SmartVax) or web-based survey (VaxTracker)
Pillsbury 2017 – 35	1 April–31 August 2015 1 April–4 September 2015	AusVaxSafety – AEFI from influenza vaccine in children	7402		NSW, VIC, SA, and WA (Based on 2015 article. No mention of location in this article)	Data collected from SMS or email-based survey via SmartVax, VaxTracker, or STARSS programmes
Munnoch 2019 – 36	February 2016–December 2017	VaxTracker – AEFI from pneumococcal polysaccharide vaccine in elderly	4725		Newcastle, NSW	Data collected from link to surveys sent via email or SMS
Gold 2020 – 37	September 2015–December 2017	STARSS – AEFI from any vaccine	6338	RCT	SA, NSW	Data collected from initial responses to SMS Data collected from telephone interview versus online report

ILI = influenza-like-illness; SMS = Short Message Service; AEFI = adverse events following immunisation; RCT = randomised controlled trial; NSW = New South Wales; WA = Western Australia; SA = South Australia; ACT = Australian Capital Territory; NT = Northern Territory; VIC = Victoria.

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Table 2.

Data reported within included studies.			
Study ID – reference number	Objective	Data reported on sub-populations	Data reported on marginalised populations
Dalton 2009 – 20	(1) Ascertain FluTracking ability to detect influenza activity and confirm vaccine effectiveness by comparing ILI syndrome rates between vaccinated and unvaccinated groups. (2) Ascertain whether influenza activity is detected earlier by FluTracking compared to other surveillance practices.	Age State/territory Vaccination status Working patients	None
Carlson 2009 – 21	Validate correlation of NSW 2007 FluTracking data with NSW data for lab-confirmed influenza	None	None
Dalton 2011 – 22	(1) Confirm vaccine effectiveness early in the season by comparing rates of ILI in vaccinated versus unvaccinated participants. (2) Use the surveillance data to compare timing, incidence, and severity of influenza over the years.	Age State/territory Vaccination status Working with patients	None
Carlson 2013 – 23	As above – with a third objective to collect data on participants' health-seeking behaviours	Age Sex State/territory Highest level of educational attainment (if 15 or older) Vaccination status Working with patients	Aboriginal and Torres Strait Islander identity added in 2012
Dalton 2015 – 24	As per Dalton 2011	Age Sex State/Territory Highest level of educational attainment (if 15 or older) Vaccination status Working with patients	Aboriginal and Torres Strait Islander identity
Dalton 2016 – 25	As per Dalton 2011	Age Sex State/territory Highest level of educational attainment (if 15 or older) Vaccination status Working with patients	Aboriginal and Torres Strait Islander identity
Carlson 2019 – 26	As per Dalton 2011	Age Sex State/territory Highest level of educational attainment (if 15 or older) Vaccination status Working with patients	Aboriginal and Torres Strait Islander identity

(Continued)

Table 2. (Continued)

Data reported within included studies.			
Study ID – reference number	Objective	Data reported on sub-populations	Data reported on marginalised populations
Moberley 2019 – 27	As per Dalton 2011	Age Sex State/territory Highest level of educational attainment (if 15 or older) Vaccination status Working with patients	Aboriginal and Torres Strait Islander identity
Howard 2022 – 28	As per Dalton 2011 – with a third objective to compare ILI consultation rates from ASPREN with the percentage of participants with ILI who visited a general practitioner	Age Sex State/territory Highest level of educational attainment (if 15 or older) Vaccination status Working with patients	Aboriginal and Torres Strait Islander identity
Zhang 2017 – 29	To assess whether Twitter can be used as a means for public health surveillance. Study specifically addresses influenza.	None	None
Leeb 2014 – 30	Performance assessment of SmartVax in response rate to, and timeliness of, SMS texts to detect AEFI postinfluenza vaccine in adults and children	Sex Age Response to SMS Response time	None
Regan 2014 – 31	Implementation of a real-time safety monitoring programme (FASTmum) for AEFI from TIV administered to pregnant women using SMS	Age Vaccination provider Trimester of pregnancy Response to SMS Type of AEFI	None
Regan 2015 – 32	Follow-up study for the FASTmum programme comparing response rate, adverse events reported, and timeliness of obtaining this information between SMS and phone call for pregnant women who had recently received TIV	Age Residence Trimester of pregnancy SES Type of vaccine Response to SMS Type of AEFI Medical attention sought	Aboriginal or Torres Strait Islander identity, response rate to SMS, and response to telephone interview

(Continued)

Table 2. (Continued)

Data reported within included studies.			
Study ID – reference number	Objective	Data reported on sub-populations	Data reported on marginalised populations
Cashman 2014 – 33	To report on the performance of the VaxTracker system in detecting AEFI in children after receiving the inactivated influenza vaccine during the 2013 influenza season	Age Sex Response rate Type of vaccine Type of AEFI Medical attention sought	None
Pillsbury 2015 – 34	To monitor the safety of different influenza vaccine brands in children aged 6 months to 4 years using the AusVaxSafety SMS-based surveillance system during the 2015 influenza season	Age Sex Underlying medical conditions Type of vaccine and if concomitant vaccines received Type of AEFI Medical attention sought	Aboriginal or Torres Strait Islander identity
Pillsbury 2017 – 35	To monitor the safety of different influenza vaccine brands in children aged 6 months to 4 years using the AusVaxSafety SMS-based surveillance system during the 2015 and 2016 influenza seasons	Age Sex Underlying medical conditions Type of vaccine and if concomitant vaccines received Type of AEFI Medical attention sought	Aboriginal or Torres Strait Islander identity, and type of AEFI experienced
Munnoch 2019 – 36	Using VaxTracker to monitor AEFI in patients aged 55–61 years enrolled in the Australian Study for the Prevention through the Immunisation of Cardiovascular Events trial who received the pneumococcal vaccine	Age Sex Response rate Type of AEFI Medical attention sought	Survey included Aboriginal or Torres Strait Islander identity, but this was not reported in results
Gold 2020 – 37	Evaluate efficacy of monitoring AEFI for any vaccination on the Australian Immunisation Schedule through SMS using the STARSS programme	Age Sex Index of Relative Socioeconomic Advantage and Disadvantage quintile Type and number of vaccines administered Type of AEFI Medical attention sought	None

ILI = influenza-like-illness; ASPREN = Australian Sentinel Practice Research Network; SMS = Short Message Service; AEFI = adverse events following immunization; TIV = trivalent influenza vaccine; NSW = New South Wales; SES = Socioeconomic status.

of the seven surveillance systems, reported data on Aboriginal and Torres Strait Islander Australians.^{23–28,32,35,36} However, completeness and representativeness of these data in some instances were identified as an issue.^{24,27,28,36} The FluTracking system has collected data on Aboriginal and/or Torres Strait Islander identity since 2012, although the number of participants was not large enough to be representative of the Aboriginal and Torres Strait Islander population.²⁴ The completeness of data has improved over time, increasing to 92.3% in 2017.²⁸ However, the proportion of participants identifying as Aboriginal and/or Torres Strait Islander remains low (approximately 1.6%) compared with 3.3% of the Australian population.²⁹ FluTracking credits the high completeness of the data with a small minimum data requirement. This means, only a few variables are collected from participants at registration, with a clear purpose for the collection of each field.⁴²

The inclusion of data in relation to Aboriginal and Torres Strait Islander Australians is important for surveillance systems to ensure that responses can be appropriately targeted where needed. Australia's Indigenous Digital Inclusion Plan, which seeks to provide all Australians with equal access to Internet, technology, and information, identifies that Aboriginal and Torres Strait Islander's level of digital inclusion is 7.9 points below the national score.⁴³ This score compares the level to which people are considered digitally included at an individual level.⁴³ There is a high rate of mobile phone use within the Aboriginal and Torres Strait Islander population⁴⁴; however, less access to^{44,45–47} and affordability of digital systems and technologies compared to non-Indigenous Australians are key contributors to this inequity.^{43,45} Hence, levels of digital literacy,^{43,45} as well as age and education level,⁴⁸ can impact recruitment into use of digital surveillance systems or technologies. Making systems accessible and culturally appropriate is necessary for the inclusion of Aboriginal and Torres Strait Islander people.

As noted earlier, there are also issues with the completeness of data as well as

variations in reporting. For example, in notifiable disease data there is still great variation in completeness across states and territories.⁴⁹ There are also additional requirements for the creation and use of any digital surveillance system when collecting and reporting Aboriginal and Torres Strait Islander data. System design should address the importance of data sovereignty, which is 'the right of Aboriginal and Torres Strait Islander peoples, communities and organisations to maintain, control, protect, develop, and use data'.⁵⁰ As well, systems should be co-designed with Aboriginal and Torres Strait Islander community representatives, with results being reported back to the community openly.

Despite these challenges, evidence suggests that digital health interventions can be effective and beneficial in marginalised populations.^{51,52} This evidence, coupled with a disproportionate impact from communicable diseases,⁵³ means that funded and accessible digital health surveillance programmes are an important aspect to lessen digital health inequity. Some programmes are currently attempting to address this disparity. For example, the ATLAS Indigenous primary care surveillance network aims to monitor the STI and BBV burden in Aboriginal and Torres Strait Islander populations across Australia.⁵⁴ This network is partnered with the Aboriginal Community-Controlled Health Organisation sector and was designed to address the disparity in testing, treatment, and management of sexually transmissible infections and blood borne viruses, but as yet only a methods article has been published.⁵⁵

There are a number of other marginalised groups who are also important to consider in infectious disease surveillance. These include those who are homeless and older individuals, both groups disproportionately affected by communicable diseases and recommended to receive annual influenza vaccination.⁵⁵ The majority of studies in this review collected and reported information in relation to age of participants.^{20,22–28,30–33,35,36} However, no studies collected or reported data on homelessness, CALD, or other marginalised populations. Historically, surveillance of diseases within homeless

populations is challenging as this information is generally not recorded in data collection systems.⁵⁶ One aspect of digital technology which is showing promise to assist with surveillance in homeless populations is data linkage.⁵⁷ However, this has not yet been used for communicable disease surveillance. There are further challenges for data collection as participation in digital reporting would require a phone or computer and homeless individuals have reduced access to digital technology.⁵⁸ Despite the challenges, the importance of surveillance to identify how best to target public health interventions remains. Further investigation into how these barriers can be overcome is warranted.

There are several limitations to this study which need to be considered in the interpretation of the findings. We restricted publications to those in English; however, as the aim was to investigate this issue in the Australian context it is unlikely that relevant articles were not included due to language. We did not incorporate grey literature into our search, which may have resulted in publication bias. There may be systems operating in Australian Health Departments which have not been part of research studies or publications. However, we believe this review provides initial evidence to highlight this issue and a follow-up study engaging the grey literature and health departments would be the next step to further this work.

Overall, there are limited research articles investigating digital surveillance for notifiable conditions in Australia. Incorporating these methods into public health practice is essential, feasible, and provides additional information which can complement existing systems. However, greater focus on the equity of these systems and the need to incorporate data for marginalised populations is essential. Issues of inequity in recruitment, varying levels of digital literacy, matters of privacy and data sovereignty, and the overall accessibility of the digital health system for inclusion of marginalised populations should be addressed, ideally prior to its use. Local data are necessary to make local decisions, and so these data should also be fed back to the communities on

which they impact for further work to be done. Therefore, it is recommended that a set of principles is established for the future creation and use of any digital surveillance system.

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CONFLICT OF INTEREST


The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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SUPPLEMENTAL MATERIAL

Supplemental material for this article is available online.

References

- WHO Health Emergency Dashboard. *WHO (COVID-19) homepage – Australia*. World Health Organization. Available online at: <https://www.health.gov.au/health-alerts/covid-19/case-numbers-and-statistics#COVID19-situation-overview> (updated 12 July 2023; last accessed 12 July 2023)
- National Notifiable Diseases Surveillance System. *National communicable disease surveillance dashboard*. Australian Government Department of Health and Aged Care. Available online at: <https://nindss.health.gov.au/pbi-dashboard/> (updated 13 July 2023; last accessed 13 July 2023)
- Australian Institute of Health and Welfare. *Disease expenditure in Australia 2018–2019*. Australian Government; 2021. Available online at: <https://www.aihw.gov.au/reports/health-welfare-expenditure/disease-expenditure-australia/contents/australian-burden-of-disease-groups> (updated 18 February 2022; last accessed 5 January 2023)
- Australian Institute of Health and Welfare. *Health expenditure*. Australian Government; 2022. Available online at: <https://www.aihw.gov.au/reports/health-welfare-expenditure/health-expenditure> (updated 18 October 2022; last accessed 5 January 2023)
- Australian Government Department of Health and Aged Care. *National Notifiable Diseases Surveillance System (NNDSS)*. Australian Government; 2022. Available online at: <https://www.health.gov.au/our-work/nindss> (updated 19 July 2022; last accessed 5 January 2023)
- NSW Health. *Rapid surveillance using PHREDSS*. NSW Government; 2022. Available online at: <https://www.health.nsw.gov.au/epidemiology/Pages/rapid-surveillance-using-PHREDSS.aspx> (updated 13 April 2022; last accessed 5 January 2023)
- Young SD, Mercer N, Weiss RE *et al*. Using social media as a tool to predict syphilis. *Prev Med* 2018;**109**:58–61.
- Young SD, Rivers C, Lewis B. Methods of using real-time social media technologies for detection and remote monitoring of HIV outcomes. *Prev Med* 2014;**63**:112–5.
- Kogan NE, Clemente L, Liautaud P *et al*. An early warning approach to monitor COVID-19 activity with multiple digital traces in near real time. *Sci Adv* 2021;**7**(10):eabd6989.
- Johnson AK, Bhaumik R, Tabidze I *et al*. Nowcasting sexually transmitted infections in Chicago: predictive modeling and evaluation study using Google trends. *JMIR Public Health Surveill* 2020;**6**(4):e20588.
- Chadwick D, Forbes G, Lawrence C *et al*. Using an electronic health record alert to prompt blood-borne virus testing in primary care. *AIDS* 2021;**35**(11):1845–50.
- Quinn SC, Kumar S. Health inequalities and infectious disease epidemics: a challenge for global health security. *Biosecur Bioterror* 2014;**12**(5):263–73.
- Harris M, Reza JN. *Global report for research on infectious diseases of poverty*. Geneva: World Health Organization; 2012. 184 pp.
- Lawrence K. Digital health equity. In: SL Linwood (ed.) *Digital health*. Brisbane, Australia: Exon Publications; 2022. pp. 121–30.
- Yao R, Zhang W, Evans R *et al*. Inequities in health care services caused by the adoption of digital health technologies: scoping review. *J Med Internet Res* 2022;**24**(3):e34144.
- Page MJ, McKenzie JE, Bossuyt PM *et al*. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Syst Rev* 2021;**10**(1):89.
- O'Donnell P, Tierney E, O'Carroll A *et al*. Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study. *Int J Equity Health* 2016;**15**(1):197.
- Baker K, Adams J, Steel A. Experiences, perceptions and expectations of health services amongst marginalized populations in urban Australia: a meta-ethnographic review of the literature. *Health Expect* 2021;**25**(5):2166–87.
- FluTracking. FluTracking Research (Australia). Australian Government. Available online at: <https://info.flutracking.net/research/australia-research/> (last accessed 5 January 2023)
- Dalton C, Durrheim D, Fejsa J *et al*. FluTracking: a weekly Australian community online survey of influenza-like illness in 2006, 2007 and 2008. *Commun Dis Intell Q Rep* 2009;**33**(3):316–22.
- Carlson SJ, Dalton CB, Tuyl FA *et al*. FluTracking surveillance: comparing 2007 New South Wales results with laboratory confirmed influenza notifications. *Commun Dis Intell Q Rep* 2009;**33**(3):323–7.
- Dalton CB, Carlson SJ, Butler MT *et al*. FluTracking weekly online community survey of influenza-like illness annual report, 2010. *Commun Dis Intell Q Rep* 2011;**35**(4):288–93.
- Carlson SJ, Dalton CB, Butler MT *et al*. FluTracking weekly online community survey of influenza-like illness annual report 2011 and 2012. *Commun Dis Intell Q Rep* 2013;**37**(4):E398–406.
- Dalton CB, Carlson SJ, McCallum L *et al*. FluTracking weekly online community survey of influenza-like illness: 2013 and 2014. *Commun Dis Intell Q Rep* 2015;**39**(3):E361–8.
- Dalton CB, Carlson SJ, Durrheim DN *et al*. FluTracking weekly online community survey of influenza-like illness annual report, 2015. *Commun Dis Intell Q Rep* 2016;**40**(4):E512–20.
- Carlson SJ, Cassano D, Butler MT *et al*. FluTracking weekly online community survey of influenza-like illness annual report, 2016. *Commun Dis Intell* (2018) 2019;**43**. DOI: 10.33321/cdi.2019.43.15.
- Moberly S, Carlson S, Durrheim D *et al*. FluTracking: weekly online community-based surveillance of influenza-like illness in Australia, 2017 annual report. *Commun Dis Intell* (2018) 2019;**43**. DOI: 10.33321/cdi.2019.43.31.
- Howard ZL, Carlson SJ, Moberly S *et al*. FluTracking: weekly online community based surveillance of influenza-like illness in Australia, 2018 annual report. *Commun Dis Intell* 2022;**46**(3):316–22.
- Zhang K, Arablouei R, Jurdak R. Predicting prevalence of influenza-like illness from geo-tagged tweets. In *Proceedings of the 26th International Conference on World Wide Web Companion 2017 (WWW'17)*, Perth, Australia, 3–7 April 2017, pp. 1327–34. Available online at: <https://eprints.qut.edu.au/131715/1/p1327-zhang.pdf>
- Leeb A, Regan AK, Peters IJ *et al*. Using automated text messages to monitor adverse events following immunisation in general practice. *Med J Aust* 2014;**200**(7):416–8.
- Regan AK, Blyth CC, Mak DB *et al*. Using SMS to monitor adverse events following trivalent influenza vaccination in pregnant women. *Aust N Z J Obstet Gynaecol* 2014;**54**(6):522–8.
- Regan AK, Blyth CC, Tracey L *et al*. Comparison of text-messaging to voice telephone interviews for active surveillance of adverse events following immunisation. *Vaccine* 2015;**33**(31):3689–94.
- Cashman P, Moberly S, Dalton C *et al*. Vaxtracker: active on-line surveillance for adverse events following inactivated influenza vaccine in children. *Vaccine* 2014;**32**(42):5503–8.

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34. Munnoch SA, Cashman P, Peel R *et al.* Participant-centered online active surveillance for adverse events following vaccination in a large clinical trial: feasibility and usability study. *J Med Internet Res* 2019;**21**(10):e14791.
35. Pillsbury A, Cashman P, Leeb A *et al.* Real-time safety surveillance of seasonal influenza vaccines in children, Australia, 2015. *Euro Surveill* 2015;**20**(43). DOI: 10.2807/1560-7917.ES.2015.20.43.30050.
36. Pillsbury A, Quinn H, Cashman P *et al.* Active SMS-based influenza vaccine safety surveillance in Australian children. *Vaccine* 2017;**35**(51):7101–6.
37. Gold MS, Lincoln G, Cashman P *et al.* Efficacy of m-Health for the detection of adverse events following immunization – the stimulated telephone assisted rapid safety surveillance (STARSS) randomised control trial. *Vaccine* 2021;**39**(2):332–42.
38. FluTracking. FluTracking Research (Australia). Australian Government. Available online at: <https://info.flutracking.net/wp-content/uploads/2020/05/IndigenousSummary.pdf> (last accessed 5 January 2023)
39. Shakeri Hossein Abad Z, Kline A, Sultana M *et al.* Digital public health surveillance: a systematic scoping review. *Npj Digit Med* 2021;**4**(1):41.
40. Vogt F, Haire B, Selvey L *et al.* Effectiveness evaluation of digital contact tracing for COVID-19 in New South Wales, Australia. *Lancet Public Health* 2022;**7**(3):e250–8.
41. Dyda A, Fahim M, Fraser J *et al.* Managing the digital disruption associated with COVID-19-driven rapid digital transformation in Brisbane, Australia. *Appl Clin Inform* 2021;**12**(5): 1135–43.
42. Dalton C, Carlson S, Durrheim D. Insights from flutracking: thirteen tips to growing a web-based participatory surveillance system. *JMIR Public Health Surveill* 2017;**3**(3):e48.
43. Australian Government National Indigenous Australians Agency. Indigenous Digital Inclusion Plan Discussion Paper. Commonwealth of Australia; 2021. Available online at: <https://www.niaa.gov.au/sites/default/files/publications/indigenous-digital-inclusion-plan-discussion-paper.pdf> (last accessed 5 January 2023)
44. Media Usage amongst Aboriginal and Torres Strait Islander people (infographic). McNair Ingenuity Research. Available online at: <https://mcnair.com.au/wp-content/uploads/Media-Usage-amongst-Aboriginal-and-Torres-Strait-Islander-People-McNai...pdf>
45. Rennie E, Thomas J, Wilson C. Aboriginal and Torres Strait Islander people and digital inclusion: what is the evidence and where is it? *Commun Res Pract* 2019;**5**(2):105–20.
46. McCallum GB, Versteegh LA, Morris PS *et al.* Mobile phones support adherence and retention of indigenous participants in a randomised controlled trial: strategies and lessons learnt. *BMC Public Health* 2014;**14**:622.
47. Kirkham R, MacKay D, Barzi F *et al.* Improving postpartum screening after diabetes in pregnancy: results of a pilot study in remote Australia. *Aust N Z J Obstet Gynaecol* 2019;**59**(3):430–5.
48. Perkes SJ, Bonevski B, Hall K *et al.* Aboriginal and Torres Strait Islander women's access to and interest in mHealth: national web-based cross-sectional survey. *J Med Internet Res* 2023;**25**:e42660.
49. Australian Government Department of Health. Australia's notifiable disease status, 2016: annual report of the National Notifiable Diseases Surveillance System. *Commun Dis Intell* 2021;**45**(28). DOI: 10.33321/cdi.2021.45.28.
50. Indigenous Data Governance Sovereignty (Information Sheet). Lowitja Institute. Available online at: https://www.lowitja.org.au/icms_docs/328550_data-governance-and-sovereignty.pdf
51. Choukou MA, Maddahi A, Polyvyana A *et al.* Digital health technology for Indigenous older adults: a scoping review. *Int J Med Inform* 2021;**148**:104408.
52. Anderson-Lewis C, Darville G, Mercado RE *et al.* MHealth technology use and implications in historically underserved and minority populations in the United States: systematic literature review. *JMIR Mhealth Uhealth* 2018;**6**(6):e128.
53. Menzies R, Turnour C, Chiu C *et al.* Vaccine preventable diseases and vaccination coverage in Aboriginal and Torres Strait Islander people, Australia 2003 to 2006. *Commun Dis Intell Q Rep* 2008;**32** Suppl:S2–67.
54. Bradley C, Hengel B, Crawford K *et al.* Establishment of a sentinel surveillance network for sexually transmissible infections and blood borne viruses in aboriginal primary care services cross Australia: the ATLAS project. *BMC Health Serv Res* 2020;**20**:769.
55. Australian Government Department of Health Aged Care. *Influenza (flu)*. Australian Government. Available online at: <https://immunisationhandbook.health.gov.au/contents/vaccine-preventable-diseases/influenza-flu> (updated April 2022; last accessed 5 January 2023)
56. Aldridge RW, Story A, Hayward AC. Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: a systematic review and meta-analysis. *Lancet* 2018;**391**(10117):241–50.
57. Trick WE, Rachman F, Hinami K *et al.* Variability in comorbidities and health services use across homeless typologies: multicenter data linkage between healthcare and homeless systems. *BMC Public Health* 2021;**21**(1):917.
58. Australian Government Australian Institute of Family Studies. *The digital divide in telepractice service delivery*. Australian Government. Available online at: <https://aifs.gov.au/resources/short-articles/digital-divide-telepractice-service-delivery#footnote-001> (updated September 2021; last accessed 5 January 2023)