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Data Resource Profile

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Data Resource Profile: MedicineInsight, an Australian national primary health care database

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Data resource basics

MedicineInsight programme

MedicineInsight is a large-scale primary care database of longitudinal de-identified electronic health records (EHRs) in Australia. The MedicineInsight programme collates routinely collected EHR data from clinical information systems (CISs) from consenting general practices which have agreed to provide data on an ongoing basis.

MedicineInsight was established by NPS MedicineWise in 2011, with core funding from the Australian Government Department of Health, to support quality improvement in Australian primary care and the post-market surveillance of medicines. MedicineInsight data are now being used to support a wide range of activities including observational[1–6] and interventional research. As participation in MedicineInsight increases and the data are continuously improved, it will become an increasingly valuable source of information for primary health care, policy and planning in Australia as well as internationally.

NPS MedicineWise

MedicineInsight is managed by NPS MedicineWise.[7] NPS MedicineWise is an independent, not-for-profit organization that works to improve the way health technologies, medicines and medical tests are prescribed and used. Established in 1998 with the primary aim of promoting the quality use of medicines, each year NPS MedicineWise designs, implements and evaluates a range of national educational and quality improvement programmes for health professionals and consumers including, for example, type 2 diabetes, stroke, hypertension, anxiety, depression and neuropathic pain.

Scope: general practice in Australia

Australia has universal health coverage across public hospitals and primary care.[8] In addition, people may take out private health insurance for private hospital and ancillary health costs. A government medical insurance scheme, managed by Medicare Australia,[8] covers all or part of a person's costs, including investigations and pathology tests, for a visit to a general practitioner (GP) or medical specialist.

GPs are typically the first point of contact for patients in the Australian health care system, and act as gatekeepers to medical specialists and Medicare-subsidized allied health professional visits.[9,10] Nearly 75% of all medical consultations in Australia take place in general practice,

and more than 80% of the population access GP services every year.[11,12] Unlike the UK, in Australia patients are not required to register with a single general practice, and are free to visit multiple practices of their choice.[13,14] Most Australian GPs use EHRs to manage patient care and information.[13,15] Access to pooled EHRs stored in general practice CISs provides an important data resource which has the potential to contribute significantly to primary care policy, health research and quality improvement activities in general practice.

Data governance, ethics, privacy and security

The MedicineInsight programme has rigorous governance processes including an independent Data Governance Committee comprising consumer advocates, data security experts, GPs and researchers. Such governance mitigates the risk that the misuse of data may pose to participants, and ensures the programme is run ethically and for the public good.

Data are encrypted during transit, following government and industry best practice standards. MedicineInsight data are collected, used and stored strictly in accordance with Australian privacy laws (including mandatory data breach notification laws).

The pilot MedicineInsight programme was approved by the Royal Australian College of General Practitioners (RACGP) National Research and Evaluation Ethics Committee (NREEC) in January 2013 (NREEC 12-011); 150 practices were recruited for the pilot programme. In December 2017, the RACGP NREEC granted ethics approval (NREEC 17-017) for the standard operation and use of the MedicineInsight programme by NPS MedicineWise. Recruitment of general practices to MedicineInsight involves provision of information to GPs and patients about the programme and use of collected data. Each participating practice is required to display a poster to inform patients that their de-identified data will be collected by MedicineInsight and makes available additional information for patients. Patients can opt out of the programme by a process handled independently at the practice.

MedicineInsight does not collect patient personal identifiers, such as name, date of birth or street address. Patient-level data are de-identified at source, encrypted and assigned a unique identifier by the data extraction tool before being securely transmitted to the NPS MedicineWise data warehouse. When providing data externally, for example to researchers, NPS MedicineWise employs confidentiality controls, such as restricting lower-level geographical information, to prevent unintended identification of patient data.

Data collected

Data extraction

MedicineInsight uses third-party data extraction tools [GeneRic Health Network Information Technology for the Enterprise (GRHANITE^{TM})[16] and Precedence Health Care's cdmNet^{TM}[17]] which de-identify, extract and securely transmit whole-of-practice data from within each general practice's CIS [Best Practice (BP)^{TM} or Medical Director (MD)^{TM}]. A whole-of-practice data collection, containing most available historical and current de-identified EHRs, is conducted when a practice joins MedicineInsight. The extraction tool collects incremental data regularly, allowing the development of a longitudinal database in which patients within each practice can be tracked over time (details of the data extraction procedure are in Supplementary Figure 1, available as Supplementary data at *IJE* online). Data from BP and MD CISs are merged within the data warehouse into a single consistent data structure, and monthly builds of the primary care database are generated and made available for use.

Data structure

Figure 1 shows a patient-centric view of the MedicineInsight data structure. The data that MedicineInsight collects include:

i. patient demographic and clinical data recorded by GPs and practice staff directly into the CIS as part of routine clinical practice, or collected in the CIS from external sources (e.g. pathology test results);
ii. system-generated information such as start time and date of a patient encounter, an encounter being defined as any professional interaction between a patient and a health care professional;
iii. site and GP information for the administration of quality improvement activities by NPS MedicineWise.

Data are collected at a 'site' level. A site is described as one or more general practices that use a shared CIS. MedicineInsight is unable to assign patient records within the database of a multipractice site to each individual practice because the separation of patients into practices within one site is not done in the source CISs. However, the majority (90%) of the sites participating in MedicineInsight comprise only one general practice.

Each patient, site and provider has a unique identifying number, which allows all the records held in the database for an individual to be linked without re-identification. The extracted data include information on patient demographics, reasons for encounters, conditions, prescriptions, observations, immunization history and pathology tests and results. Data recorded by providers about patient care

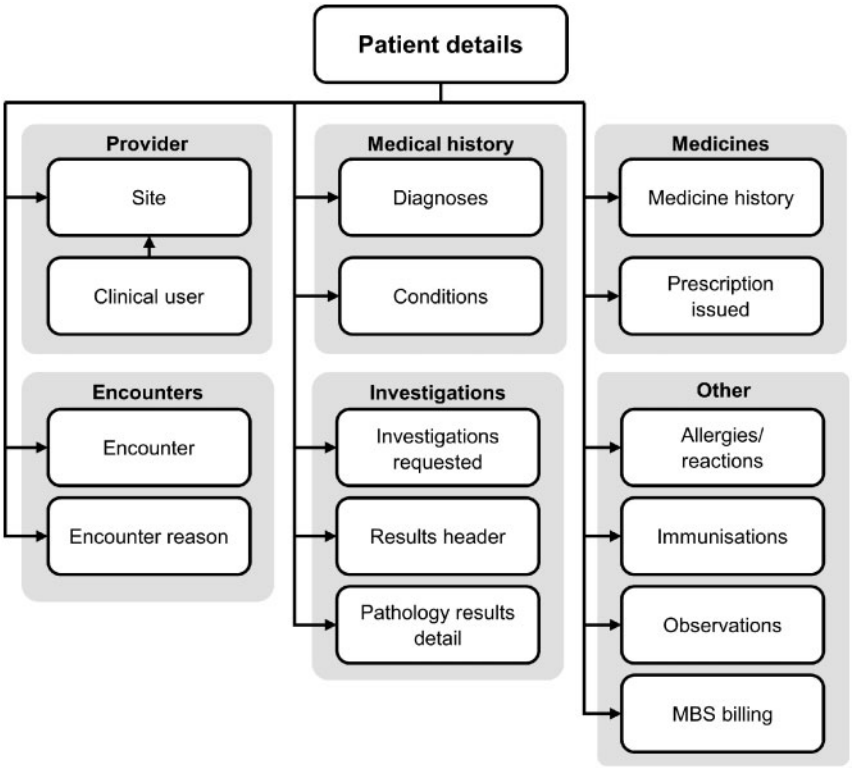

Figure 1. Structure of MedicineInsight database—patient-centric view. MBS: Medicare Benefits Schedule. Reproduced from the MedicineInsight data-book [https://www.nps.org.au/medicine-insight/using-medicineinsight-data].

in the unstructured area of the medical record, called 'progress notes', are not collected because these data may contain identifiable information. To further minimize the potential risk of retaining identifiable information from the fields where free-text data are recorded, algorithms are implemented in MedicineInsight's monthly processing which remove residual identifiable information from these fields. A list of data tables and examples of variables in the MedicineInsight database are presented in Table 1.

In Australia, CISs use different coding or terminology systems.[18,19] The well-known ICD-10 classification system is used in hospital settings but is not commonly used in Australian general practice. The majority of general practices use coding systems such as 'Docle' in MD, 'Pyefinch' in BP or the International Classification of Primary Care 2 (ICPC-2).[19,20] It is not mandatory to use a coded diagnosis, and clinicians can also enter terms as free-text; therefore, both coded (Docle and Pyefinch) and free-text data are extracted from the CIS. Both Docle and Pyefinch consist of clinical terminologies for diseases, clinical findings and therapies.[20] These coding systems can be mapped to SNOMED-CT (Systematized Nomenclature of Medicine - Clinical Terms),[21] an international standard clinical terminology system which is the preferred clinical reference terminology for Australia.[18,19]

Current and past medicine history, including over-the-counter medicines when recorded, are available as well as printed prescriptions. MedicineInsight provides mapping of medicines to Anatomical Therapeutic Chemical Classification System (ATC) codes where possible.

Results of pathology tests are commonly added to the patient record via electronic links from laboratories, but PDFs and scanned documents are not collected. Results of tests requested by other providers (e.g. hospitals, outpatient clinics or specialists) which have been copied to the patient's GP may be included in MedicineInsight if they have been electronically transferred or manually recorded into the CIS.

Data quality

To maximise the suitability of data for research purposes, selection criteria and extensive data cleaning procedures are applied. MedicineInsight data quality criteria are evolving and include site selection criteria such as having been established for at least 2 years, no gaps of more than 6 weeks in the previous 2 years in practice data and a consistent volume of transactions over the preceding 2 years. These measures are a first step to selecting sites with research-quality data records. Quality criteria are also applied to patients (e.g. defined or plausible age and sex). The completeness of variables that are restricted to a defined list of options within the CIS (such as prescriptions or coded diagnoses) is usually superior to variables where information is recorded as free-text.

Table 1. Summary of MedicineInsight data tables and fields

Data table	Description	Examples of fields
Patient	Patient demographics and other information	Patient ID, gender, year of birth, year of death, Indigenous status, concession/pension status, current smoking status, remoteness indicator, IRSAD (SEIFA) decile and PHN
Encounter	Information about recorded patient encounters including both clinical and administrative encounters	Date of encounter, provider ID, encounter type and duration
Encounter reason	Reason for patient encounter	Date of encounter and reason(s) for encounter (free-text or coded)
Diagnoses	Patient diagnosis details	Date of diagnosis, diagnosis and active flag
Conditions	Derived table. Identifies specific conditions (e.g. asthma, diabetes etc.) documented in any of the Diagnosis, Encounter reason or Prescription tables	Specific condition flags
Investigations requested	Details of any investigations requested through the CIS e.g. pathology, radiology, ECG etc. (Does not contain test results)	Request date and requested test(s)
Results, header	General information regarding results (e.g. pathology, radiology etc.) received. Includes results from requests made by the practice, or from external providers who have copied results to the practice	Request date, requested test(s), collection date, report date and summary normal flag (i.e. result is normal or not)
Pathology results detail	Details of results for specific individual investigations, whether ordered individually or as a group. Includes results from requests made by the practice or from external providers who have copied results to the practice	Result date, LOINC, result name, result value, units, normal range and abnormal flag
Medicine history	Information about current and past history of medicines for a patient	First date prescribed, latest date prescribed, medicine name, active ingredient, reason for prescription, deletion date and reason, dose, frequency, quantity, strength, form, route, number of repeats and restriction code (PBS/RPBS)
Prescription issued	Each prescription printed from the CIS	Date issued, medicine name, active ingredient, dose, frequency, quantity, strength, route, number of repeats and restriction code (PBS/RPBS)
Observations	Observations recorded about the patient e.g. blood pressure, height, weight, BMI, temperature, blood sugar etc.	Observation date, observation type and observation value
Allergies/reactions	Data about allergies and adverse reactions	Date recorded, allergy substance and reaction type
Immunization	Vaccine and immunization details	Vaccine name, date given, batch number, route of administration and sequence number
MBS billing	Description of MBS item codes billed to the patient	Service date and MBS item number
Site[a]	Descriptors of sites	Site ID, multi-practice flag, CIS name, remoteness indicator, IRSAD decile and PHN
Clinical user	Information about the staff member who logs information in the CIS, including clinical (GP, nurse, allied health) and administrative staff	Provider ID, provider type (e.g. doctor or nurse)

This list excludes fields that allow linkage between tables or that record when a field is updated. Adapted from the MedicineInsight databook, with further details available at [https://www.nps.org.au/medicine-insight/using-medicineinsight-data].

BMI, body mass index; CIS, clinical information system; ECG, electrocardiogram; GP, general practitioner; ID, identifier; IRSAD, Index of Relative Socio-economic Advantage and Disadvantage; LOINC, Logical Observation Identifiers Names and Codes; MBS, Medicare Benefits Schedule; PBS/RPBS, Pharmaceutical Benefits Scheme/Repatriation Pharmaceutical Benefits Scheme; PHN, Primary Health Network; SEIFA, Socio-Economic Indexes for Areas.

[a]A site is described as one or more general practices that share the same general practice clinical information system.

As standards for improving general practice data are applied and enhancements to the CISs occur, we anticipate that the quality of MedicineInsight data will be incrementally improved.

The prevalence estimates of several common chronic conditions, such as diabetes mellitus and asthma, in the MedicineInsight population[22] are similar to those reported in other Australian sources.[23,24] Previous studies also have

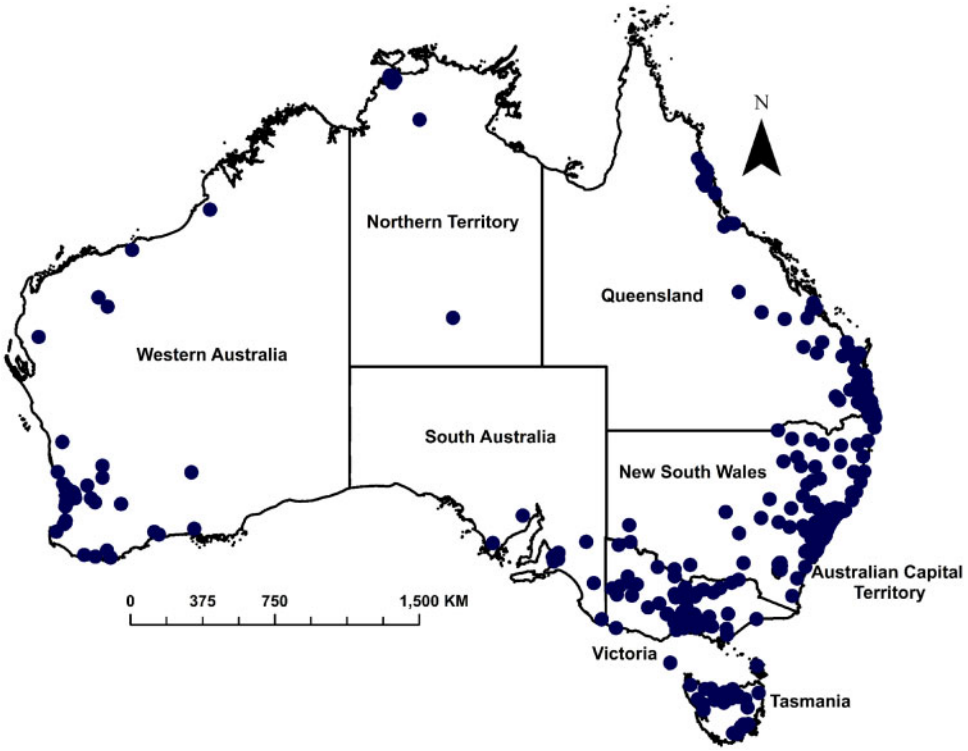

Figure 2. Geographical distribution of general practices that contribute data to MedicineInsight.

Table 2. Distribution of MedicineInsight and national general practices by state/territory

State/territory	MedicineInsight general practices[a]	National general practices[b]	MedicineInsight practices as a proportion (%) of national practices
Australian Capital Territory	11	98	11.2
New South Wales	236	2809	8.4
Northern Territory	12	127	9.4
Queensland	118	1604	7.4
South Australia	19	570	3.3
Tasmania	49	171	28.7
Victoria	141	1990	7.1
Western Australia	76	696	10.9
National total	662	8065	8.2

[a]General practices participating in MedicineInsight as of October 2018.
[b]Reproduced from NPS MedicineWise. General Practice Insights Report July 2016–June 2017: a working paper.[22]

found MedicineInsight data viable for estimating the prevalence of musculoskeletal disorders,[3] describing trends in prescribing[25] and post-market drug surveillance.[2] A formal external validation study is underway and is yet to be completed.

Data coverage

As of October 2018, MedicineInsight has recruited 662 participating general practices from across Australia, representing approximately 8.2% of all general practices in Australia[22] (Table 2 and Figure 2) and over 2700 GPs.

MedicineInsight is an open cohort and patients in Australia are able to visit multiple general practices. To improve data quality, a cohort of regularly attending patients, who are more likely to be receiving most of their care at the MedicineInsight practice (thereby enabling sufficient opportunities for diagnoses, tests and prescriptions to be recorded), is often used for analyses. Regular patients are defined as those who have at least three consultations in any 2 consecutive years, in accordance with the RACGP's definition of 'active' patients.[26] At the October 2018 database build there were 2.3 million regular MedicineInsight patients from 419 sites meeting data quality selection

Table 3. Demographic characteristics of regular patients in MedicineInsight database (31 October 2018)

Characteristic	MedicineInsight regular patients ($N = 2\ 265\ 540$)[a]		MBS patients 2016/17 ($N = 21\ 177\ 823$)[b]	
	n	% (95% confidence interval)	*n*	%
Sex				
Men	998 989	44.1 (43.6, 44.6)	10 074 002	47.6
Women	1 262 417	55.7 (55.2, 56.2)	11 103 821	52.4
Intersex/indeterminate	141	0.0 (0.0, 0.0)	–	–
Missing[c]	3993	0.2 (0.1, 0.2)	–	–
Age group (years)				
0–9	281 388	12.4 (11.9, 12.9)	2 804 404	13.2
10–19	210 240	9.3 (9.0, 9.6)	2 296 417	10.8
20–29	290 398	12.8 (12.1, 13.5)	2 648 342	12.5
30–39	324 368	14.3 (13.7, 14.9)	2 920 718	13.8
40–49	300 386	13.3 (13.0, 13.5)	2 834 634	13.4
50–59	291 670	12.9 (12.6, 13.1)	2 748 067	13.0
60–69	264 243	11.7 (11.2, 12.1)	2 386 182	11.3
70–79	190 367	8.4 (7.9, 8.9)	1 588 715	7.5
80–89	89 446	3.9 (3.7, 4.2)	781 022	3.7
90+	23 031	1.0 (0.9, 1.1)	169 314	0.8
Missing[d]	3	0.0 (0.0, 0.0)	8	0.0
Indigenous status				
Aboriginal and/or Torres Strait Islander	58 642	2.6 (2.1, 3.1)	–	–
Not Aboriginal or Torres Strait Islander	1 719 886	75.9 (73.5, 78.3)	–	–
Missing[c]	487 012	21.5 (19.0, 24.0)	–	–
State/territory				
New South Wales	788 228	34.8 (29.5, 40.1)	6 838 475	32.3
Victoria	466 849	20.6 (15.5, 25.7)	5 384 792	25.4
Queensland	422 168	18.6 (14.4, 22.8)	4 258 657	20.1
Western Australia	329 171	14.5 (10.1, 19.0)	2 196 542	10.4
South Australia	30 133	1.3 (0.3, 2.4)	1 514 529	7.2
Tasmania	144 297	6.4 (3.7, 9.1)	450 279	2.1
Australian Capital Territory	47 376	2.1 (0.5, 3.6)	346 800	1.6
Northern Territory	35 778	1.6 (0.5, 2.7)	187 240	0.9
Missing[c]	1540	0.1 (0.0, 0.2)	509	0.0

[a]Data are from practices that had a complete data extract as of 31 October 2018 and met the site quality criteria. Regular patients are alive and had at least three encounters (each recorded on a different day) in the 2 years preceding the 31 October 2018 database build.

[b]Medicare Benefits Schedule (MBS) total GP non-referred attendances.

[c]Not recorded or not stated/inadequately described or missing value.

[d]Missing year of birth or inadequately recorded or invalid year of birth.

criteria; this represents 10.7% of all patients who visited a GP in the 2016/17 financial year according to Medicare Benefits Schedule (MBS) data.[22] Characteristics of regular MedicineInsight patients are broadly comparable to patients who visited a GP in 2016/17 in the MBS data (Table 3).

Data resource use

MedicineInsight data have been used by academic researchers. MedicineInsight reports have been used by industry and government agencies for primary care research, post-market surveillance of medicines, informing medicines policy and supporting quality improvement activities in general practice. Further details about the projects and publications involving MedicineInsight data are available on the NPS MedicineWise web page [https://www.nps.org.au/approved-projects-using-medicineinsight-data]. A list of publications involving MedicineInsight data is also available as Appendix 1, available as Supplementary data at *IJE* online.

Strengths and weaknesses

MedicineInsight data are a valuable source of detailed longitudinal information on general practice activities across Australia. While harnessing its value, it is vital that users also understand the complexities of using the data for

research purposes, to enable accurate interpretation of the data. MedicineInsight data are real-world data recorded by clinicians into CISs for the purposes of providing patient care, and there are limited standards for data collection. Most of the limitations mentioned below are inherent in data extracted from general practice CISs and are not necessarily confined to MedicineInsight.

Strengths

A significant strength of the MedicineInsight database is its size and national coverage. The large volume of data provides a unique opportunity to analyse in detail the activities that occur within general practice, and to measure the patient health outcomes and quality of general practice care. Large datasets enable the study of less common exposures and outcomes such as adverse effects of medicines.

The ability to follow patients over time and perform longitudinal analyses using up-to-date clinical data is a key asset of MedicineInsight, allowing analyses of trends over time and sequence of therapy. Using EHR data reduces subjective biases found in self-reported health surveys, since EHR data comprise GP-identified diagnoses, objective laboratory and examination results and medicines prescribed to patients.

When compared with MBS data for Australians who visited a GP in the 2016/17 financial year, regular MedicineInsight patients are broadly representative of the Australian population, in terms of age and sex. Based on the 2016 Census of Population and Housing, the proportion of Indigenous patients (2.6%) in MedicineInsight is comparable to that of the Australian population (2.8%).[27] However, MedicineInsight data may not be representative of all practices in Australia based on geography and size.

Unlike other national prescribing datasets, MedicineInsight has comprehensive medicines information and can complement prescribing information with data about the conditions and pathology tests recorded for patients who are prescribed medicines.

Weaknesses

MedicineInsight data are dependent on the accuracy and completeness of data recorded in general practice CISs, in fields that can be extracted or in a useable format. The completeness of data varies across practices and patients. For example, information about lifestyle risk factors, such as body mass index, may be selectively recorded for patients with particular health problems but not recorded for other patients, or recorded in the progress notes which are not extracted.

Without standardized definitions, users develop algorithms to identify conditions and exposures based on coded and free-text information. Definitions may vary between projects and research groups using the same data.

If a patient visits practices that are not enrolled in MedicineInsight, this activity will not be captured. MedicineInsight is currently unable to link patients across different sites and, consequently, there is potential for duplication of patient information where patients attend multiple MedicineInsight sites. Patient loyalty data demonstrate that 53% of patients attended a single practice in 2016–17, and these patients had an average of 4.6 encounters per year.[22] Assuming that there is no change in patient behaviour and using the patient loyalty data in combination with the estimate of the proportion of practices in MedicineInsight, we estimate that the rate of duplication of patients in MedicineInsight is approximately 4%.[22]

Practices are recruited to MedicineInsight using non-random sampling, producing systematic sampling differences between states/territories and regions. Initial recruitment focused on practices with more than three GPs, as it was considered that these practices were more likely to have EHRs. There has been targeted recruitment of practices into MedicineInsight from some Primary Health Networks to support local quality improvement programmes and research. Thus, unadjusted geographical comparisons should be interpreted with caution.

There is no unique identifier linking events that happen during an encounter, such as prescriptions, to the encounter record. Date and time stamps for events can be used as a proxy link to encounter records. Clinical knowledge and inference can also be used to associate events like diagnoses and prescriptions.

It may be difficult to determine a clinical encounter in MedicineInsight, as an 'encounter' occurs in the CIS whenever the patient record is opened, regardless of the associated activity, whether administrative or clinical. Additionally, MBS item number billing data are not available for approximately 20% of sites because of a technical limitation where the CIS and the management system at a practice are incompatible.

Future directions

Current or planned activities to improve the quality of MedicineInsight data include the following.

i. Linkage of MedicineInsight primary care data with other databases, such as hospital and death data, to better assess patient outcomes, prediction of hospitalizations and health care system use. The data extraction tools are able to make use of identifiable information in the CIS to generate 'hash keys', which preserve patient confidentiality while enabling probabilistic linkage of MedicineInsight to other health and administrative datasets.[28]
ii. Studies for formal comprehensive validation of the data and implementation of reference standards, systematic

coding of free-text and systematic hierarchical classification. NPS MedicineWise's medical and clinical coding experts are developing coding algorithms to identify conditions and symptoms of interest, both coded and free-text, within the MedicineInsight database, using commonly accepted clinical definitions, terms and synonyms from SNOMED CT-Australia, Australian Medicines Terminology and Logical Observation Identifiers Names and Codes (LOINC).

iii. De-duplication of patients across sites through probabilistic record linkage using unique identifiers.[29]

Data resource access

More information about MedicineInsight data and how they can be accessed is available on the website [https://www.nps.org.au/medicine-insight]. De-identified data extracts are available to internal and external organizations for research, quality improvement and other purposes, subject to compliance with our data governance framework, licensing and fees (details in Supplementary Figure 2, available as Supplementary data at *IJE* online). Following approval of the data access application, including ethics approval where required, a study-specific extract of the raw data can be provided or the MedicineInsight team can be commissioned to provide analysis and reporting services.

Profile in a nutshell

- MedicineInsight is a large Australian primary care database available for research and quality improvement in primary care.
- Established in 2011, MedicineInsight currently comprises 662 participating general practices and 2700 general practitioners.
- MedicineInsight data originate from routine clinical practice, and their use for research may require extensive data processing and an understanding of the recording and storage of the original data.
- MedicineInsight data include patient demographics, diagnoses, medicines, laboratory results, physical observations, risk factors, allergies or adverse reactions, immunizations and MBS billing information.
- Information about accessing MedicineInsight data, including the databook and list of approved projects, is available at [https://www.nps.org.au/medicine-insight/using-medicineinsight-data].

Supplementary Data

Supplementary data are available at *IJE* online.

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Conflict of interest: The authors, except N.S., are employees of NPS MedicineWise. N.S. is a member of the independent Data Governance Committee.

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