MedicineInsight

DATA BOOK

JUNE 2019

2.2

**NPS
MEDICINEWISE**

More information

For more information about this document or MedicineInsight enquiries, please visit www.medicineinsight.org.au or email medicininsight@nps.org.au.

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Contents

1. INTRODUCTION

NPS MedicineWise is an independent, not-for-profit and evidence-based organisation that works to improve the way health technologies, medicines and medical tests are used. MedicineInsight was initially established by NPS MedicineWise in 2011, with core funding from the Australian Department of Health (DOH). MedicineInsight data are available to support research that aligns with the NPS MedicineWise mission and the ethos of the MedicineInsight program.

The purpose of this document is to provide information about data collection, data variables and the strengths and limitations of the data. For further details about MedicineInsight go to www.nps.org.au/medicine-insight/using-medicineinsight-data. A summary document addressing frequently asked questions about accessing MedicineInsight is also available by emailing MedicineInsight@nps.org.au or phoning 1300 721 726.

MedicineInsight is a large general practice dataset that was originally established to support quality improvement in Australian primary care and post-market surveillance of medicines. MedicineInsight consists of monthly longitudinal, de-identified, whole-of-practice data extracted from the clinical information systems (CIS) of consenting general practices across Australia. MedicineInsight contains data that can be used to support research and analysis of general practice patients and their management, including their symptoms and diagnoses, the treatment provided and their outcomes over time.

As participation in MedicineInsight increases, and as the data are continuously improved, this will become an increasingly valuable source of information to inform primary healthcare, policy and planning in Australia. MedicineInsight data can also be used to support a wide range of activities including improving the delivery of health care and population health, influencing and driving policy development, and informing health care decision making at local, regional and national levels (Figure 1).

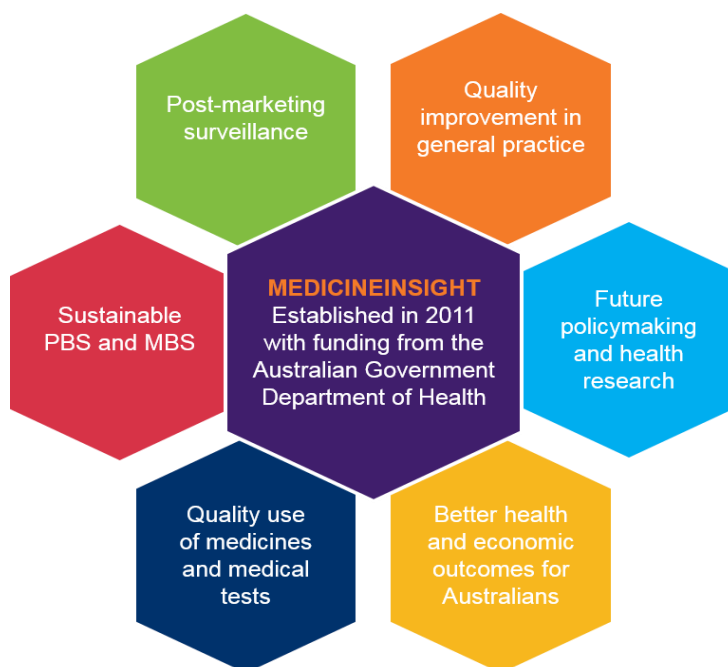**Figure 1   MedicineInsight capabilities**

As CIS data are not entered with the intent of being used in research, MedicineInsight data are subject to limitations which should be borne in mind by users when designing studies. Users may wish to follow reporting guidelines such as those outlined in the REporting of studies Conducted using Observational Routinely collected health data (RECORD) statement.[1]

Data governance and ethics

MedicineInsight has rigorous governance processes in place to mitigate any risk to participants and to ensure the program is run lawfully, ethically and for the purpose of public good. Sharing of MedicineInsight data is subject to a robust data governance framework, including approval by an external and independent Data Governance Committee. The committee provides advice to NPS MedicineWise on general data governance issues, reviews and where appropriate approves applications to access MedicineInsight data. The committee comprises consumer advocates, privacy and security experts, general practitioners and researchers.

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

The pilot MedicineInsight program was approved by the Royal Australian College of General Practitioners (RACGP) National Research and Evaluation Ethics Committee in January 2013. In December 2017, NPS MedicineWise was granted ethics approval for the MedicineInsight program. This approval covers our standard operations and uses of the MedicineInsight database.

Organisations seeking access to a data extract - that is data at an individual, de-identified patient level – are required to obtain separate approval from an NHMRC-registered ethics committee before data are released. NPS MedicineWise requires a copy of the ethics application, as well as the ethics approval.

For further information about data governance and ethics go to www.nps.org.au/medicine-insight/privacy-security-governance.

2. ABOUT MEDICINEINSIGHT

MedicineInsight uses third-party data extraction tools to de-identify, extract and securely transmit whole-of-practice data from within each general practice's CIS. An all-of-practice data collection, containing all available historic and current de-identified electronic health records, 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 sites can be tracked over time.
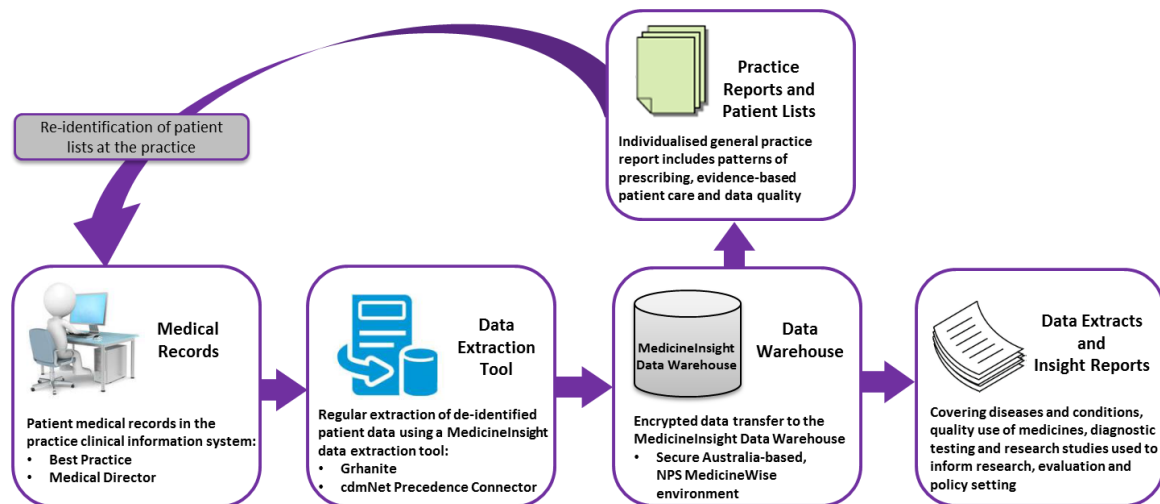
Figure 2   Collection of MedicineInsight data

The data that MedicineInsight collects from sites include:

- general practice and general practitioner (GP) information for the administration of quality improvement activities by NPS MedicineWise

- patient demographic and clinical data entered by GPs and practice staff directly into the system, or collected in the CIS from external sources (eg, pathology test results)

- system-generated data such as start time and date of a patient encounter.

Patient level data are de-identified at source, which means patients' personal identifiers such as name, date of birth and street address are used to produce encrypted patient identifiers. The data held in the MedicineInsight database are de-identified. However, each patient, site and provider has a unique identifying number which allows all the records held in the database for a particular individual to be linked without re-identification.

3. MEDICINEINSIGHT DATA

MedicineInsight stores data in tables containing fields in both coded and free-text formats. Figure 3 shows a patient-centric view of the types of information currently available from MedicineInsight. Further information about the tables and examples of data fields is displayed in Table 1.

PATIENT DETAILS

PROVIDER
- SITE
- CLINICAL USER

ENCOUNTERS
- ENCOUNTER
- ENCOUNTER REASON

MEDICAL HISTORY
- DIAGNOSES
- CONDITIONS

INVESTIGATIONS
- INVESTIGATIONS REQUESTED
- RESULTS HEADER
- PATHOLOGY RESULTS DETAIL

MEDICINES
- MEDICINE HISTORY
- PRESCRIPTION ISSUED

OTHER
- ALLERGIES/ REACTIONS
- IMMUNISATIONS
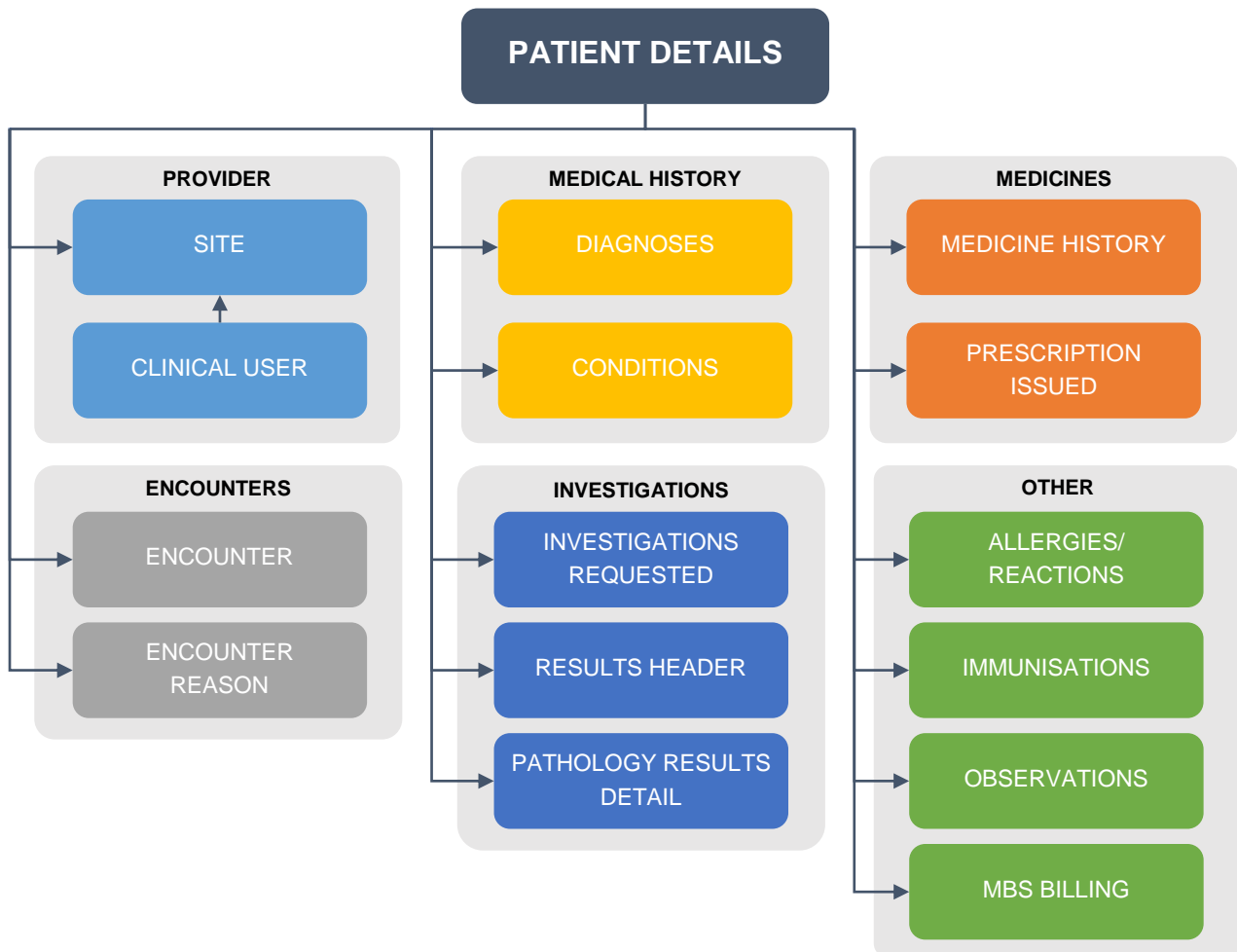- OBSERVATIONS
- MBS BILLING

Figure 3   MedicineInsight database – Patient-centric view

Table 1   MedicineInsight data tables

Table [TABLE NAME]	Description	Data fields available (examples only[a])
PATIENT DETAILS		
PATIENT [EMI_PATIENT]	Patient-specific information.	▪ Patient ID ▪ Gender ▪ Year of birth ▪ Year of death ▪ Indigenous status ▪ Concession/pension status ▪ Current smoking status ▪ Remoteness indicator ▪ IRSAD decile ▪ PHN
PROVIDER		
SITE [EMI_SITE]	Descriptors of practice sites.	▪ Site ID ▪ Multi-practice flag ▪ CIS name ▪ Remoteness indicator ▪ IRSAD decile ▪ PHN
CLINICAL USER [EMI_CLINICAL _USER]		▪ Provider ID ▪ Provider type
ENCOUNTERS		
ENCOUNTER [EMI_ENCOUNTER]	Information about recorded patient encounters including both clinical and administrative encounters.	▪ Date ▪ Provider ID ▪ Encounter type ▪ Duration
ENCOUNTER REASON [EMI_ENCOUNTER_REASON]	Reason for patient encounter.	▪ Date ▪ Reason
MEDICAL HISTORY		
DIAGNOSES [EMI_DIAGNOSIS]	Patient diagnosis.	▪ Date ▪ Diagnosis ▪ Active flag
CONDITIONS [EMI_CONDITIONS_DETAIL] [EMI_CONDITIONS_SUMMARY]	Derived tables. Identifies specific conditions (eg, asthma, diabetes, etc) documented in any of the *Diagnosis, Encounter Reason* or *Prescription* tables.	▪ Condition 1 ▪ Condition 2 ▪ Condition 3 … ▪ Condition n
INVESTIGATIONS		
INVESTIGATIONS REQUESTED [EMI_REQUESTED_TEST]	Details of any investigations requested through the CIS eg, pathology, radiology, ECG etc. (Does not contain any test results.)	▪ Request date ▪ Requested test(s)
RESULTS HEADER [EMI_PATHOLOGY]	General information regarding results (eg, 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 ▪ Summary normal flag
PATHOLOGY RESULTS DETAIL [EMI_PATHOLOGY_RESULT_ ATOM]	Details of results for specific 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 code ▪ Result name ▪ Result value ▪ Units ▪ Normal range ▪ Abnormal flag

Table [TABLE NAME]	Description	Data fields available (examples only[a])
MEDICINES		
MEDICINE HISTORY [EMI_PRESCRIPTION]	Current and past history of medicines for a patient.	▪ First date ▪ Last date ▪ Medicine name ▪ Medicine active ingredient ▪ Reason for prescription ▪ Ceased ▪ Dose ▪ Frequency ▪ Quantity ▪ Strength ▪ Number of repeats ▪ Restriction code (PBS/RPBS)
PRESCRIPTION ISSUED [EMI_SCRIPT_ITEM]	Each prescription printed from the CIS.	▪ Date ▪ Medicine name ▪ Medicine active ingredient ▪ Dose ▪ Frequency ▪ Quantity ▪ Strength ▪ Number of repeats ▪ Restriction code (PBS/RPBS)
OTHER		
ALLERGIES/REACTIONS [EMI_ALLERGY_REACTION]	Allergies and adverse reactions.	▪ Date recorded ▪ Allergy substance ▪ Reaction type
IMMUNISATIONS [EMI_IMMUNISATION]	Vaccine and immunisation details.	▪ Vaccine name ▪ Date given ▪ Batch number ▪ Sequence number
OBSERVATIONS [EMI_OBSERVATION]	Observations recorded about the patient. eg, blood pressure, height, weight, BMI, temperature, blood sugar etc.	▪ Observation date ▪ Observation type ▪ Observation value
MBS BILLING [EMI_BILLING_SERVICE]	Description of MBS codes billed to the patient.	▪ Service date ▪ MBS Item number

[a] For further information about MedicineInsight data please email medicineinsight@nps.org.au

4. EXPLANATORY NOTES

Patients

Patient information is entered in the CIS at the practice and each patient is given a unique digital number at each site visited. If a patient visits practices that are not enrolled in MedicineInsight, this information and activity will not be captured. We are currently unable to link patients across different sites within MedicineInsight, and consequently there is potential for duplication of patient information where patients attend multiple included sites. We estimate that the rate of duplication is less than 4% of patients.

MedicineInsight applies definitions of 'active' patients for inclusion in analyses as appropriate. Custom patient cohorts may utilise different definitions of active and can be built as required for different research questions or topics.

Common definitions used by MedicineInsight include:

- Current patients – all patients that are active in the CIS, ie, not marked inactive, deleted or deceased, regardless of clinical or administrative activity.

- Visitor patients – marked as visitors in the CIS.

- Regular patients – frequently seen patients, ie patients with three or more encounters recorded in two years.

Demographic information is available for patients, including year of birth, year of death, sex and indigenous status. Risk factors such as patient BMI, and smoking and alcohol use status are contained as variables within the patient table. However, GPs may record information on BMI, smoking or alcohol use in different places within the CIS, for example in the progress notes (which are not available to MedicineInsight), and this can have a significant effect on completeness rates of these variables.

Geographic location indicators for patients, including state, remoteness, SEIFA decile, IRSAD decile and Primary Health Network (PHN), are derived from the recorded patient postcode, however postcode is not available to researchers.

**Table 2   Indicative demographic distribution of regular MedicineInsight patients
(MedicineInsight, October 2018, n= 2,974,031[a])**

Characteristic		MedicineInsight % patients	National data sources[b,c] % patients
Sex (missing 0.2%)	Male	44.1	47.6
	Female	55.7	52.4
Age group (years) (missing 0.02%)	0-9	12.3	13.2
	10-19	9.4	10.8
	20-29	13.2	12.5
	30-39	14.4	13.8
	40-49	13.2	13.4
	50-59	12.7	13.0
	60-69	11.5	11.3
	70-79	8.3	7.5
	80-89	3.9	3.7
	90+	1.0	0.8
Indigenous status (missing 21.4%)	Aboriginal and/or Torres Strait Islander	2.6	2.9
	Not Aboriginal or Torres Strait Islander	76.0	97.1
State	NSW	32.4	32.3
	VIC	22.8	25.4
	QLD	18.7	20.1
	WA	12.6	10.4
	TAS	6.5	2.1
	SA	2.8	7.2
	ACT	2.4	1.6
	NT	1.7	0.9
Socio-economic status (SEIFA IRSAD quintile) (missing 0.3%)	1 (most disadvantaged)	15.3	16.1
	2	16.4	16.2
	3	22.5	19.6
	4	19.1	20.6
	5 (most advantaged)	24.9	27.5

[a] Patients marked as 'Active' and 'RACGP Active'

[b] Sex, Age group, State, Socio-economic status: Data source: Medicare Benefits Schedule statistics, 2016–17 (data provided by DoH).[2].

[c] Indigenous status: Data source: Adjusted non-referred GP (total) services claimed by Indigenous status, Australia, 2015-16, AIHW.[3]

Table 2a Indicative distribution of regular MedicineInsight patients by Age and Sex (MedicineInsight, October 2018, n= 2,974,031[a])

Characteristic		Sex (missing 0.2%)	
		Female % patients	Male % patients
Age group (years) (missing 0.02%)	0-4	3.2	3.5
	5-9	2.7	2.9
	10-14	2.2	2.3
	15-19	2.7	2.2
	20-24	3.9	2.4
	25-29	4.3	2.6
	30-34	4.5	2.8
	35-39	4.2	2.9
	40-44	3.7	2.8
	45-49	3.8	2.9
	50-54	3.5	2.8
	55-59	3.6	2.9
	60-64	3.2	2.7
	65-69	3.0	2.6
	70-74	2.6	2.3
	75-79	1.8	1.6
	80-84	1.3	1.1
	85-89	0.9	0.6
	90+	0.7	0.3

[a] Patients marked as 'Active' and 'RACGP Active'

Sites

Site is used to describe one or more practices that share the same installation of the clinical information system (CIS). For example, one organisation may consist of a number of geographically diverse general practices who all share the same CIS, or a site may be a single GP practice (Figure 4).
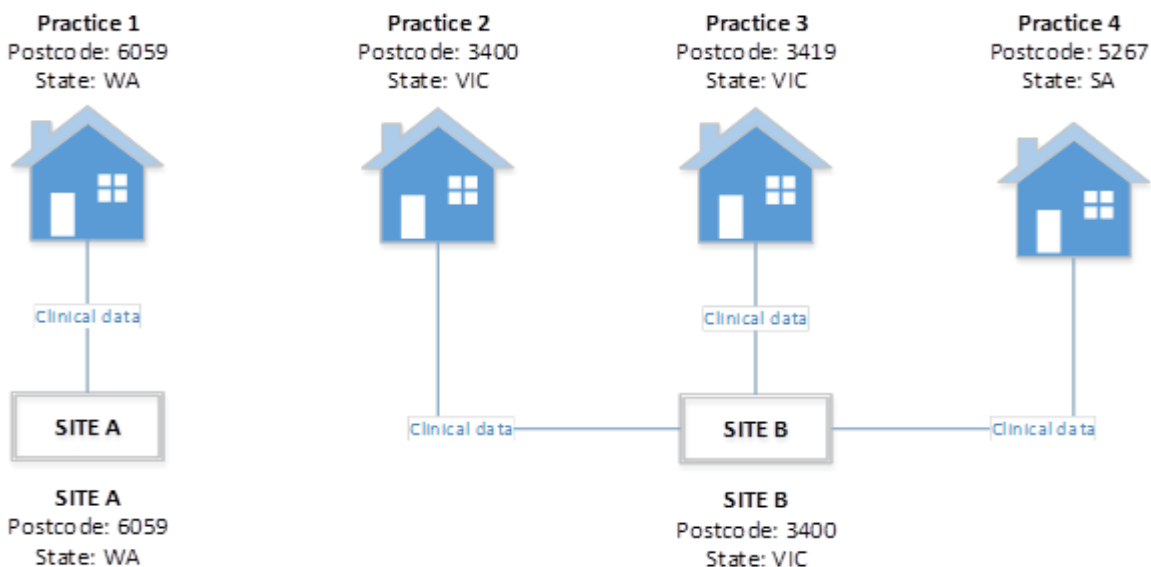

Figure 4 Schematic of practices, sites and postcode allocation (postcodes are for illustrative purposes only)

Regardless of the number of practices, MedicineInsight collects data at the site level rather than at the level of an individual general practice, and we are currently unable to assign patient records within the database of a multi-practice site to the individual practices. Most sites currently participating in MedicineInsight consist of a single general practice (Table 3).

Table 3   General practices per site (NPS MedicineWise, October 2018)

Number of general practices within each site	Sites	Total general practices	Percentage of general practices
1	496	496	74
2	47	94	14
3	5	15	2
>3	7	66	10
TOTAL	555	671	100

Site quality criteria

To ensure high quality data, MedicineInsight applies the following acceptability criteria to sites for inclusion in analyses or extracts. Sites must have:

- been established for at least two years before the end of the analysis period

- had no interruptions of six weeks or more in practice data in the two years to the end of the analysis period, and

- had consistent volume of transactions over the preceding two years.

Further detail about how these criteria are implemented is available on request and these criteria can be adapted if required for particular projects.

Site postcode is collected in MedicineInsight and there is a single value for each site. For multi-practice sites the postcode allocated is the lowest numerical value of all available practice postcodes within that site. Postcode is not available to researchers, but it is used to provide coded state and remoteness indicators using the Australian Bureau of Statistics (ABS) mapping (Postcode 2012) to Australian Statistical Geography Standard (ASGS) Remoteness Areas 2011. It is also used to calculate the SEIFA decile of the site location in accordance with the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) deciles[4].

PHN is also available where the researchers can justify this request, and where it maintains practice and patient confidentiality. However, due to potentially small cell sizes, and the potential for re-identification, this is likely to meet with Data Governance Committee approval only in very limited circumstances.

Table 4   Sites and practices by state or territory, October 2018

	Sites		Practices		
	Medicine-Insight	%	Medicine-Insight[a]	National[b]	%
NSW	200	36	238	2809	8.5
VIC	111	20	145	1990	7.3
QLD	103	19	119	1604	7.4
WA	67	12	78	696	11.2
TAS	41	7	49	171	28.7
SA	14	3	19	570	3.3
ACT	9	2	11	98	11.2
NT	10	2	12	127	9.4
TOTAL	555	100	671	8065	8.3

[a] MedicineInsight practices information from NPS MedicineWise Customer Records Management (CRM) system

[b] National practices information from National Health Services Directory (NHSD)[5], as at September 2017

Clinical users

Clinical users include any staff member who logs information in the CIS, including clinical (GP, nurse, allied health) and administrative staff. We identify individual GPs using their assigned role in the CIS in combination with their unique prescriber number, which mitigates the potential for duplication across (or within) practices. We can also identify nurse practitioners using assigned CIS user role.

Demographic information including age and gender is not available for providers. However, data can be used to estimate provider activity (number of patients, number of encounters etc).

Table 5   Indicative number of GPs by state and remoteness (MedicineInsight, October 2018)

	MedicineInsight GPs		National GPs[a]	
	No.	%	No.	%
State/Territory				
NSW	1,655	34.2	10,861	30.2
VIC	1,113	23.0	8,652	24.1
QLD	815	16.9	7,929	22.1
WA	603	12.5	3,712	10.3
TAS	381	7.9	883	2.5
SA	112	2.3	2,795	7.8
ACT	91	1.9	547	1.5
NT	64	1.3	563	1.6
TOTAL	**4,834**	**100**	**35,942**	**100**
Remoteness				
Major cities	2,925	60.5	24,657	68.6
Inner regional	1,192	24.7	6,649	18.5
Outer regional	626	12.9	3,266	9.1
Remote/very remote	91	1.9	1,371	3.8
TOTAL	**4,834**	**100**	**35,942**	**100**

[a] Data source: GP Workforce Statistics – 2001–02 to 2016–17[6].

Encounters

There is currently no single consistent definition of an 'encounter' for general practice electronic health records in Australia. A clinical encounter is generally defined as an interaction between a patient and a healthcare professional. However, this is difficult to determine in MedicineInsight, as an 'encounter' occurs in the CIS whenever a patient's electronic health record is opened. This may occur for clinical reasons (such as a consultation) or for administrative purposes (such as reviewing or updating a patient record). In addition, CISs work differently, for example, in Medical Director, if a patient record is opened and no changes or entries are made to the record, the user may choose to discard the encounter. If discarded, the encounter record is still created in the database but with a discarded flag, and a deleted record flag.

Medical history

The CIS uses coding systems such as 'Docle' in Medical Director or 'Pyefinch' in Best Practice to code data entered into the system. However, it is not mandatory to use a code and clinicians can also enter terms as free text. Both coded and free-text data are extracted from the CIS, however data are not extracted from fields such as the progress notes that may contain identifying information.

Medical, pharmaceutical and other experts in the MedicineInsight team develop algorithms to identify specific conditions and measures of interest in the MedicineInsight database, based on commonly accepted definitions. A patient may be flagged as having a specific condition flagged based on:

- a relevant 'Docle' or 'Pyefinch' code recorded by the user, and/or

- a free-text term in a designated field ('diagnosis_reason', 'encounter_reason' or 'reason' in the prescription table).

Note that both the diagnosis date (which may be used for conditions with an earlier date of onset) and the actual date entered into the clinical system are captured. The contents of these fields may vary with differing clinical workflows.

Examples of conditions which have been identified include:

- cardiovascular conditions (eg, atrial fibrillation, heart failure, ischaemic heart disease, stroke)

- chronic kidney disease

- dyslipidaemia

- diabetes (including subtypes)

- mental health (eg, anxiety, depression, schizophrenia)

- osteoarthritis

- respiratory conditions (eg, asthma, chronic obstructive pulmonary disease)

- infectious diseases (eg, hepatitis C, HIV).

Custom cohorts may be generated as required for specific projects.

Investigations

Investigations requested through the CIS (eg, pathology, radiology etc) are recorded in MedicineInsight.

The results of investigations may be received electronically by the CIS or may be manually entered into the CIS and in both cases are captured in MedicineInsight. Pathology results received electronically by the CIS are recorded in MedicineInsight using Logical Observation Identifiers Names and Codes (LOINC). Where investigations are requested as a group (eg, full blood count) but reported as several individual values (eg, haemoglobin, mean cell volume, haematocrit,

etc) each individual result is stored in MedicineInsight. Results of tests requested by other providers (eg, hospitals, outpatient clinics or specialists) which have been copied to the patient's GP are included in MedicineInsight if they have been electronically transferred or manually entered into the CIS.

Investigation results which are not captured in MedicineInsight include historical results in Pathology Information Transfer (PIT) format, results listed in letters from specialists which are scanned into the CIS as PDF documents and results documented in the progress notes not collected by MedicineInsight.

Medicines

Medicine information is available in two separate tables. The Medicine History table provides information on current and past medicines for a patient. It does not record the number of times a prescription has been issued. The Prescription Issued table contains data regarding prescriptions that have been printed out using the CIS.

Considerations when using the medicines information include:

- the data relates to prescribed medicines, not necessarily dispensed medicines

- there may be delays between prescribing and dispensing of up to 12 months

- medicines prescribed elsewhere (eg, by specialists or hospitals) are only included if manually entered into the CIS

- over-the-counter (OTC) medicines are included only if manually entered into the CIS.

Allergies and adverse reactions

The allergies table is used to track substances which patients are allergic (or have an adverse reaction) to, and the response. For example, a patient might be recorded as allergic to penicillin with an anaphylactic response. This is not an event-based data table and does not necessarily record each occurrence of an allergic response.

Immunisations

Immunisations can be recorded in the clinical system as either immunisations or prescriptions. For an immunisation to be transmitted to the Australian Immunisation Register (AIR), it must be recorded as an immunisation. Immunisations are recorded by brand name and have some additional data points available including batch number and date administered.

Observations

Clinical observations recorded about the patient at the time of the encounter eg, blood pressure (systolic and diastolic), heart rate, height, weight, BMI, temperature, blood sugar etc.

MBS billing

MBS billing data are available when sites use integrated clinical and practice management software from the same vendor. If a site changes their combination of software this can affect the completeness of billing data over time. Billing data can be used to identify different groups of patients such as those who are seen in a Residential Aged Care Facility or those who have cycles of care completed.

APPENDIX 1: Worked examples

Recording a patient's clinical encounter

Scenario: A 65-year-old male patient sees his regular GP at a MedicineInsight practice in December 2017 and discusses two issues (chest pain and shortness of breath) during the encounter. The GP takes his blood pressure and asks if he has been taking his hypertension medication. The GP provides him with a provisional diagnosis of cardiovascular disease and he receives a repeat of his hypertension medication and a new script for a bronchodilator inhaler.

➤ How this is recorded in MedicineInsight tables.

- Patient – No change. The patient already exists in the database.

- Encounter – A new row is added with details of the date/time and other administrative information.

- Encounter reason – Two rows are added for chest pain and shortness of breath.

- Observation – A row is added for blood pressure.

- Diagnosis – A row is added for cardiovascular disease and the provisional diagnosis variable is flagged.

- Prescription issued – A new row is added for the hypertension medication. A new row is added for the bronchodilator inhaler.

- Medicine History – The last script date changes for the hypertension medication. A new row is added for the bronchodilator inhaler.

Scenario: A female patient with diabetes visits a GP for the first time at a MedicineInsight practice to have her blood sugar (HbA$_{1c}$) tested using a GP who bulk bills. The GP documents her basic demographics and medical history (including a previous diagnosis of irritable bowel syndrome) on the new intake form. The GP asks about her diet, smoking history and measures her height and weight.

➤ How this is recorded in MedicineInsight tables.

- Patient – A new row is added, including her basic demographics and smoking status.

- Observation – Two new rows are added for patient's height and weight.

- Diagnosis – Two new rows are added including the patient's medical history of diabetes and irritable bowel syndrome.

- Encounter – A new row is added with details of the date/time and other administrative information.

- Encounter reason – One row is added for the HbA$_{1c}$ testing.

- Pathology – A row is added for the HbA$_{1c}$ test ordered.

- Pathology result atom – Once received, a new row is included for the results of her HbA$_{1c}$ test.

- Smoking – A new row is added capturing her smoking status and history for the visit date.

- MBS Billing – A new row is added to the billing service table using the appropriate MBS code for the consultation.

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