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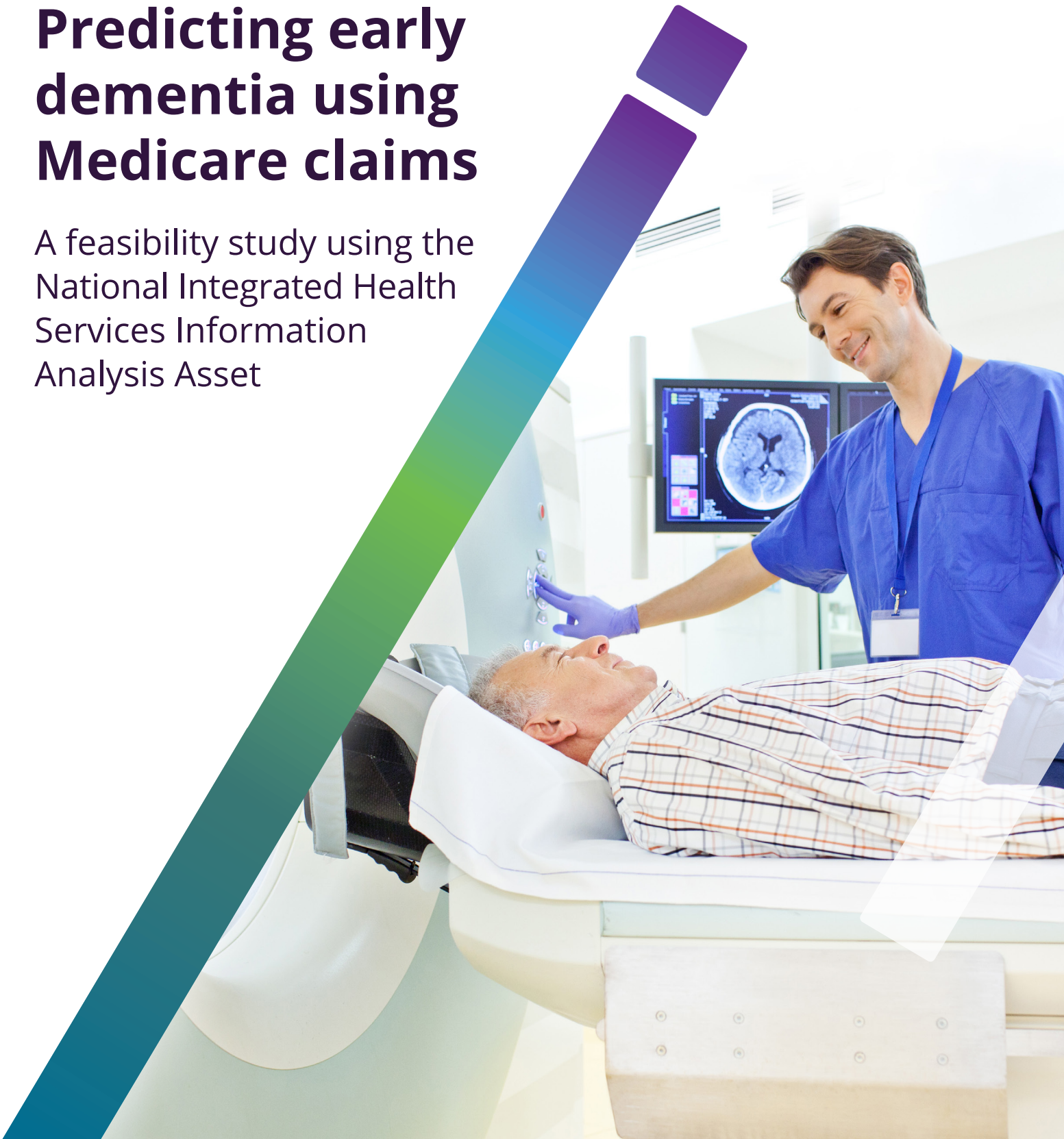
Predicting early dementia using Medicare claims

A feasibility study using the National Integrated Health Services Information Analysis Asset



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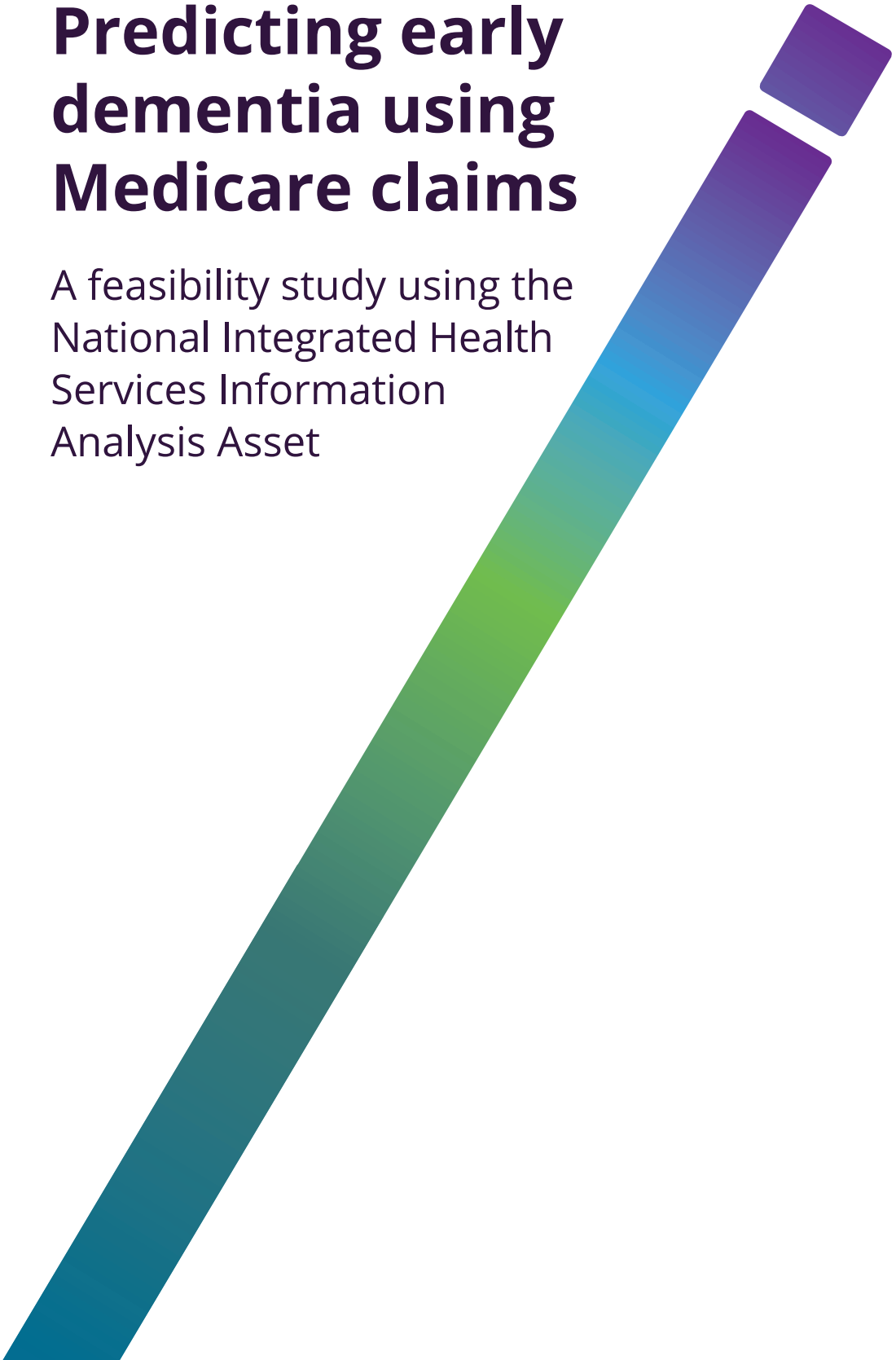

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Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Tel: (02) 6244 1000
Email: info@aihw.gov.au

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Summary

Background

Administrative data provides a wealth of information that can be used to monitor dementia in Australia. Currently, a diagnosis of dementia can be identified in hospital admitted patient care, mortality, aged care and Pharmaceutical Benefits Scheme (PBS) data. However, these sources tend to be best at identifying people with later stages of dementia, as disease progression leads to more frequent contact with various parts of the health and aged care systems.

Primary and secondary care data provide the best opportunity to identify people living in the community who are in the early stages of dementia. However, the lack of explicit identification of a dementia diagnosis in primary and secondary care data is currently a key data gap for dementia monitoring in Australia. There are, however, several Medicare-subsidised services that are commonly accessed by practitioners and their patients in the course of diagnosing dementia in its earlier stages. These include services such as the practitioner appointments themselves, diagnostic imaging and pathology, and team care arrangements.

This feasibility study aims to test whether, at a given point in time, the presence of dementia can be identified from Medicare Benefits Schedule (MBS) item claims that reflect the steps taken by medical practitioners in the diagnosis of dementia. This analysis was undertaken on the National Integrated Health Services Information Analysis Asset (NIHSI-AA), which links together the MBS, PBS, hospitals and aged care data needed to identify a cohort of people with early dementia. Two techniques were tested for identifying early dementia: a decision tree and logistic regression analysis.

Results and future directions

When deployed, both models enumerated around 30,000 possible cases of early dementia. Around 25,000 of these were true cases of early dementia, as far as can be identified by the PBS data. Overall, the models were able to capture approximately 80% of people who went on to receive a dementia-specific medication prescription within 2 years of their use of these Medicare service items.

The models developed and tested in this study have shown that geriatric services and brain scans are highly associated with early dementia, both individually and in combination as a service 'pathway'. More niche services, such as those associated with consultant psychiatrists, have strong association for individuals accessing them but do not appear to be a common feature of the general early dementia diagnosis and management pathway.

While these initial results demonstrate that MBS items can feasibly be used to bring estimates of dementia prevalence in Australia closer to the true prevalence, these models should continue to be improved to enable more complete and accurate measurement of dementia. Further exploratory work into the characteristics of misclassified individuals will likely yield improvements to this detection method. This may include:

- exploring further individuals who are misclassified due to data gaps (such as missing hospital information, alternative services streams such as Aboriginal Health Service use)
- assessing similarity between dementia diagnosis pathways and other conditions
- identifying individuals who did not access the PBS during the period of time assessed but are captured in other data sets in later years.

This refinement, alongside alternative identification approaches such as machine-learning techniques, may allow for better identification of individuals with early dementia and therefore more accurately assess the service needs and burden of disease.

1 Introduction

Dementia monitoring and diagnosis in Australia

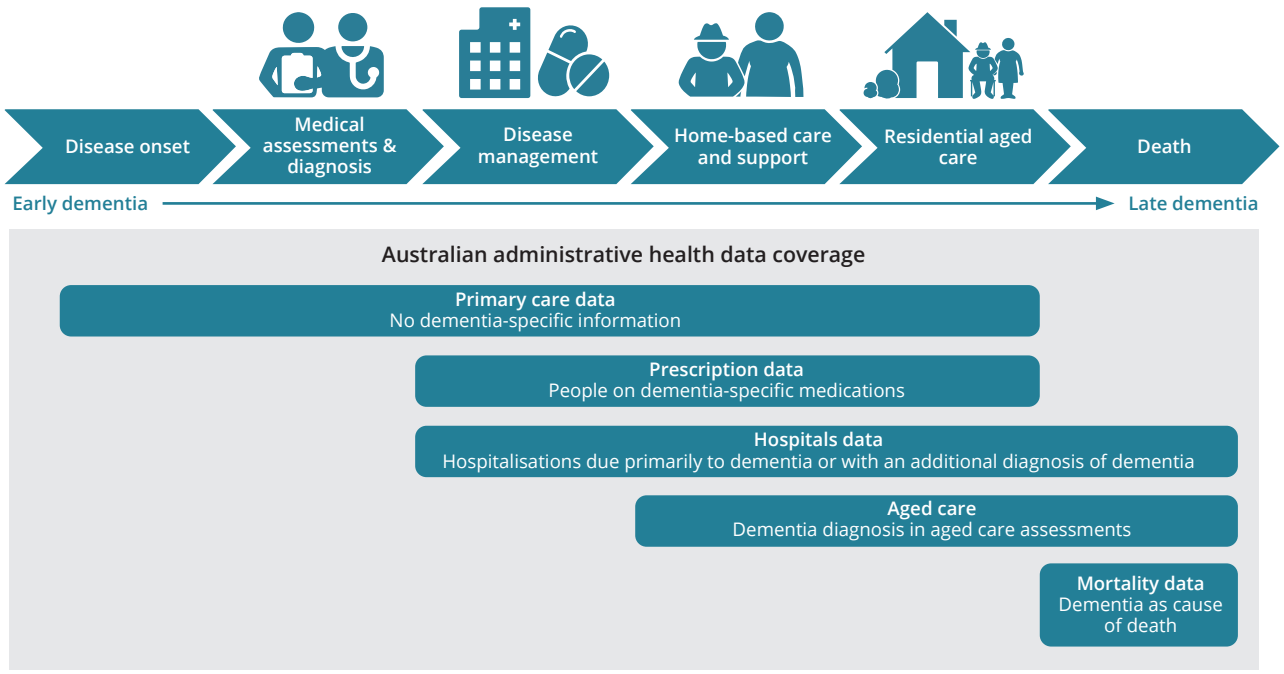
As the third leading cause of burden of disease (AIHW 2021a) and the second-leading cause of death overall (AIHW 2020a) in 2018, dementia represents a major population health issue in Australia. Dementia is a collection of symptoms caused by a range of disorders affecting the brain and is a progressive and usually irreversible condition that develops substantial health and personal care needs over time (WHO 2019).

Until recently there has been little systematic monitoring or reporting on dementia in Australia. It is estimated that in 2021 there were between 386,200 and 472,000 Australians with dementia (AIHW 2021b), an estimate based on rates derived from published international and local studies that have been applied to the Australian population. While these sources do provide valuable information on dementia prevalence, they become quickly outdated and are often based on small studies and international data that do not necessarily translate to the Australian context (AIHW 2020b).

There are several Australian health data collections in which a diagnosis of dementia can be identified, including hospital admitted patient care, mortality, aged care and Pharmaceutical Benefits Scheme (PBS) data. While these data sources each have their own limitations and population coverage considerations (see Figure 1 for an overview), they have the potential to provide an ongoing and regularly updateable source of information on dementia prevalence that is directly relevant to the Australian population. However, the picture painted of dementia in Australia by these data sources may be incomplete. With the exception of the PBS, these sources predominantly reflect service use by people with more severe and progressed dementia. Information is therefore missing on the cohort of people with early, mild dementia who are less likely than those with more progressed disease to use tertiary and residential care services. People with early dementia are instead more likely to make use of primary and secondary care services, especially during the diagnosis and early management stages.

Primary and secondary care data provide the best opportunity to identify people living in the community who are in the early stages of dementia. However, as noted in Figure 1, there is currently no national source of general practitioner (GP) and specialist care data with dementia-specific information that would make these sources suitable for dementia monitoring (AIHW 2020b). Knowledge of how dementia is diagnosed through primary and secondary care, and which health services are used in the process, can provide further insights into identifying patients at the earlier stages of the dementia pathway.

Figure 1: Dementia pathway and associated national data collections and their coverage for reporting dementia



To diagnose dementia, medical practitioners typically go through a series of steps when a patient presents with symptoms of cognitive decline (Dementia Australia 2014; CeRDI 2013). The key services that may be utilised in this process include:

- the initial GP consultation at which the patient may present with symptoms of dementia, as well as any follow-up consultations throughout the diagnosis process
- administration of cognitive screening tools to check for altered cognitive function
- investigative activities such as home medicines reviews and pathology testing
- diagnostic imaging such as magnetic resonance imaging (MRI) or computed tomography (CT) head scans to check for structural changes in the brain
- referral to other specialists such as geriatricians, neurologists or psychiatrists for treatment
- development of a team care arrangement or GP management plan.

There are also multidisciplinary specialist clinics such as memory clinics that aim to streamline these assessment and diagnosis processes.

Not everyone with early dementia will utilise this exact set of services (or in this order) in the lead up to initial diagnosis and treatment. However, these steps provide a good indication of combinations of services that could potentially help to uniquely identify people with early dementia in Medicare data before they appear in other administrative health data sets.

Medicare claims can help fill the primary–secondary care data gap

Linkage of multiple administrative health data sources is helping to overcome some of the challenges with dementia monitoring in Australia, and progress toward demonstrating the feasibility of using linked data as an ongoing source of dementia prevalence data is promising. With medical services being the first point of contact for patients with potential dementia, finding a means of detecting dementia cases in Medicare Benefits Schedule (MBS) data would be an important step to filling the data gaps for primary and secondary care and better measuring the prevalence of early (and overall) dementia.

Medicare is Australia's universal health insurance scheme. The MBS lists the medical services covered by Medicare and the benefit that people can claim when they access services on the schedule. Each type of service is identified by a unique code, which provides some detail of the services being accessed by patients under the Medicare scheme. However, most of the data do not include information on health conditions, and none contain information on dementia, so in most cases it is not possible to deduce for what conditions these services are being provided. Nevertheless, similar health claims data have been utilised elsewhere in the world as a source of information to improve dementia monitoring.

Just as this study hopes to do, Di Francesco et al. (2019) used Italian administrative health data to generate and validate different algorithms for identifying individuals with dementia in the community. The study found that specific indicators produced some good results for identifying dementia—for example, treatment with dementia-specific medications, CT/MRI scans and neuropsychological tests—but their models struggled to achieve satisfactorily high sensitivity in detecting cases of dementia. Albrecht et al. (2018) conducted a similar study using US health-care utilisation data and obtained models with moderate (area under the ROC curve (AUC) = 0.78) to poor (AUC = 0.60) discriminatory power.

Often, more detailed data improve the ability of statistical models to predict disease. Studies by Jammeh et al. (2018) and Shao et al. (2019) utilised both routinely collected structured and unstructured health records to create indicators for dementia and predict probable dementia. Structured data refers to data that are quantitative in nature, such as measurements, counts and categories, while unstructured data come from sources such as notes and records or verbatim answers. Both studies achieved stronger predictive power than previous studies based on administrative health data alone and produced a predictive model with both good sensitivity (0.84 and 0.83, respectively) and specificity (0.87 and 0.83, respectively) for detecting dementia.

What are sensitivity and specificity?

When trying to predict an outcome from data, a model is developed that represents the data as accurately as it possibly can. While a model will rarely fit the underlying data perfectly, a good model should classify the known outcomes (in this case, whether or not a record is identified as having early dementia) correctly most of the time. Two measures that describe how well a model does this are sensitivity and specificity.

Sensitivity refers to how well the model detects the outcome of interest. It is the probability that a record is predicted as a dementia case (a true positive) among those identified as having dementia (all true cases).

Specificity refers to how well the model detects those without the outcome of interest. It is the probability that a record is predicted as a non-dementia record (a true negative) among those not identified as having dementia (all true controls).

Area under the curve (AUC) compares the true positive rate (the sensitivity) to the false positive rate (1-specificity) along all predicted probability values. It provides an overall measure of the ability of the model to accurately distinguish true positives from false ones.

So despite the absence of explicit dementia diagnosis coding in Australian primary and secondary care data, it is reasonable to expect that there may be unique patterns of MBS item claims that signal a probable dementia diagnosis in advance of any diagnosis being recorded in other sources of information. In order to test this, extra data are needed that do capture dementia to allow the development of a cohort for model training and validation.

In this study, we used linked data from aged care assessments, hospital admissions and the PBS in the AIHW-held National Integrated Health Services Information Analysis Asset (NIHSI-AA) to isolate a cohort of people with newly diagnosed dementia. This cohort was then used to train predictive models to use MBS item claims to predict early dementia. Excluding the MBS, collectively, these data sources are estimated to be able to detect approximately 80% of all underlying cases of dementia in their populations (Welberry et al. 2020).

Aims of this report

This project aims to:

- describe the primary care and secondary health-care service use of people with early dementia
- improve prevalence and incidence estimates for dementia by estimating cases of early dementia that, at a given point in time, do not have a diagnosis recorded in national administrative data
- provide insight to the feasibility of using routinely collected administrative data (in the absence of GP and specialist dementia-specific data) to identify people in the early or mild stages of dementia.

2 Methodology overview

There are 2 main components to the analysis methodology for this project: identifying people with early dementia in the linked data, and developing an algorithm that can accurately identify people with early dementia. The full methodology is outlined in Figure 2.

Identifying people with early dementia

The methodology for building a cohort of people with early dementia drew on the approach for dementia cohort construction developed for the project *Patterns of health service use by people with dementia in their last year of life: New South Wales and Victoria* (AIHW 2020c), using the National Data Linkage Demonstration Project (NDLDP) data set. This approach was refined to include aged care data, new jurisdictions and modifications to capture newly diagnosed dementia and was applied to the NIHSI-AA.

For this study, someone was identified as having newly diagnosed dementia if they were prescribed dementia-specific cholinesterase inhibitor medications for the first time under the PBS. Cholinesterase inhibitors (donepezil, rivastigmine, galantamine) are listed on the PBS for use in the treatment of mild to moderate Alzheimer's disease specifically, however, clinical trials suggest that cholinesterase inhibitors may also provide limited benefits for people with dementia with Lewy bodies, vascular dementia or mixed dementia (Dementia Australia 2018). Given the nature of the medication, the dementia cohort will likely be largely comprised of people recently diagnosed with Alzheimer's disease for whom dementia-specific medications are clinically indicated. These medications are usually prescribed initially by specialists such as geriatricians, neurologists and psychiatrists, however, as of November 2011, they may also be prescribed by a GP after a diagnosis is made in consultation with a specialist (DUSC 2016).

It is important to note that not all people with dementia are prescribed these medications and this cohort will therefore likely not include people in the early stages of some specific types of dementia (e.g. vascular dementia or Lewy body dementia). It is also important to note that this method won't pick up people who may be treated early on using other therapies rather than medications, such as occupational therapy or through environment modification. The implications of this are that while the people with dementia in this study are very likely to actually have dementia (since they are being pharmacologically treated for it), they are likely to be a subset of people with early dementia for whom medication was indicated.

People recently initiated on dementia-specific medications were excluded from the initial cohort if they had:

- an Aged Care Funding Instrument (ACFI) assessment (with or without a diagnosis of dementia) before their first recorded PBS claim
- a hospitalisation with any diagnosis of dementia prior to their first recorded PBS claim
- claimed an item through Medicare before their first recorded PBS claim that is only available to residents of aged care facilities.

These exclusions are designed to limit the PBS cohort to those who have no history of hospitalisation for dementia or of living in residential aged care. This step is very important for 2 reasons: it isolates true early dementia cases in the community that will not have had a diagnosis recorded elsewhere in Australian health data, and it ensures that the analysis is focused on differentiating the service use of people with early dementia from people without dementia, to the best of our ability to do so within this data set, rather than from a population that includes existing dementia patients.

Developing an algorithm to predict early dementia

The approach used to develop an algorithm for predicting early dementia from MBS items involved 3 steps: training and refining the models on a 'training' cohort; testing the model using cross-validation (where applicable); and deploying the model on a fresh 'deployment' cohort.

Training, cross-validation and deployment

When developing any form of model or algorithm, it is important to test the model against fresh data to check how well it performs. For this reason we initially develop what is called a **training cohort** and then a second **deployment cohort**.

The **training cohort** is an initial set of data where a group with the outcome of interest—in this case having a first dementia medication prescription—are identifed and matched with a group with a similar age and sex profile (but with no dementia medication prescription). The variables suspected of holding some predictive value (in this case, MBS items relating to dementia diagnosis) are put into a model to assess just how well they differentiate between the 2 groups.

From this model we may find that some variables almost exclusively occur in 1 group (say the dementia cohort) but not the other. This may mean that these variables could be a good indicator of a person ending up with a dementia medication prescription; however, to be sure that these patterns apply beyond the data that the model was trained on, we need to validate the model and apply it to fresh data.

Cross-validation is used as a way to test and validate a machine-learning model when limited data are available. This process essentially creates new data sets by resampling, that is, taking a new subset of the full training data set, and then applying the model to check how well it performs in the 'new' data.

Once a model is validated and the performance is satisfactory, it is then deployed. The **deployment cohort** provides a fresh set of data in which none of the original participants are included. The algorithm is applied to this cohort, and the number of correctly and incorrectly identified participants is noted—providing information about how accurate the algorithm is.

For this analysis, the training cohort comprised individuals whose first prescription for a dementia medication occurred in 2015–2017 and a control group of age- and sex-matched individuals without a dementia prescription or history of dementia. The deployment cohort comprised individuals with their first prescription in 2012–2014 and a random selection of people without a dementia prescription or history of dementia. These years were chosen specifically to enable a 2-year look-back period for examination of MBS items prior to the index prescription.

Groups of people with early dementia will be demographically different to groups of people without dementia, particularly in their age, and consequently will have systematically different patterns of health service use. Training an algorithm to predict early dementia based on service use without taking this into account risks illuminating more about service use patterns in older age groups compared to younger, healthier age groups, rather than patterns specifically unique to early dementia. For this reason, an age- and sex-matched control group with no history of dementia was used as a training cohort, with the subsequent derived algorithm deployed on a cohort more reflective of a general population.

The target MBS items that were selected for exploration, as well as their groupings, are shown in Table 1. The MBS items shortlisted were informed by the AIHW's Dementia Working Group, which includes clinical, policy and data experts, academic researchers, service providers, advocacy groups and people with a lived experience of dementia. All analysis was performed in SAS Viya.

Figure 2: Analysis methodology summary

Step 1. Generate a provisional training cohort from PBS records during years 2015–2017	
1a. If first dementia medication prescription occurs in 2015–2017, assign to provisional dementia group	1b. If no dementia medication prescription across entire data period (2009 to 2017) but individual present in PBS data between 2015–2017 then assign to provisional non-dementia group
Step 2. Apply exclusions to refine training cohort	
2a. Remove people with *prior* records of dementia hospitalisation or aged care residence from dementia group	2b. Remove people with *any* record of dementia hospitalisations or aged care residence from provisional non-dementia group
Step 3. Select an age- and sex- matched control group from provisional non-dementia group	
Step 4. Examine target MBS item claims in 2 years leading up to first prescription in 2015–2017 (first dementia or other non-dementia prescription)	
Step 5. Develop algorithms to predict dementia status from MBS target item use	
Step 6. Follow steps 1 and 2 then select a randomised group of people without dementia to create a deployment cohort for years 2012–2014	
Step 7. Apply algorithms developed in Step 5 to previous 2 years of MBS item claims leading up to prescription in 2012–2014	
Step 8. Test predictive strength, sensitivity and specificity of algorithm on deployment cohort	

Table 1: MBS target item groups

MBS item	Description
GP and non-specialist attendances	
3, 23	General practitioner (GP) attendance in relation to 1 or more health-related issues (less than 20 mins long)
701, 703, 705, 707, 715	Professional attendance by a GP to perform a brief (less than 30 mins), standard (30–45 mins), long (45–60 mins) or prolonged (60+ mins) health assessment
53, 54	Professional attendance at consulting rooms by a medical practitioner (who is not a GP) or a Group A1 disqualified GP (item 53: 5–25 mins long; item 54: 25–45 mins long)
229, 231, 232, 233, 721, 729, 731, 732	Preparation, contribution and review of a GP Management Plan (GPMP) for a patient; GP participation in case conferencing organised/coordinated by another provider
900	Domiciliary Medication Management Review (DMMR) by a GP for a patient living in a community setting
36, 44	GP attendance consultation in relation to 1 or more health-related issues (item 36: at least 20–40 mins long; item 44: over 40 mins long)
230, 723	Attendance by a GP to coordinate the development of team care arrangements for a patient
235, 236, 237, 238, 239, 240, 735, 739, 743, 747, 750, 758, 820, 822, 823, 825, 826, 828, 830, 832, 834, 835, 837, 838, 855, 857, 858, 861, 864, 866	Contribution to a Multidisciplinary Care Plan, or Review of a Multidisciplinary Care Plan, for a patient who is not a care recipient in a residential aged care facility
Non-GP specialist consultations	
99, 104, 105, 107, 108, 111, 115	Specialist attendances
110, 112, 114, 116, 117, 119, 120, 122, 128, 131, 132, 133	Consultant physician attendances (other than psychiatrist)
141, 143, 145, 147, 149	Geriatrician attendances
288, 289, 291, 293, 296, 297, 299, 300, 302, 304, 306, 308, 310, 312, 314, 316, 318, 319, 320, 322, 324, 326, 328, 330, 332, 334, 336, 346, 338, 342, 344, 348, 350, 352, 353, 355, 356, 357, 358, 359, 361, 364, 366, 367, 369, 370	Consultant psychiatrist attendances
880	Specialist or consultant physician (geriatrician or rehabilitation) attendance in case conferencing
Diagnostic imaging services	
56001–56036 (CT scan of head – all items in subgroup) and 57001–57007 (CT scan of brain, chest and upper abdomen – all items in subgroup)	Computed tomography (CT)
61523–61647 (all items in subgroup)	Positron emission tomography (PET)
63001–63010, 63040–63073 (MRI of head – for specific conditions)	Magnetic resonance imaging (MRI)

(continued)

Table 1 (continued): MBS target item groups

MBS item	Description
Pathology services	
73802–73804, 73805, 73829–73831 (blood count tests)	Simple basic tests
73899–73939 (all items in group)	Patient episode initiation
65060–65181 (all items in group)	Haematology
66500–66512; 66566–66584, 66599*, 66602*, 66608–66609*, 66719, 66833–66837, 66838–66840	Chemical
69381, 69384–69415	Microbiology

* Items discontinued in November 2014. Included for deployment cohort history only as a proxy for the newer items.

3 Results

Early dementia group characteristics

The dementia group in both the training and deployment cohorts were those living in the community (i.e. not in a residential aged care facility) who had no history of dementia prior to their first dementia record (FDR) in the PBS and who had a history of at least 1 MBS item in the 2 years leading up to that first prescription.

People with dementia in the training and deployment cohorts have very similar age, sex and state/territory profiles (Table 2). Records identified as early dementia primarily belonged to people aged 65 and over, comprising 94% of both the training and deployment cohorts. There were slightly more women than men, with the training cohort being 55.5% female and the deployment cohort being 57.5% female. The distribution of state or territory of usual residence (as recorded in the PBS at the time of their prescription) is broadly in line with the national population distribution, with some small differences to be expected due to the age of the cohorts and limitations in data availability.

Table 2: Dementia cohort demographics

	Training cohort FDR in 2015–2017		Deployment cohort FDR in 2012–2014	
	Number	%	Number	%
Age group (years)				
30–34	n.p.	n.p.	n.p.	n.p.
35–39	n.p.	n.p.	n.p.	n.p.
40–44	29	0.1	25	0.1
45–49	70	0.3	57	0.2
50–54	170	0.6	181	0.6
55–59	421	1.5	459	1.5
60–64	932	3.3	1,017	3.2
65–69	2,170	7.7	2,262	7.2
70–74	4,349	15.3	4,559	14.5
75–79	6,798	24.0	7,637	24.2
80–84	7,378	26.0	8,629	27.4
85+	6,042	21.3	6,702	21.2
Sex				
Females	15,736	55.5	18,145	57.5
Males	12,642	44.6	13,402	42.5
State/territory[(a)(b)]				
NSW	9,021	32.0	10,447	33.3
VIC	6,843	24.2	7,739	24.7
QLD	6,125	21.7	6,069	19.3
WA	2,585	9.2	3,108	9.9
SA	2,517	8.9	2,941	9.4
TAS	532	1.9	564	1.8
ACT	554	2.0	485	1.5
NT	50	0.18	46	0.2

FDR first dementia record

n.p. not publishable because of small numbers, confidentiality or other concerns about the quality of the data

(a) 294 records from the training cohort were missing state of residence information.

(b) 327 records from the deployment cohort were missing state of residence information.

Which services did patients with and without early dementia use?

The item utilisation patterns of people in the training cohort form the basis of the models developed, and any large differences between the dementia and non-dementia group will likely be reflected in the final predictive algorithm.

In the training cohort, people in the dementia group were generally more likely to have accessed each of the target MBS items in the look-back period than people in the non-dementia group. When compared to the non-dementia group, people in the dementia group were relatively least likely to use PET items (rate ratio = 0.8) and relatively most likely to use geriatrician attendance items (rate ratio = 47.6) (Table 3).

People in the dementia group of the training cohort were substantially more likely than those in the non-dementia group of the training cohort to have accessed a geriatrician through Medicare in the look-back period (34% compared with 0.7%). They were also much more likely than the non-dementia group to have accessed psychiatrist services (9% compared with 1%), had at least one MRI or CT scan (26% and 65%, respectively, compared with 3% and 18%, respectively) and undergone microbiological pathology testing (10% compared with 3%).

Some target items had very little differentiating power between the dementia and non-dementia groups. People in the dementia group in the training cohort were equally as likely as people without dementia to have claimed items related to short GP attendances (less than 20 minutes) and specialist attendances. These target items—short GP attendances and specialist attendances—are commonly claimed among people with and without dementia (around 98% for short GP attendances and around 63% for specialist attendances). Similarly, items that are known to be important to dementia management, such as medication reviews and GP management plans, are not as differentiating as might be expected due to being fairly commonly used by patients in older age groups. This further highlights the importance of having a matched cohort for training, as the importance of these items might otherwise have been overstated if the comparison were to a younger group of people.

Overall, the items that are highly differentiating between the dementia and non-dementia groups (i.e. have high rate ratios) remain so in both the training and deployment cohorts. Geriatrician attendances particularly stand out more as an indicator of dementia when the non-dementia cohort has a broader age mix, rather than being age-matched. Additionally, some large differences can be seen between the non-dementia groups in each cohort. This is predominantly due to the structural differences in the populations, with the training non-dementia group being much older than the deployment non-dementia group.

Table 3: Number and percentage of dementia and non-dementia groups that used target items at least once in look-back period, by cohort

	Training cohort					Deployment cohort				
	Dementia		Non-dementia		Rate ratio	Dementia		Non-dementia		Rate ratio
MBS item group[a]	Number	%	Number	%		Number	%	Number	%	
General practitioner (GP) attendances (<20 minutes)	27,739	97.8	47,621	98.0	1	30,675	97.2	58,136	96.6	1
Health assessment	10,934	38.5	14,765	30.4	1.3	11,403	36.2	3,435	5.7	6.3
Professional attendances	3,198	11.3	4,779	9.8	1.1	3,145	10.0	7,090	11.8	0.8
GP Management Plan preparation, contribution and review	15,450	54.4	22,061	45.4	1.2	14,996	47.5	10,480	17.4	2.7
Domiciliary Medication Management Review in community	1,591	5.6	1,988	4.1	1.4	1,971	6.3	436	0.7	8.7
GP attendances (>20 minutes)	24,027	84.7	32,553	67.0	1.3	25,314	80.2	29,805	49.5	1.6
Team Care Plan coordination or development	12,562	44.3	17,013	35.0	1.3	11,640	36.9	7,540	12.5	2.9
Multidisciplinary case conference	989	3.5	717	1.5	2.4	865	2.7	248	0.4	6.7
Specialist attendances	17,941	63.2	30,944	63.7	1	19,487	61.8	22,963	38.2	1.6
Consultant physician attendances	19,701	69.4	22,119	45.5	1.5	21,187	67.2	13,842	23.0	2.9
Geriatrician attendances	9,587	33.8	344	0.7	47.6	8,732	27.7	102	0.2	162.8
Consultant psychiatrist attendances	2,547	9.0	476	1.0	9.2	2,813	8.9	1,245	2.1	4.3
Computed tomography (CT) scan	18,572	65.5	8,983	18.5	3.5	21,051	66.7	5,502	9.1	7.3
Positron emission tomography (PET) scan	218	0.8	482	1.0	0.8	174	0.6	183	0.3	1.8
Magnetic resonance imaging (MRI) scan	7,501	26.4	1,281	2.6	10	7,285	23.1	1,015	1.7	13.7
Simple basic tests	635	2.2	959	2.0	1.1	627	2.0	599	1.0	2
Chemical pathology	22,155	78.1	17,520	36.1	2.2	28,381	90.0	25,173	41.8	2.2
Microbiology	2,932	10.3	1,222	2.5	4.1	3,506	11.1	1,572	2.6	4.3
Consultant physician (geriatrician or rehabilitation) case conferencing	971	3.4	942	1.9	1.8	810	2.6	203	0.3	7.6

(a) For detailed MBS items in each group, see Table 1.

Predicting early dementia from service items

How does predicting newly diagnosed dementia from service items work?

Items that are heavily differentiating (i.e. are used a lot more or a lot less often by people with early dementia than those without) can be used as an indication of the likelihood that a person is in the process of being diagnosed with dementia. As discussed in the previous section, some types of services are clearly utilised more often by people with early dementia. Most of the time, the services that differentiate between the groups make real-world sense in that they are services that would be accessed in the course of diagnosing a cognitive disease in an older person.

By combining highly differentiating characteristics into a single model, each characteristic (in this case, the target MBS service items) contributes its differentiation power to an overall model that can be used to predict the likelihood of someone having early dementia.

How is predictive power assessed?

Predictive power is assessed using multiple measures that each say something different about how well a model discriminates between groups, as well as how completely and reliably it captures those groups.

The broadest measure is the overall **misclassification** rate. This measures the overall accuracy of a model, which is the proportion of all records that weren't correctly predicted. A misclassification rate of 0.15, or 15%, means that 85% of all predictions made were correct.

There are 2 measures of completeness, which refer to how well the model captures everyone who is known to belong to the target and non-target groups. The first of these, **sensitivity**, measures how well the model accurately classifies the target group (in this case, people with dementia). A sensitivity of 0.85 means that 85% of all known people in the target group were classified correctly. The second measure, **specificity**, measures how well the model accurately classifies everyone else (in this case, people without dementia). A specificity of 0.85 means that 85% of all non-target people were classified correctly.

There are also 2 measures of the reliability of the results of a predictive model. **Positive predictive value (PPV)**, also known as precision, measures the accuracy of the model's predicted target group. A PPV of 0.85 means that, out of the group of people predicted to be in the target group (in this case of having dementia), 85% are truly in the target group. Conversely, **negative predictive value (NPV)** measures the accuracy of the predicted non-target group. An NPV of 0.85 means that, of the predicted non-target group (in this case those without dementia), 85% are truly not in the target group.

Finally, the area under the **ROC curve (AUC)** measures how well the model distinguishes between actual target and non-target groups along a continuum of threshold probabilities. A large AUC indicates that the probabilities calculated by the model for each person are largely correct in their reflection of the likelihood of that person being in the target group. A smaller AUC indicates that the probabilities the model has calculated to classify people are not very reflective of the true group that person belongs to. Some models may perform really well at lower probabilities (i.e. are good at classifying people not in the target group), but will not be able to maximise the AUC because they do not also perform well classifying people with higher probabilities into the target group.

Predicting early dementia with a decision tree

What is a decision tree?

A decision tree is a flowchart-like diagram that shows the various outcomes from a series of decisions. Decision trees learn how to best split the data set into smaller and smaller subsets to predict the target value. The conditions, or tests, are represented as the nodes and the possible outcomes as 'branches'. This splitting process continues until no further gain can be made and the classification terminates at a 'leaf' node.

Each leaf node is a unique combination of outcomes. In this study, these outcomes are whether or not an individual has utilised 1, or a series, of MBS services. The leaf node represents where an individual 'falls out' of the decision tree. It is important to note that once an individual has been classified based on whether they had utilised the MBS services leading to their leaf node, none of the following tests apply. For example, in this analysis, anyone who saw a geriatrician 'falls out' of the algorithm first, regardless of whether they have utilised any other MBS services. For individuals who had not seen a geriatrician, further MBS service items are successively considered. Once everyone has been classified, we can look at which individuals are captured in each node, and how much more likely certain combinations are to have individuals with dementia compared to those without.

Decision trees are easily interpreted and provide a graphical and intuitive way to understand what an algorithm does. They do not require a lot of data to train and are tolerant to missing values (that is, they can incorporate them into the algorithm rather than discarding those records). However, decision trees can be prone to overfitting and are therefore sensitive to outliers. Compared to other more complex machine-learning techniques, they are weak learners.

Why use one?

The advantages of the decision tree approach make it a good option for generating an algorithm or series of steps that can be easily understood and applied to new data, and choosing a simpler tree with fewer leaves can help avoid overfitting. More complex approaches with better learning capacity could be used instead, but this would negate the simplicity of having a single set of classification rules.

Refining the model

An important method for refining a decision tree is called pruning. This analysis used minimal cost complexity pruning, an algorithm that helps to avoid overfitting by removing leaf nodes that are not contributing useful information. This pruning approach results in the 'best' decision tree that minimises misclassification.

Even a tree that has had a pruning algorithm applied can still end up being a tree with a very high number of leaves, resulting in an equally large number of classification rules. A common approach to simplifying a large decision tree is to look for a less complex tree that meets the 1+SE rule (Breiman 1984). This rule states that if the misclassification rate of a less complex tree fits within 1 standard error (SE) of the misclassification rate of the 'best' tree, it is not statistically different in its ability to classify the outcome and is acceptable to use instead.

Following cost complexity pruning, the tree with the lowest overall misclassification rate for this analysis was 111 leaves, meaning the algorithm would have 111 classification rules. However, following the 1+SE rule, the pruning statistics for this decision tree indicated that a tree with any amount of leaf nodes above 5 would perform acceptably. Ten leaves were chosen to maintain simplicity, but also to regain some sensitivity over what the 5-leaf tree produced.

Model results

The chosen tree retained 5 variables from the 23 target variables: the geriatrician item variable was most important for classification, followed by CT scans, MRI scans, chemical pathology and psychiatric items.

Reminder: assessing the predictive power of models

Misclassification = overall accuracy

Sensitivity = accuracy classifying the actual dementia cases as dementia cases

Specificity = accuracy classifying actual non-dementia cases as non-dementia cases

Positive predictive value = reliability of the predicted dementia group

Negative predictive value = reliability of the predicted non-dementia group

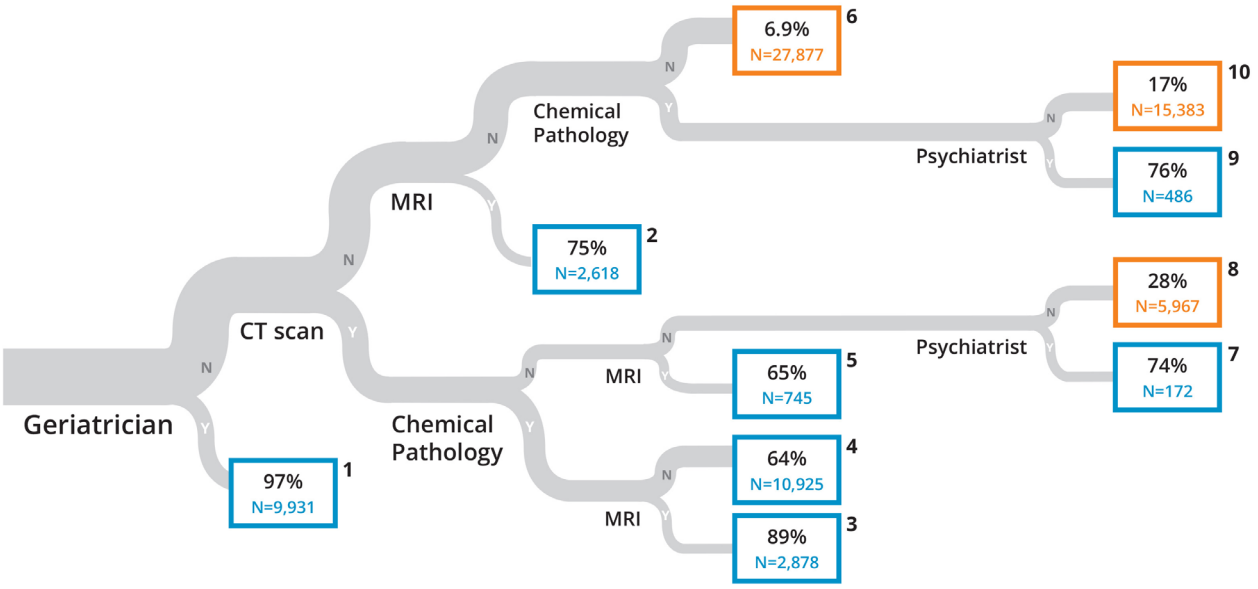
Area under the curve (AUC) = accuracy distinguishing between actual dementia and non-dementia cases across probabilities

Table 4 shows that the selected tree had an overall misclassification rate of 15% and a cross-validated error of 16%. The largest contributors to misclassification were false negatives (i.e. the misclassification of true dementia records, with a sensitivity of 0.78 or 22% misclassified as non-dementia). Misclassification of the true non-dementia records (false positives) was lower, with a specificity of 0.88 or 12% misclassified. Although 22% of dementia records overall were misclassified, Table 5 shows that certain classification rules had much lower misclassification rates than others.

Table 4: Fit statistics for selected tree, training cohort

	Model based	Cross-validation (k = 10)
Number of leaves	10	10
Average square error	0.12	0.12
Misclassification	0.15	0.16
Sensitivity	0.78	0.78
Specificity	0.88	0.88
Area under the curve	0.89	-

Figure 3: Decision tree results with leaf node description (training data)



1. **Geriatrician**
2. No geriatrician, no CT scan, **MRI**
3. No geriatrician, **CT scan**, **chemical pathology**, **MRI**
4. No geriatrician, **CT scan**, **chemical pathology**, no MRI
5. No geriatrician, **CT scan**, no chemical pathology, **MRI**
6. No geriatrician, no CT scan, no MRI, no chemical pathology
7. No geriatrician, **CT scan**, no chemical pathology, no MRI, **psychiatrist**
8. No geriatrician, **CT scan**, no chemical pathology, no MRI, no psychiatrist
9. No geriatrician, no CT scan, no MRI, **chemical pathology**, **psychiatrist**
10. No geriatrician, no CT scan, no MRI, **chemical pathology**, no psychiatrist

CT = computed tomography

MRI = magnetic resonance imaging

Predicted group:

Dementia Non-dementia

Note: The numbers displayed in each leaf node box shows the percentage of records in that leaf node that are known to have dementia, as well as the total number of records that were classified into that leaf node.

Figure 3 shows the full decision tree generated from the training data, with blue boxes representing leaf nodes predicting the dementia group and orange representing nodes predicting the non-dementia group. The numbers displayed in each leaf node box show the percentage of records in that leaf node that are known to have dementia, as well as the number of records that were classified into that leaf node. For example, the first leaf node (Geriatrician = Yes) predicts dementia and contains 9,931 records, 97% of which are actual dementia records. This means that a group of 9,931 people in the training cohort were billed using geriatrician-specific MBS items, and people with dementia made up 97% of that group, making that MBS service a good predictor.

Table 5 shows all of the classification rules generated by the algorithm, which correspond to each of the 10 leaves on the tree. Seven out of the 10 rules generated are related to the classification of early dementia records. The accuracy rate of these rules ranges from 97% for Leaf 1 down to 64% for Leaf 4. The remaining 3 rules for classifying the non-dementia group records had slightly higher accuracy overall, ranging between 93% (Leaf 6) and 72% (Leaf 8).

Table 5: Classification rules

Leaf node	Number	Service path	Classified group	% accurately classified (Training)	% accurately classified (Deployment)
1	9,931	**Geriatrician**	Dementia	96.5	98.9
2	2,618	No geriatrician, no CT scan, **MRI**	Dementia	74.5	75.8
3	2,878	No geriatrician, **CT scan, chemical pathology, MRI**	Dementia	89.4	92.9
4	10,925	No geriatrician, **CT scan, chemical pathology**, no MRI	Dementia	64.4	78.0
5	745	No geriatrician, **CT scan**, no chemical pathology, **MRI**	Dementia	64.8	56.1
6	27,877	No geriatrician, no CT scan, no MRI, no chemical pathology	Non-dementia	93.1	95.4
7	172	No geriatrician, **CT scan**, no chemical pathology, no MRI, **psychiatrist**	Dementia	73.8	50.0
8	5,967	No geriatrician, **CT scan**, no chemical pathology, no MRI, no psychiatrist	Non-dementia	72.4	74.8
9	486	No geriatrician, no CT scan, no MRI, **chemical pathology, psychiatrist**	Dementia	75.9	42.3
10	15,383	No geriatrician, no CT scan, no MRI, **chemical pathology**, no psychiatrist	Non-dementia	82.6	83.6

Model deployment

The decision tree model identified 29,945 probable early dementia cases in the deployment data (Table 6a.). When checked against the actual cases, this represented 80% of all true cases. The predicted dementia group consisted of 84% true cases and 16% false positives.

Compared to the training cohort, the sensitivity and specificity increased very slightly (Table 6b).

Tables 6a and b: Confusion matrix and predictive performance, deployment cohort

	Predicted		
Actual	**Dementia**	**Non-dementia**	**Total**
Dementia	25,215	6,332	31,547
Control	4,730	55,468	60,198
Total	29,945	61,800	91,745

Sensitivity	0.80
Specificity	0.92
Positive predictive value	0.84
Negative predictive value	0.90

The accuracy of each classification rule in Table 5 indicates that, for the deployment cohort, many of the actual dementia records are being misclassified at leaf nodes 7 (50% accuracy) and 9 (42% accuracy). Fortunately, these rules are only applicable to a relatively small number of records, so the misclassification at these nodes does not particularly affect the overall accuracy of the model.

Predicting early dementia using logistic regression

What is logistic regression?

Logistic regression is used in statistics to estimate the probability of an event occurring—in this case, having early dementia—based on the underlying data used to create the model. The results for logistic regression analysis are generally presented as odds ratios. It is often utilised as a supervised machine-learning classification algorithm.

Logistic regression is easy to implement, interpret and train. It provides a measure of importance for each variable in the size of the odds ratio, as well as the direction of the relationship. In addition to classifying each record, it also calculates continuous probabilities, providing more information with which to assess model effectiveness.

Unlike some other approaches, it can be difficult to capture complex relationships in logistic regression. It is also sensitive to outliers and missing data, and it requires statistical assumptions to be met that rarely hold up in the real world.

Why use it?

The advantages of logistic regression make it a good option for describing the influence of individual variables on an outcome and the magnitude of the effects.

Refining the model

The model was refined using backwards selection, with a significance cut off of p = 0.001. All target MBS items were included in the initial model, and items that were above the p value threshold were removed from the model 1 by 1 in descending p value order, rerunning the model each time to assess the impact of variable removal on the remaining variables. All remaining significant variables were checked for multicolinearity and none were found to be highly correlated. The highest correlation among target items was found between CT scan items and chemical pathology items (r = 0.3).

Model results

Reminder: assessing the predictive power of models

Misclassification = overall accuracy

Sensitivity = accuracy classifying the actual dementia cases as dementia cases

Specificity = accuracy classifying actual non-dementia cases as non-dementia cases

Positive predictive value = reliability of the predicted dementia group

Negative predictive value = reliability of the predicted non-dementia group

Area under the curve (AUC) = accuracy distinguishing between actual dementia and non-dementia cases across probabilities

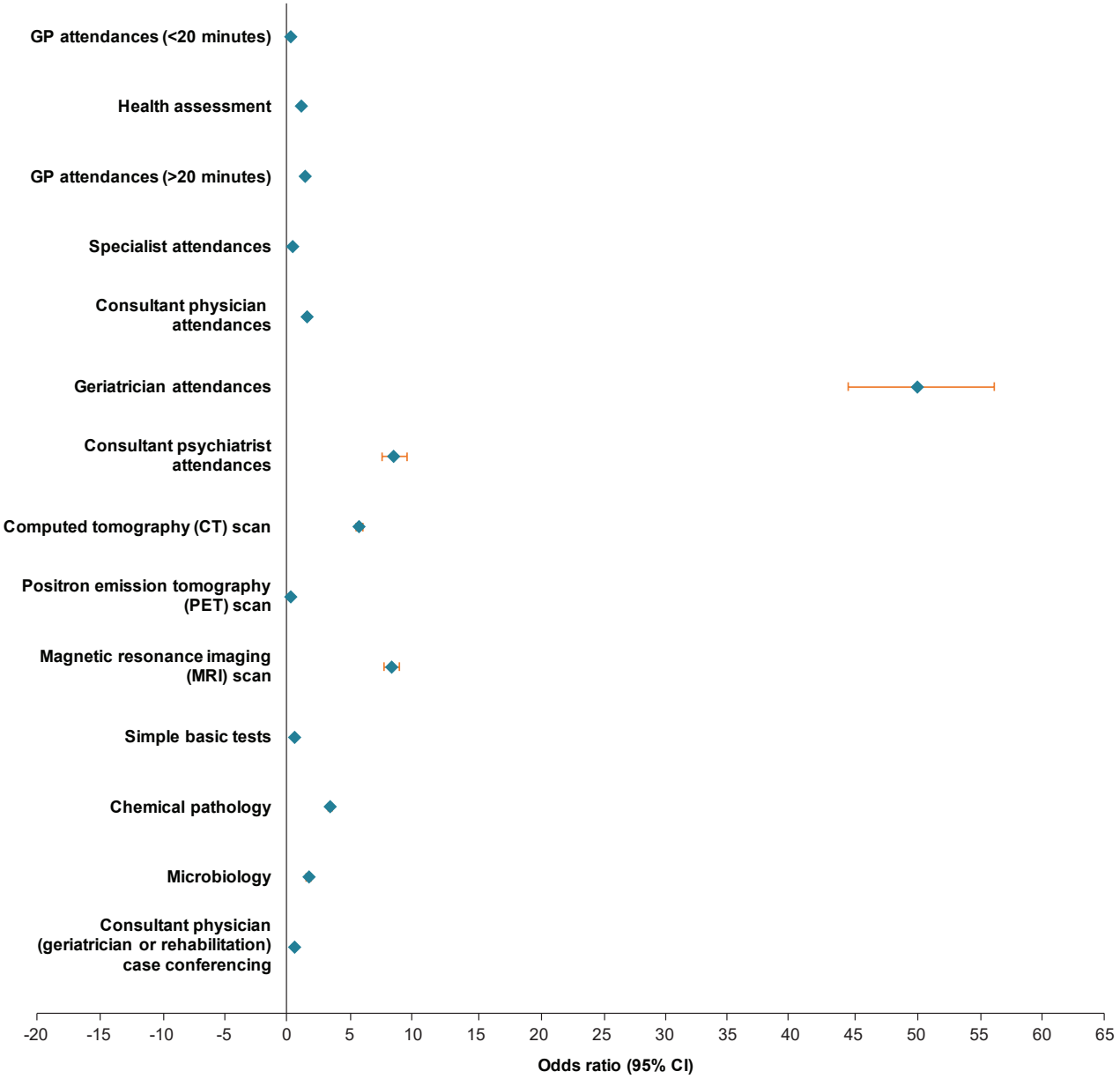
The final model fit the data moderately well (R squared = 0.44) and discriminated well between the 2 outcomes (AUC = 0.90) (Table 7).

Table 7: Fit statistics for final regression model

R squared	0.44
Sensitivity	0.74
Specificity	0.91
Positive predictive value	0.83
Negative predictive value	0.86
Area under the curve	0.90

Figure 4 shows the results for the logistic regression model developed on the training cohort. Geriatrician items were by far the largest contributor to the model—people who had this in their 2-year history had 50 times the odds of someone without these items of being in the identified early dementia group. Other moderately contributing items were MRI scans (odds ratio = 8.3), consultant psychiatrist items (odds ratio = 8.5), CT scans (odds ratio = 5.8) and chemical pathology (odds ratio = 3.5). The remaining items made comparatively marginal contributions to the final model, such as GP consultation and health assessment items, specialist and consultant physician items, PET scan items, and both haematology and microbiology pathology items.

Figure 4: Adjusted odds ratios for target MBS item groups and early dementia



Source: Analysis of NIHSI-AA linked data.

From regression co-efficients to predicted probabilities

While there are many ways to present the output of the various types of regression analyses, all regressions—be it linear or logistic—result in an equation that can be used to calculate the outcome of interest for any given value of the characteristics included in the model.

For this analysis, this equation calculates the predicted probability that a record with a given set of MBS target items in their history is a record belonging to a person with early dementia. Calculating these probabilities allows further exploration of how the presence of multiple items influences predictions, rather than the presence of each individually (as shown by the odds ratios).

For example, within this cohort, a person with none of the target items in their 2-year history is predicted as p = 0.15, or 15% likely to have early dementia. However, if that person had a geriatrician appointment in that time, the predicted probability becomes p = 0.90. If that person has also had a CT scan, their predicted probability goes up to p = 0.98.

Having only accessed chemical pathology results in a predicted probability of p = 0.38, which doesn't quite meet the threshold to be classified as a dementia record, but add in a CT scan and the probability jumps to p = 0.78.

This equation, refined during the training process, can then be applied to new data to assess how well it performs. It simply calculates the probability for each new record and classifies the record based on a threshold value (usually, but not always, p = 0.5) which can then be compared to the known dementia status of that record. In this study, the equation has been applied to the deployment data with a 0.5 threshold, where those with early dementia have been identified through their first dementia medication prescription.

Model deployment

Despite not being tested using cross-validation, the logistic regression model performed just as well when deployed, identifying 27,224 probable early dementia cases in the deployment data. When checked against the actual cases, this represented 75% of the total true cases. The predicted dementia group was comprised of 86% true cases and 14% false positives.

Tables 8a and b: Confusion matrix and predictive performance, deployment cohort

	Predicted		
Actual	**Dementia**	**Non-dementia**	**Total**
Dementia	23,639	7,908	31,547
Control	3,585	56,613	60,198
Total	27,224	64,521	91,745

Sensitivity	0.75
Specificity	0.94
Positive predictive value	0.86
Negative predictive value	0.88
Area under the curve	0.92

4 Discussion

Which service items are predictive of dementia?

Geriatrician services and brain scans are highly predictive of early dementia

Both the logistic regression modelling and decision tree approaches found that similar MBS items were useful for predicting newly diagnosed dementia. These items were those associated with seeing a geriatrician and utilising diagnostic imaging (CT and MRI scans).

In the logistic regression model this was reflected in the very high odds ratios for these items (50.1 for geriatric services, 8.3 for MRI scans and 5.8 for CT scans). Considering that these odds ratios are adjusted to control for the effect of all other items included in the model, this is strongly indicative that these particular services are useful for distinguishing patients with newly diagnosed dementia from patients without.

The decision tree approach uses an 'importance' measure, a value between 0 and 1 that indicates which variables best split the data into their respective dementia and non-dementia groups. The same 3 variables—geriatric items, CT scans and MRI scans—were identified as the best 3 for classification purposes, with geriatrician attendance item claims being a highly reliable way to accurately identify newly diagnosed dementia cases (97% probability of being an actual dementia case in the training cohort).

An interesting difference between the 2 models is the importance of items related to accessing a consultant psychiatrist. While people with these items in their claims history have 8.5 times higher odds of having early dementia, these items do not feature strongly (although they do feature) in the decision tree. This highlights an important difference between the 2 approaches, in that the regression approach will be more sensitive to small groups of people with a highly predictive feature. The decision tree algorithm, on the other hand, aims to classify the most people in a way that maximises information gain (a strategy also known as a greedy algorithm), meaning that better classifiers with greater coverage are favoured over classifiers that may have good distinguishing power but only for a niche group of patients.

Additionally, the decision rules relating to psychiatrist items showed much lower accuracy than other rules when applied to the new data, indicating that a tree without this extra information might be more stable for prediction. The ability to identify items provided specifically by psychiatrists who specialise in care of older people (psychogeriatricians) may improve this node, however, this is not currently possible using the data linked into the NIHSI AA.

Early dementia can be predicted using combinations of services

The biggest advantage of the decision tree approach is that it provides clear rules that, when followed, make classifying records very straightforward. This also has the benefit of providing information around the combination of services that patients have utilised in the lead up to diagnosis. While these are not complete or sequential pathways through health services, they are the services that best distinguish early dementia patients from similar patients in the community without a dementia diagnosis. For example, it is unlikely that GP appointments would feature as predictive in a dementia diagnosis-specific model for the simple reason that most people utilise these services at some point and for various reasons unrelated to dementia.

The most predictive service found in this analysis is very simple—seeing a geriatrician. Given that geriatricians specialise in care of the elderly and the diseases that affect them—the most common ailments being the various types of dementia and falls—this finding is a useful but unsurprising one.

Despite the strong predictive value of geriatrician items, only around 30% of our dementia cohorts (both training and deployment) had these items in their 2-year look-back period (Table 3). When dementia patients have not taken a diagnosis pathway that includes seeing a geriatrician, classification becomes more difficult as they have instead been diagnosed by practitioners in specialties that are less unique to patients with early dementia (and thus, are less precise as a predictive measure).

In the absence of geriatrician attendance items, it can be seen from the decision tree that the next best service type for classifying newly diagnosed dementia is if the patient has at any point claimed CT scan, chemical pathology and MRI items within the 2-year period prior to being prescribed dementia-specific medication. This path provides good, but less, certainty in its classification (89% are actual cases in the training cohort). If there are no claimed CT scans, MRI items have less accurate but still moderate predictive power on their own (75% accuracy). Table 3 shows that CT scans were much more commonly used among dementia patients than MRI scans (around 65% of patients compared with around 25%). While MRI may be able to detect more subtle anatomical and vascular changes owing to the higher resolution compared to CT (HQO 2014), the use of MRI is not suitable for patients with pacemakers and other implanted medical devices, or for patients with claustrophobia or an inability to stay still for a long period, a consideration for patients suffering confusion (GAC 2016).

These item claims are the main classifiers in the decision tree model. A full list of the items and their combinations are available in Table 5.

Which model performed better?

Overall, the performance achieved by both models was good. When deployed on new data, the models captured the majority of all known dementia cases (a sensitivity of 80% and 75% for the decision tree and regression, respectively).

Both the decision tree and the logistic regression model achieved similar performances on the training data, indicating that both approaches were able to represent the data fairly accurately. Both achieved similar overall misclassification rates, with good discriminatory power (AUC of 0.89 and 0.90, respectively). Both models had higher specificity than sensitivity, indicating that they were slightly better at classifying the non-dementia records than the dementia records, as often occurs when applying decision trees to unbalanced data. Both also achieved good precision (PPV) (around 0.85 or 85% accuracy), meaning that only around 1 in 7 people in the group of predicted dementia records shouldn't have been there.

When deployed on new data, both models performed slightly better than they had on the training data. This is most likely due to the items in the algorithms being even better at differentiating between people with dementia and without dementia when the comparison group includes younger—and likely healthier—people who are less likely to utilise these services.

The similar performance of these 2 approaches highlights that either could be used to a similar level of effectiveness, and that 1 could be chosen over the other based on the relative strengths that are most important. The simplicity of the decision tree is a strong case for using that approach, particularly since it requires a lot less information than the logistic regression approach to be just as accurate.

Reasons for misclassification of dementia records

Both models had good precision when tested, with around 85% of the predicted positives being true positives. High precision is desirable in a classification model, as it provides assurance that those who are predicted as the group of interest are very likely to be accurate. The achieved sensitivity, while fairly good, is not yet sufficient for the purposes of providing reliable measures of incidence or prevalence, as around 1 in 4 of the known dementia cases are not being captured.

For the small group of misclassified non-dementia group records (the false positives), there are several possible explanations for why they were incorrectly classified:

- The person has a non-Alzheimer's type of dementia for which the dementia-specific medications were not an appropriate treatment and has no subsequent health or aged care records indicating a dementia diagnosis.
- The person does in fact have early dementia and has either not yet been treated with medication, was not eligible for PBS-subsidised medication or was treated under the PBS but outside the prescription window for this analysis.
- The person was investigated for dementia, and therefore accessed services associated with dementia diagnosis, but was found not to have it.
- The key services being used to predict dementia are also used in the diagnosis of another illnesses.

Given the strong reliance of both models on geriatric specialist care and brain scans, they are likely particularly sensitive to other neurological issues being investigated in patients from older age groups.

As with false positives, there are a few possible reasons that the models might misclassify cases of early dementia as non-dementia records (false negatives):

- Known data gaps, such as missing emergency department and hospitals information, may have prevented pre-existing, more progressed dementia cases from being excluded from the early dementia cohort. These patients would not be recently diagnosed and would therefore not have been accessing diagnostic or management services in the look-back period.
- Key services utilised by these patients in dementia diagnosis are not being captured in the target items. Future work can look into this in more detail by examining patterns of services that were used by this particular group of misclassified patients (the false negatives) and incorporating them into the target items.

What does this all mean for improving dementia monitoring?

The results from this feasibility test strongly indicate that some MBS items can be highly predictive of early dementia. The high reliability of some items in patients' histories such as geriatrician appointments, MRI and CT scans—separately and in conjunction with each other—mean that these items could be used as a proxy for identifying patients with early dementia who may not have appeared in other administrative data sets. Although this will only identify a subset of early dementia patients at this stage, it will help to bring dementia prevalence estimates closer to the true prevalence.

While the models couldn't necessarily identify all early dementia patients—making them unsuitable in their current form as a reliable way to capture every new case of dementia—they can provide an indication or a lower bound for the incidence of dementia in Australia.

Future directions

The results from this study provide a stepping stone for measuring and understanding early dementia incidence and prevalence. The ability to reliably capture a large subset of the early dementia population in Australia using their MBS history before they appear in other health administrative data sets is very promising for improving estimates of both prevalence and incidence of dementia in Australia.

In the shorter term, the results from this feasibility study can be applied to newer data and to the MBS item histories of the full PBS-based non-dementia cohort, rather than a subset. Using a subset has the benefit of being time-efficient and keeping computational power needs low, but it also runs the risk of being less applicable to the broader population due to the use of a sample.

As linked data improves and expands, new information may become available that could allow for replication of the current approach with more comprehensive data. This may improve the identification of people with early dementia, resulting in a more accurate community-dwelling, early dementia cohort. For dementia in particular, having more comprehensive existing aged care and hospital data linked to MBS and PBS data would greatly contribute to refining a more accurate early dementia cohort with which to train future predictive models. In the medium to longer term, greater availability of primary care data with accurate diagnostic information would provide a gold standard for validating existing predictive algorithms and eventually reliably measuring early dementia.

Also in the shorter term, greater examination of misidentified cases from this feasibility study may enable further refinement of this algorithm to increase accuracy and reliability. Misclassified cases may have additional useful MBS items that are not already captured, or it may be possible to look across data sets to identify the presence of 1 or more different conditions being captured unintentionally. Identifying such things may allow us to include more MBS items in the future or place exclusions on the cohort, reducing the incidence of misclassification. Greater detail about items in the MBS, such as the specific practice area of a specialist, may also improve the accuracy and predictive strength of items. For example, MBS items relating to psychiatrists who specialise in the care of older people (i.e. psychogeriatricians) may have strong predictive value but are currently insufficiently specific to distinguish them from other psychiatry items.

In lieu of diagnostic information from primary care settings, a feasible short-term way to validate this work is to link in clinical cohort studies where the actual dementia status of patients is known. Further work to explore potential diagnosis service combination differences for younger onset dementia patients, or other groups of interest who may differ from the expected service combination, may also increase the accuracy and reliability of the algorithm.

This analysis was done in a top-down fashion, with MBS items relevant to dementia diagnosis being synthesised from diagnostic pathways found in the literature and as advised by dementia experts. While this approach has had very promising results as it is, exploring a data-mining approach—whereby all items are analysed for association, with eventual inclusions for modelling being identified from the ground up—may illuminate unexpected items or patterns that can make predictions more accurate. This approach is most often used for machine-learning as it utilises all available information and makes no starting hypotheses about what might be valuable. Additionally, techniques that can factor in the sequences of service utilisation to strengthen predictions may further improve accuracy and would provide useful detail about the pathways that people with early dementia take in health care.

Limitations

Limitations with using administrative data

The most important part of developing a model to recognise a target characteristic from other information is to have complete and accurate data on the target characteristic with which to train the model. Caveats to the coverage of administrative data often mean that it is unlikely that any cohort identified with a characteristic of interest will be complete and accurate. For this analysis, to be accurately identified in or excluded from the early dementia cohort, a person needed to have been in contact with multiple parts of the Australian health system.

Identifying people with dementia using the PBS is likely to provide an incomplete picture of dementia because, in Australia, patients must have an Alzheimer's diagnosis, or symptoms consistent with Alzheimer's disease, confirmed by a specialist to be eligible for subsidised medication. Not all patients with Alzheimer's disease receive these medications. In addition, there may be people with other types of dementia in the data who have not been identified because they are either not being treated with the drugs of interest in this analysis, or they are being treated but outside of the subsidy scheme. The same applies to MBS data—visibility of the health services used by people with and without early dementia relies on those services having been subsidised through Medicare. This is an important limitation of using administrative data for prediction of population estimates—sometimes there are people who just don't touch the system, and usually these people are systematically different, and often more vulnerable, than those who do touch the system. For example, people attending an approved Remote Area Aboriginal Health Service can receive eligible PBS medicines without the need for a PBS prescription and without cost, and thus would not be captured in the PBS data.

Another consideration for the transferability of the results of this analysis is that, to be present in the PBS data set, a person must have needed and been prescribed a PBS-subsidised medication. This means that the population captured by the PBS data will likely be slightly biased towards those with worse health than the general Australian population. The control cohort generated from this data may therefore have had greater contact with the health system compared to a hypothetical age- and sex-matched control group selected from the general Australian population.

Limitations with using linked data

Most linked data sets in Australia are discrete linkages and are not kept updated in perpetuity. This means that they often only cover a certain period of time, and the events of interest may not be captured within the available time period. The NIHSI 0.5 linkage covers July 2010 to June 2017, so this is the specific time period within which it can be identified whether or not people have had dementia-related health-care events. It is possible, therefore, that this analysis may have missed excluding pre-existing dementia sufferers or residents of aged care facilities due to their hospitalisations, prescriptions or assessments occurring prior to mid 2010.

The NIHSI 0.5 hospitals data are also incomplete, with admitted patient care data only provided by New South Wales, Victoria, South Australia and Tasmania. It is likely that those states and territories had pre-existing dementia sufferers who could not be excluded from the cohorts due to not being in the NIHSI hospitalisations data. The updated NIHSI AA version 1.0 will have more states' and territories' admitted patient care data, enabling this limitation to be overcome in future work.

Limitations with the chosen methodology

The decision to identify target items from the literature on dementia diagnosis pathways has advantages and disadvantages. While it provides a clear, clean structure for the claims data underlying the modelling—an important step in using administrative data for research purposes—it also imposes a structure on the results that can limit the predictive power of the models. Bottom-up approaches that examine all claim items for associations, although laborious, would help to determine all items that are substantially differentiating for early dementia patients.

The chosen modelling techniques, while suitable for the aims of this feasibility test, are also among the more basic options for predictive exercises. Although moving into more complex methodologies may somewhat reduce the communicability of the results and implications of the algorithm, the actual predictions made will likely be improved. One such technique for consideration is a random forest, which extends the decision tree type of algorithm by creating multiple decision trees and ascertaining a statistical consensus for predicting the dementia status of a record.

5 Conclusion

There are several strongly differentiating MBS service items and item combinations associated with dementia diagnosis and management that can help to identify people with early dementia before they appear in other administrative data sets. While the tested models require a better ability to detect people with early dementia to be feasible as a reliable method of measuring prevalence and incidence on their own, some MBS items alone and in combination are predictive enough that they could be used to top up or adjust prevalence estimates. There are known limitations that, if addressed, may improve the performance of these modelling approaches for measuring the prevalence and incidence of early dementia.

Appendix A: Methodology

Cohort specifications

Table A1: Pharmaceutical Benefits Scheme, Aged Care Funding Instrument assessment items and Admitted Patient Care diagnosis codes used to create and refine the initial cohort with newly diagnosed dementia

Inclusion criteria	Pharmaceutical Benefits Scheme	ATC code
Prescribed dementia-specific medication from 2010 and first recorded prescription during 2015–2017 (first dementia record)	Donepezil	N06DA02
	Rivastigmine	N06DA03
	Galantamine	N06DA04
Exclusion criteria	**Aged Care Funding Instrument assessment**	**Description**
Any ACFI assessment from 2010 to first dementia record in PBS	Assessment completed	With or without record of dementia
Exclusion criteria	**Admitted Patient Care data**	**ICD-10-AM diagnosis code**
Any dementia diagnosis from 2010 to first dementia record in PBS	Alzheimer's disease	F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9
	Vascular dementia	F01.0, F01.1, F01.2, F01.3, F01.8, F01.9
	Fronto-temporal dementia	F02.0 *and* G31.0
	Dementia in Creutzfeld-Jakob disease	F02.1 *and* A81.0
	Dementia in Huntington's diseases	F02.2 *and* G10
	Dementia in Parkinson's disease	F02.3 *and* G20
	Dementia in human immunodeficiency virus (HIV) disease	F02.4 *and* B22
	Lewy body dementia	F02.8 *and* G31.3
	Dementia in other diseases (remainder)	F02.8 *and* not G31.3
	Dementia due to effect of substances	F10.7, F13.7, F18.7
	Unspecified dementia	F03 *and not* F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F10.7, F13.7, F18.7
	Delirium superimposed on dementia	F05.1 *and not* F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F03, F10.7, F13.7, F18.7

(continued)

Table A1 (continued): Pharmaceutical Benefits Scheme, Aged Care Funding Instrument assessment items and Admitted Patient Care diagnosis codes used to create and refine the initial cohort with newly diagnosed dementia

Exclusion criteria	Medicare Benefits Schedule	Item number
Claimed MBS items specific to residing in a Residential Aged Care Facility prior to first dementia record in PBS	Services for patients in residential aged care facilities	Group A35
	Telehealth attendance at a residential aged care facility	Group A30, Subgroup 2
	Telehealth support on behalf of a medical practitioner at a residential aged care facility	Group M12, Subgroup 2
	Telehealth attendance at a residential aged care facility	Group M14, Subgroup 3
	Individual items relating to other services provided to residents of aged care facilities	232, 249, 731, 772, 776, 788, 789, 903, 10947, 10948, 10984, 57541, 73934, 73935, 82223, 82224, 82225

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Abbreviations

ACFI	Aged Care Funding Instrument
AIHW	Australian Institute of Health and Welfare
AUC	area under the ROC curve
CI	confidence interval
CT	computed tomography
FDR	first dementia record
GP	general practitioner
MBS	Medicare Benefits Schedule
MRI	magnetic resonance imaging
NDLDP	National Data Linkage Demonstration Project
NIHSI-AA	National Integrated Health Services Information Analysis Asset
PBS	Pharmaceutical Benefits Scheme
PET	Positron emission tomography
PPV	positive predictive value
NPV	negative predictive value
ROC	receiver operating characteristic
SE	standard error
WHO	World Health Organization

Symbols

n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data
-	not applicable to this test

References

AIHW (Australian Institute of Health and Welfare) 2020a. Deaths in Australia. Cat. no. PHE 229. Canberra: AIHW.

AIHW 2020b. Dementia data gaps and opportunities. Cat. no. AGE 105. Canberra: AIHW.

AIHW 2020c. Patterns of health service use by people with dementia in their last year of life: New South Wales and Victoria. Cat. no. AGE 102. Canberra: AIHW.

AIHW 2021a. Australian Burden of Disease Study 2018: Key findings. Cat. no. BOD 30. Canberra: AIHW.

AIHW 2021b. Dementia in Australia. Cat. no. DEM 2. Canberra: AIHW.

Albrecht J, Hanna M, Kim D & Perfetto E 2018. Predicting diagnosis of Alzheimer's disease and related dementias using administrative claims. Journal of Managed Care and Specialty Pharmacy 24(11):1138–1145. doi: 10.18553/jmcp.2018.24.11.1138.

Breiman L and Ihaka R 1984. Nonlinear discriminant analysis via scaling and ACE. Department of Statistics, University of California.

CeRDI (Centre for eResearch and Digital Innovation) 2013. Diagnostic pathways for the assessment and management of dementia. Viewed 16 February 2021, https://www.dementiapathways.com.au/view_resource.php?resource_id=76.

Di Francesco JC, Pina A, Giussani G, Cortesi L, Bianchi E, d'Oro LC, Amodio E, Nobili A, Tremolizzo L, Isella V and Appollonio I 2019. Generation and validation of algorithms to identify subjects with dementia using administrative data. Neurological Sciences, 40(10), pp.2155-2161.

Dementia Australia 2014. Tests used in diagnosing dementia. Sydney: Dementia Australia. Viewed 16 February 2021, https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-DementiaQandA10-TestsUsedInDiagnosingDementia_english.pdf.

Dementia Australia 2018. Drug treatments for Alzheimer's disease: cholinesterase inhibitors. Sydney: Dementia Australia. Viewed 9 August 2021, https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-DementiaQandA01-CholinesteraseInhibitors_english.pdf.

DUSC (Drug utilisation sub-committee of the Pharmaceutical Benefits Advisory Committee) 2016. Medicines for Alzheimer disease, February 2016. Viewed 9 August 2021, https://www.pbs.gov.au/industry/listing/participants/public-release-docs/2016-02/alzheimer%20dusc-prd-2016-02.pdf.

GAC (Guideline Adaptation Committee) 2016. Clinical practice guidelines and principles of care for people with dementia. Sydney: Guideline Adaptation Committee.

HQO (Health Quality Ontario) 2014. The appropriate use of neuroimaging in the diagnostic work-up of dementia: an evidence-based analysis. Ontario Health Technology Assessment Series 14(1):1–64.

Jammeh E, Carroll C, Pearson S, Escudero J, Anastasiou A, Zhao P et al. 2018. Machine-learning based identification of undiagnosed dementia in primary care: a feasibility study. British Journal of General Practice Open 2:2. doi: 10.3399/bjgpopen18X101589.

Shao Y, Zeng Q, Chen K, Schutes-David A, Thielke S & Tsuang D 2019. Detection of probable dementia cases in undiagnosed patients using structured and unstructured electronic health records. BMC Medical Informatics and Decision Making 19:128. https://doi.org/10.1186/s12911-019-0846-4.

Welberry HJ, Brodaty H, Hsu B, Barbieri S & Jorm LR 2020. Measuring dementia incidence within a cohort of 267,153 older Australians using routinely collected linked administrative data. Scientific Reports 10:8781. https://doi.org/10.1038/s41598-020-65273-w.

World Health Organization, 2019. Risk reduction of cognitive decline and dementia: WHO guidelines.

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This feasibility study aimed to identify whether early dementia could be predicted from primary and secondary care service utilisation, as recorded in Medicare claims data, in the absence of diagnosis information. The 2 techniques tested showed that Medicare items associated with geriatrician attendances, imaging of the head, and some pathology had strong predictive value, especially where a patient has a combination of these items in their recent medical history.

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