Iran Red Crescent Med J. 2017 November; 19(11):e14441. doi: 10.5812/ircmj.14441.

Published online 2017 November 17. **Review Article**

A Global Comparison of Dementia and Alzheimer Disease Registries: A Systematic Review

Aida Sarsarshahi,[1] Maryam Ahmadi,[2,*] and Zahra Niazkhani[3,4]

[1]Health Information Management Department, School of Management and Medical Information Sciences, International Campus (IUMS-IC), Iran University of Medical Sciences, Tehran, IR Iran
[2]Health Information Management Department, School of Management and Medical Information Sciences, Iran University of Medical Sciences, Tehran, IR Iran
[3]Health Information Technology Department, Urmia University of Medical Sciences, Urmia, IR Iran
[4]Nephrology and Kidney Transplant Research Center, Urmia University of Medical Sciences, Urmia, IR Iran

[*]*Corresponding author*: Maryam Ahmadi, School of Health Management and Information Sciences, Iran University of Medical Sciences, Tehran, IR Iran, No 6, Rashid Yasemist., Vali-e-asr Ave., P.code:1995614111, Tehran, IR Iran. Tel: +98-2188794300, Fax: +98-2188883334, E-mail: ahmadi.m@iums.ac.ir

Received 2017 May 03; **Revised** 2017 June 01; **Accepted** 2017 July 29.

Abstract

Context: Population aging is one of the most important health concerns worldwide, leading to an increase in the prevalence of chronic diseases such as dementia and Alzheimer disease (AD). Disease registries have great potential to determine the effect of clinical care, healthcare costs, and healthcare improvement for patients. Although there are several registries for dementia and AD worldwide, no systematic review is so far performed in this area. Therefore, the current study aimed at identifying the basic information in dementia and AD registries and comparing their characteristics.

Evidence Acquisition: The current systematic review studied the dementia and AD registries in English literature based on keywords in the title with no time limitations, using the following databases: Institute of Electrical and Electronics Engineers (IEEE), ProQuest, PubMed, Science Direct, Web of Science, Scopus, Ovid Medline, Scientific Information Database (SID), and IranMedex (earliest entry to 07 February, 2017). In the current research, only the studies related to disease registries were evaluated.

Results: A total of 28 articles meeting the inclusion criteria were evaluated in the current study. Based on the findings, 22 dementia and AD registries were identified. The majority of the registries (13 registries) were from North America. In half of the registries, patient recruitment was performed among outpatients and inpatients referred to healthcare centers. The comparison of the structural information in these registry systems showed that they differed in terms of objectives, data sources, minimum data sets, and data quality.

Conclusions: The current study was the 1st systematic review of dementia and AD registries. Since there are no international standards to develop dementia and AD registries, comprehensive analysis can be effective to promote disease registry systems.

Keywords: Dementia, Alzheimer Disease, Registries, Database

1. Context

A disease registry is an organized system in which uniform data (clinical and nonclinical) are gathered to assess the outcomes in a given population with a particular disease, condition, or exposure to disease (1). Use of registry systems can provide a better understanding of the natural history of a disease and offer treatment instructions for patients and organizations (2). Analysis of the registered data in these systems can be used to present activity reports, propose research hypotheses, and improve patient care (3).

Population aging is one of the most important health concerns worldwide, associated with certain consequences, outcomes, and costs (4). As a result, healthcare systems require effective strategies to improve the process of healthcare provision to meet the needs of the elderly (5). Increased life expectancy and significant growth in the elderly population are associated with increased prevalence of chronic diseases such as dementia (6).

Alzheimer disease (AD) is one of the most common causes of dementia in people aged over 65 years (7). AD is a degenerative disease that causes various social, economic, and psychological problems for the elderly and their families (8). In addition, according to statistics, nearly 46 million people have dementia worldwide, which is speculated to reach 130 million people by 2050 (9).

Use of dementia and AD registry systems is a standard method for data collection and is considered a reliable source of information (10). The purpose of AD registries is to collect information to identify, locate, and analyze the incidence, frequency, prevalence, etiology, outcome, and

prognosis of AD (11). In addition, the information and reports in these systems can be used to run surveillance studies, perform epidemiological research (to identify the risk factors for the pathogenesis of AD and dementia), plan healthcare services, and improve disease diagnosis and treatment (12).

Use of different dementia and AD registry systems, at the state and local levels, dates back to the 1980s in the United States. These systems aimed at improving the statistical power of clinical research in this area (13-20). The consortium to establish a registry for Alzheimer disease (CERAD), a national registry system, was developed in the 1980s to standardize disease assessment procedures and improve epidemiological studies (21, 22). Many initiatives are undertaken in other countries, such as the United Kingdom (23), Spain (10), and France (3), to collect data on patients undergoing dementia and AD. Despite major efforts to develop AD and dementia registries, no international standards are proposed for these systems (24). Furthermore, only few comparative studies are conducted on the structure of these systems (12, 25, 26), and no systematic review is so far performed in this area. Therefore, review of the available registries and studies in this area can play a significant role in the collection and presentation of findings to design and develop such systems. The current study, as the 1st systematic review, aimed at focusing on AD and dementia registries and summarizing the required characteristics such as the objectives, resources, sampling procedures, minimum data sets (MDSs), and data quality to promote the design and implementation of such systems in other healthcare contexts.

2. Evidence Acquisition

2.1. Search Strategy

The current systematic review searched for studies published in English with no time limitations, using the following databases: institute of electrical and electronics engineers (IEEE), ProQuest, PubMed, Science Direct, Web of Science, Scopus, Ovid Medline, Scientific Information Database (SID), and IranMedex. The final search was performed on 07 February, 2017, using a combination of keywords and mesh terms related to AD, ie, "Alzheimer disease" and "dementia", and registry systems, ie, "database" and "registries" (along with Boolean operators AND/OR in the title). The details of the search strategy are available in supplementary file Appendix 1 for each database. In addition, the study adhered to the protocol to review articles, based on preferred items to report in systematic reviews (PRISMA) (27).

3. Study Selection

First, based on the search strategy, a total of 799 articles were retrieved. No article was found in the SID and IranMedex databases. Overall, there were 483 duplicates among the databases, which were excluded. In the next step, the abstract and title of 316 articles were studied with respect to the inclusion criteria. Screening of titles and abstracts was conducted independently by 2 researchers and the Cohen Kappa coefficient was used to compare the consistency (k = 0.87). The disagreement between researchers was resolved by consensus. To prevent assessment bias, researchers were blind to journal name, the author name, and the decision of each other.

The inclusion criteria in the present study were: journal articles and conference proceedings related to dementia and AD registries and databases, and being published in English. On the other hand, since there are no distinct classifications for registry systems, the study was mainly focused on dementia and AD registries, excluding prevention registries, risk registries, research registries, gene databases, and skill and resource registries, based on the classification proposed by Weddell (28). Editorials and letters to editors were also excluded.

At this stage, 213 articles were excluded, considering the irrelevance of the article title or abstract. The full texts of 103 articles, which seemed relevant to the objectives, were reviewed by 3 researchers. Any disagreement was resolved by consensus. To identify the articles, the references of all articles were also reviewed. Figure 1 presents the process of study selection. In addition, to include the gray literature in the current review, the websites of registry systems identified in the final stage as well as their forms and annual reports were also assessed.

4. Data Extraction

In the current review article, different registry systems were evaluated based on a checklist with variables and data items presented in Table 1. They included the title of the registry system, year of implementation, country of origin, current status of the system, main objectives based on use (29), type of data sources (30), minimum data set (MDS) (31), and data quality (32).The validity of this checklist in extracting main data items in the registries was assessed by 2 independent researchers. Based on the current study aims and objectives, only the qualitative variables from the included studies were extracted (Table 1). As there was little consensus on assessing the quality of qualitative studies to include in a review (33-35), the quality of included studies was not assessed.

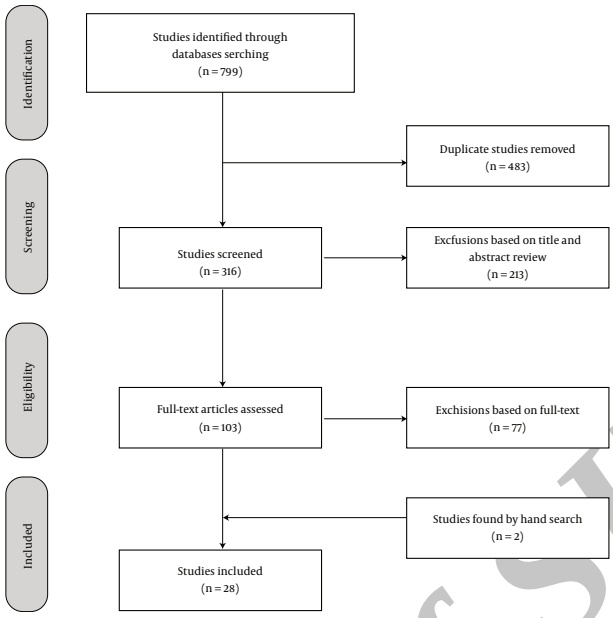

Figure 1. Flow Chart for the Study Selection

5. Results

Following the literature search and final analysis, 28 articles, considered eligible, were included (3, 10-24) (36-47). In addition, annual reports and records, extracted from the registries websites, were examined for complementary information (48-50). Overall, 22 dementia and AD registries were identified at the national, state, and local levels in different countries from 1986 to 2014. Table 2 presents the information extracted from these databases and registries, including the purpose of the registry based on use, basic registry information, data sources, MDSs, and data quality.

Based on the extracted data, the highest frequency of dementia and AD registries was reported in North America (n = 13) (13-21, 42-44, 46). Based on the analyses, most information in this region was reported at the local and state levels; in addition, Europe (n = 7) (3, 10, 23, 24, 38-40), Asia (n = 1) (37), and South America (n = 1) (12) followed North America. However, no AD or dementia registry, meeting the inclusion criteria, was found in Africa. Meanwhile, among the extracted registries, 9 were implemented in the 1980s (13-21).

In half of the registry systems, patient recruitment was performed among inpatients and outpatients in a variety of healthcare centers, including hospitals, specialized clinics, elderly care centers, and research centers (10-12, 14, 17, 20, 23, 37, 40, 41, 44). Furthermore, based on the analysis of these systems, 13 had active systems (3, 10, 11, 14, 16, 17, 36, 38, 39, 41, 43, 46, 47), while 3 were the pilot trials (12, 24, 44).

With regard to basic and structural information in the registries, the extracted data were somehow inconsistent in terms of objectives, data sources, and MDS. The majority of registries (n = 20) were implemented with clinical and epidemiological purposes to analyze the effectiveness of clinical care and present comprehensive information to formulate policies and planning (3, 10-12, 14-17, 19-21, 23, 24, 37-41, 43, 44).

With respect to data sources in registry systems, 16 population-based registries were reported (3, 11, 12, 14, 16-20, 22, 24, 38, 41, 43-45). MDSs were also evaluated, among which only 8 met all 4 characteristics of patient and service provider, as well as diagnostic and treatment parameters (3, 10-12, 21, 38, 46, 49).

Regarding data completeness, a total of 10 articles reported this feature (3, 10, 11, 16, 38-41, 45, 50). Moreover, in terms of diagnostic criteria, the international classification of diseases, revisions 9 and 10 (ICD-9 and ICD-10) were identified as the most prevalent diagnostic codes in 8 registries (3, 12, 14, 20, 38, 40, 49, 50).

6. Discussion

The current study was the 1st systematic review providing a global overview on dementia and AD registries and summarizing the required characteristics to design and implement these systems. The results of the comparisons indicated inconsistency in the structural characteristics of

Table 1. Data Elements

Category	Data Element
Basic registry information	Full name, acronym, country, year of establish, number of patients, type of patients (outpatient, inpatient), reporting, status
Purpose of registry based on use	Clinical, epidemiology, research, surveillance
Data source of registry	Local registry hospital (1 hospital)
	Central registry (selected hospitals within a region (city, state)
	Population-based (all cases in population of known size and composition)
MDS (A standard tool for data collection)	Patients' characteristics (age, gender, marital status, educational level, residential status, insurance data, address, contact information)
	Service providers' characteristics (type of care center, address, phone number/fax, date of admission)
	Diagnostic characteristics (heredity, BMI, MMSE Score, type of Alzheimer, history of other disorder, history of depressive disorder, a history of Alzheimer disease and related disorders, blood test, clock-test, CT, MRI)
	Treatment characteristics (pharmacological treatment, number of drugs, non-pharmacological treatment)
Data quality	Completeness of data (the proportion of all cases in the defined population)
	Validity of diagnostic coding (stringent criteria for diagnosis)

Abbreviations: BMI, body mass index; CT, computed tomography; MDS, minimum data set; MMSE, mini mental state examination; MRI, magnetic resonance imaging.

dementia and AD registries, particularly in areas such as domain coverage, objectives, data sources, data type, and diagnostic criteria.

Based on the current findings, in recent years, the geographical coverage of dementia and AD registries extended from the local and state levels to the national scale. In addition, the majority of these registries were developed with the purpose of improving epidemiological studies, evaluation processes, and clinical procedures (3, 10-12, 14-17, 19-21, 23, 24, 37-41, 43, 44). In recent years, considering the rapid pace of population aging and the importance of longitudinal and prospective studies to progress clinical procedures and presentation of research hypotheses, there is a major focus on the development of registries with an emphasis on research (3, 15, 18, 19, 24, 37, 38, 41, 45) and surveillance (10, 11).

The current study revealed the lack of uniformity in data types and sources. In the registry systems, demographic, diagnostic, and treatment information was heterogeneous, with respect to the geographical coverage, range of activities, and different diagnostic, therapeutic, and assessment methods (25, 26). Meanwhile, the impact of factors such as cost, source of funding, and the required time for system implementation should not be neglected (1).

Data quality was another important factor in the current study. Although different methods of data quality assessment are available for registries (particularly data validity and completeness presented by Goldberg) (32), few studies are performed regarding the implementation of these methods and few articles focus on data validity and data completeness in dementia and AD registries (51). In fact, these 2 parameters are among the biggest challenges against the implementation of disease registries (11).

In the majority of the registries reviewed in the present study, data completeness was observed to some extent, regarding the target population of the registry, data sources, and consistency among databases and registries (10, 11, 16, 40, 41, 45, 50). In addition, in some of these registries, data completeness was manually evaluated by experts (3, 38, 39).

In the current study, the comparison of diagnostic coding validity was somehow different from other characteristics, considering the use of different standard diagnostic coding systems, including the criteria proposed by the national institute of neurological and communicative disorders and stroke and the Alzheimer disease and related disorders association, the diagnostic and statistical manual of mental disorders, 4th Edition, and the ICD-10 for the diagnosis and treatment of AD, as the most prevalent type of dementia (52). In addition, it should be noted that different diagnostic criteria for different subtypes of dementia were applied, including the movement disorder society task force criteria (53), the McKeith criteria (54), and the Lund-Manchester criteria (55). Overall, the application of these classification systems and diagnostic codes increases the chance of various diagnostic decisions (56). However, factors such as the development and promotion of guidelines to diagnose AD and the identification of disease stage can be effective in the use of these different coding systems (52).

The present study was the 1st review of dementia and AD registries. Despite the comprehensive review performed in the current study through combining different keywords, the study had certain limitations. First, the focus of the study was only on articles related to disease registries, while other registries such as research registries, risk registries, gene databases, and prevention registries

were disregarded based on the exclusion criteria. Second, in the current study, only articles written in English were reviewed; therefore, there was a possibility of missing some relevant data in articles that published in other languages. Third, in the review of the extracted registries, all the variables involved in the assessment of registries (such as the reporting method) could not be studied due to the scarcity of information in the extracted articles and lack of access to reports on registries.

7. Conclusions

Today, registry systems, in addition to providing valuable information for the promotion of treatment and educational services can facilitate qualitative and quantitative developments and promote cooperation among clinicians and research groups. Nevertheless, in the present review, the extracted registries differed in terms of objectives, user domain, and structural features. Therefore, analysis and comparison among these systems could be effective in developing and expanding dementia and AD registries.

Supplementary Material

Supplementary material(s) is available here [To read supplementary materials, please refer to the journal website and open PDF/HTML].

Acknowledgments

The current study was part of a PhD dissertation supported by the Iran University of Medical Sciences, international campus (grant No: IUMS/SHMIS/I_2017/96/d/110/416).

Footnotes

Financial Disclosure: The authors declared no conflict of interest.

Funding Support: The study was funded by the Iran University of Medical Sciences, International Campus.

References

1. Gliklich R, Dreyer N, Leavy M. Registries for Evaluating Patient Outcomes: A User's Guide. Two volumes.(Prepared by the Outcome DEcIDE Center [Outcome Sciences, Inc., a Quintiles company] under Contract No. 290 2005 00351 TO7.) AHRQ Publication No. 13 (14)-EHC111. Rockville, MD: Agency for Healthcare Research and Quality. April 2014. *Rockville, MD: Agency for Healthcare Research and Quality.* 2014.
2. Bushby K, Lynn S, Straub T, Treat-Nmd Network . Collaborating to bring new therapies to the patient–the TREAT-NMD model. *Acta Myol.* 2009;**28**(1):12–5. [PubMed: 19772190].
3. Anthony S, Pradier C, Chevrier R, Festraets J, Tifratene K, Robert P. The French National Alzheimer database: a fast growing database for researchers and clinicians. *Dement Geriatr Cogn Disord.* 2014;**38**(5-6):271–80. doi: 10.1159/000360281. [PubMed: 24994018].
4. Wortmann M. Dementia: a global health priority - highlights from an ADI and World Health Organization report. *Alzheimers Res Ther.* 2012;**4**(5):40. doi: 10.1186/alzrt143. [PubMed: 22995353].
5. Suzman R, Beard JR, Boerma T, Chatterji S. Health in an ageing world–what do we know? *Lancet.* 2015;**385**(9967):484–6. doi: 10.1016/S0140-6736(14)61597-X. [PubMed: 25468156].
6. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. World Alzheimer Report 2015. The global impact of dementia. An analysis of prevalence, incidence, cost & trends. London: Alzheimer's Disease International; 2015.
7. Alzheimer's A. 2015 Alzheimer's disease facts and figures. *Alzheimers Dement.* 2015;**11**(3):332–84. [PubMed: 25984581].
8. Pratchett T. A global assessment of dementia, now and in the future. *Lancet Neurol.* 2015;**14**:691.
9. Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers Dement.* 2013;**9**(1):63–75 e2. doi: 10.1016/j.jalz.2012.11.007. [PubMed: 23305823].
10. Garre-Olmo J, Flaque M, Gich J, Pulido TO, Turbau J, Vallmajo N, et al. A clinical registry of dementia based on the principle of epidemiological surveillance. *BMC Neurol.* 2009;**9**:5. doi: 10.1186/1471-2377-9-5. [PubMed: 19175921].
11. Lillquist PP. Challenges in surveillance of dementias in New York State. *Prev Chronic Dis.* 2004;**1**(1):A08. [PubMed: 15634370].
12. Gonzalez JA. Global comparisons for developing a national dementia registry in Cuba. *MEDICC Rev.* 2015;**17**(1):59–63. [PubMed: 25725771].
13. Henry M, Gerber TM, Bunn G, Stacy A, Tsan L. The New York State Department of Health's Alzheimer's disease and other dementias registry first year experience. *Am J Alzheimer's Care Relat Disord Res.* 1988;**3**(6):13–20.
14. Macera CA, Still CN, Brandes DA, Abramson RK, Davis DR. The South Carolina Alzheimer's disease patient registry: A progress report. *Am J Alzheimer's Care Relat Disord Res.* 2016;**6**(1):35–8. doi: 10.1177/153331759100600108.
15. Pfeiffer E, Keller DM, Doblas-Shaw R, McCarthy E. The first year operating experience of the Florida Dementia Registry. *Am J Alzheimer's Care Relat Disord Res.* 2016;**3**(6):21–8. doi: 10.1177/153331758800300608.
16. Petersen RC, Kokmen E, Tangalos E, Ivnik RJ, Kurland LT. Mayo Clinic Alzheimer's Disease Patient Registry. *Aging Clin Exp Res.* 2013;**2**(4):408–15. doi: 10.1007/bf03323961.
17. Larson EB, Kukull WA, Teri L, McCormick W, Pfanschmidt M, van Belle G, et al. University of Washington Alzheimer's Disease Patient Registry (ADPR): 1987–8. *Aging Clin Exp Res.* 2013;**2**(4):404–8. doi: 10.1007/bf03323960.
18. Kuller LH, Ganguli M, Ratcliff GG, Huff FJ, Belle SH, Detre KM. The University of Pittsburgh Alzheimer's Disease Patient Registry: the Monongahela Valley Independent Elders Survey (MoVIES). *Aging (Milano).* 1990;**2**(3):302–5. [PubMed: 2094370].
19. Evans DA, Scherr PA, Smith LA, Albert MS, Funkenstein HH. The east Boston Alzheimer's Disease Registry. *Aging (Milano).* 1990;**2**(3):298–302. [PubMed: 2094369].
20. Kohout FJ. The University of Iowa Prototype Alzheimer's Disease Registry: plans and progress. *Aging (Milano).* 1990;**2**(3):308–12. [PubMed: 2094372].
21. Morris JC, Mohs RC, Rogers H, Fillenbaum G, Heyman A. Consortium to establish a registry for Alzheimer's disease (CERAD) clinical and neuropsychological assessment of Alzheimer's disease. *Psychopharmacol Bull.* 1988;**24**(4):641–52. [PubMed: 3249766].
22. Fillenbaum GG, Beekly D, Edland SD, Hughes JP, Heyman A, van Belle G. Consortium to establish a registry for Alzheimer's disease: development, database structure, and selected findings. *Top Health Inf Manage.* 1997;**18**(1):47–58. [PubMed: 10173753].

23. Holmes C, Lovestone S. The clinical phenotype of familial and sporadic late onset Alzheimer's disease. *Int J Geriatr Psychiatry.* 2002;**17**(2):146–9. [PubMed: 11813277].
24. Hosseini K, Gaujoux-Viala C, Baertschi A, Oudot J, Rat AC, Guillemin F. Developing a Population-Based Dementia Registry Focusing on Patients and Carer Needs: Methodological Challenges. *Value Health.* 2013;**16**:A323–636.
25. Fereshtehnejad SM, Johannsen P, Waldemar G, Eriksdotter M. Dementia Diagnosis, Treatment, and Care in Specialist Clinics in Two Scandinavian Countries: A Data Comparison between the Swedish Dementia Registry (SveDem) and the Danish Dementia Registry. *J Alzheimers Dis.* 2015;**48**(1):229–39. doi: 10.3233/JAD-150144. [PubMed: 26401943].
26. Garre-Olmo J, Garcia-Ptacek S, Calvo-Perxas L, Turro-Garriga O, Lopez-Pousa S, Eriksdotter M. Diagnosis of Dementia in the Specialist Setting: A Comparison Between the Swedish Dementia Registry (SveDem) and the Registry of Dementias of Girona (ReDeGi). *J Alzheimers Dis.* 2016;**53**(4):1341–51. doi: 10.3233/JAD-160098. [PubMed: 27392854].
27. Moher D, Liberati A, Tetzlaff J, Altman DG, Prisma Group . Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med.* 2009;**6**(7):e1000097. doi: 10.1371/journal.pmed.1000097. [PubMed: 19621072].
28. Weddell JM. Registers and registries: a review. *Int J Epidemiol.* 1973;**2**(3):221–8. [PubMed: 4359831].
29. Brooke EM. The current and future use of registers in health information systems. ; 1974.
30. Pedersen E. Some uses of the cancer registry in cancer control. *Br J Prev Soc Med.* 1962;**16**:105–10. [PubMed: 14484845].
31. Mohammadi A, Ahmadi M, Gharagozlu A. Developing a Minimum Data Set for an Information Management System to Study Traffic Accidents in Iran. *Iran Red Crescent Med J.* 2016;**18**(3):e23677. doi: 10.5812/ircmj.23677. [PubMed: 27247791].
32. Goldberg J, Gelfand HM, Levy PS. Registry evaluation methods: a review and case study. *Epidemiol Rev.* 1980;**2**:210–20. [PubMed: 7000537].
33. Spencer L, Ritchie J, Lewis J, Dillon L. Quality in qualitative evaluation: a framework for assessing research evidence. ; 2003.
34. Sadoughi F, Kimiafar K, Ahmadi M, Shakeri MT. Determining of factors influencing the success and failure of hospital information system and their evaluation methods: a systematic review. *Iran Red Crescent Med J.* 2013;**15**(12):e11716. doi: 10.5812/ircmj.11716. [PubMed: 24693386].
35. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol.* 2008;**8**:45. doi: 10.1186/1471-2288-8-45. [PubMed: 18616818].
36. Kim EJ, Park KW, Lee JH, Choi S, Jeong JH, Yoon SJ, et al. Clinical and Neuropsychological Characteristics of a Nationwide Hospital-Based Registry of Frontotemporal Dementia Patients in Korea: A CREDOS-FTD Study. *Dement Geriatr Cogn Dis Extra.* 2014;**4**(2):242–51. doi: 10.1159/000360278. [PubMed: 25177333].
37. Park HK, Na DL, Han SH, Kim JY, Cheong HK, Kim SY, et al. Clinical characteristics of a nationwide hospital-based registry of mild-to-moderate Alzheimer's disease patients in Korea: a CREDOS (Clinical Research Center for Dementia of South Korea) study. *J Korean Med Sci.* 2011;**26**(9):1219–26. doi: 10.3346/jkms.2011.26.9.1219. [PubMed: 21935279].
38. Religa D, Fereshtehnejad SM, Cermakova P, Edlund AK, Garcia-Ptacek S, Granqvist N, et al. SveDem, the Swedish Dementia Registry - a tool for improving the quality of diagnostics, treatment and care of dementia patients in clinical practice. *PLoS One.* 2015;**10**(2):e0116538. doi: 10.1371/journal.pone.0116538. [PubMed: 25695768].
39. Johannsen P, Jorgensen K, Korner A, Elmo EG, Lauesen LB, Utzon J. Development of a dementia assessment quality database. *Aging Ment Health.* 2011;**15**(1):40–6. doi: 10.1080/13607863.2010.508769. [PubMed: 21271390].
40. Francesconi P, Gini R, Roti L, Bartolacci S, Corsi A, Buiatti E. The Tuscany experimental registry for Alzheimer's disease and other dementias: how many demented people does it capture? *Aging Clin Exp Res.* 2007;**19**(5):390–3. [PubMed: 18007117].
41. Leonard EW, Bu R, Brown AA. Best practices for establishing Georgia's Alzheimer's Disease Registry. *Minn JL Sci Tech.* 2016;**17**:221.
42. McGill N. Georgia health department offers Alzheimer's disease registry. *Nation's Health.* 2015;**45**(6):13.
43. Schreurs BG. The West Virginia Alzheimer's Disease Registry: helping West Virginia cope. *West Virginia Med J.* 2010;**107**(3):44–5.
44. Cohen CA, Drummond N, Tsai O. Developing a dementia care registry for community-based care. *Dementia.* 2004;**3**(2):239–45.
45. Beekly DL, Ramos EM, Lee WW, Deitrich WD, Jacka ME, Wu J, et al. The National Alzheimer's Coordinating Center (NACC) database: the Uniform Data Set. *Alzheimer Dis Assoc Disord.* 2007;**21**(3):249–58. doi: 10.1097/WAD.0b013e318142774e. [PubMed: 17804958].
46. Beekly DL, Ramos EM, van Belle G, Deitrich W, Clark AD, Jacka ME, et al. The National Alzheimer's Coordinating Center (NACC) Database: an Alzheimer disease database. *Alzheimer Dis Assoc Disord.* 2004;**18**(4):270–7. [PubMed: 15592144].
47. Fillenbaum GG, van Belle G, Morris JC, Mohs RC, Mirra SS, Davis PC, et al. Consortium to Establish a Registry for Alzheimer's Disease (CERAD): the first twenty years. *Alzheimers Dement.* 2008;**4**(2):96–109. doi: 10.1016/j.jalz.2007.08.005. [PubMed: 18631955].
48. West Virginia Alzheimer's Disease Registry . Registry History 2017. Available from: http://www.wvadr.hsc.wvu.edu/registry-history.
49. West Virginia Alzheimer's Disease Registry . West Virginia Alzheimer's Disease Registry Health Care Provider Reporting Form 2017. Available from: http://www.wvadr.hsc.wvu.edu/media/2474/wvadrd_fillable_dataform.pdf.
50. Arnold School of Public Health at the University of South Carolina . The 2013-2014 Annual Report of south carolina Alzheimer's Disease Registry 2017. Available from: https://www.sc.edu/study/colleges_schools/public_health/documents/osa_annualreport_2014.pdf.
51. Gerber TM, Henry ME, Bunn G, Johnson C, White J, Sayetta R. Validating the accuracy and quality of data in the New York State Alzheimer's Disease and Other Dementias Registry. *Am J Alzheimer's Care Relat Disord Res.* 2016;**3**(5):25–33. doi: 10.1177/1533317558800300507.
52. Cummings J. Alzheimer's disease diagnostic criteria: practical applications. *Alzheimers Res Ther.* 2012;**4**(5):35. doi: 10.1186/alzrt138. [PubMed: 22947665].
53. Emre M, Aarsland D, Brown R, Burn DJ, Duyckaerts C, Mizuno Y, et al. Clinical diagnostic criteria for dementia associated with Parkinson's disease. *Mov Disord.* 2007;**22**(12):1689–707. doi: 10.1002/mds.21507. [PubMed: 17542011] quiz 1837.
54. McKeith IG, Dickson DW, Lowe J, Emre M, O'Brien JT, Feldman H, et al. Diagnosis and management of dementia with Lewy bodies: third report of the DLB Consortium. *Neurology.* 2005;**65**(12):1863–72. doi: 10.1212/01.wnl.0000187889.17253.b1. [PubMed: 16237129].
55. Englund B, Brun A, Gustafson L, Passant U, Mann D, Neary D. Clinical and neuropathological criteria for frontotemporal dementia. The Lund and Manchester Groups. *J Neurol Neurosurg Psychiatr.* 1994;**57**(4):416–8. doi: 10.1136/jnnp.57.4.416.
56. Erkinjuntti T, Ostbye T, Steenhuis R, Hachinski V. The effect of different diagnostic criteria on the prevalence of dementia. *N Engl J Med.* 1997;**337**(23):1667–74. doi: 10.1056/NEJM199712043372306. [PubMed: 9385127].

Table 2. Characteristics of Reported Registries

Region	Country, Coverage	Registry Name, Year of Establish	Purpose of Registry	Type of Patients	Data Source	MDS	Data Quality		Current Status
							C	DCV	
Asia (n = 1)	South Korean, National	Clinical Research Center for Dementia of South Korea Registry (CREDOS), 2010 (36, 37)	Clinical, epidemiological, research	OP/IP	CR	PC, SPC, DC	NP	NINCDS-ADRDA, DSM-IV	Active
Europe (n = 7)	Germany, National	German Population-based Dementia Registry, 2013 (24)	Clinical, epidemiological, research	OP	PB	PC, SPC, DC	NP	NP	Pilot
	France, National	The French National Alzheimer Database, 2009 (3)	Clinical, epidemiological, research	OP	PB	PC, SPC, DC, TC	84% of all French memory units	ICD-10	Active
	Sweden, National	Swedish Dementia Registry (SveDem), 2007 (38)	Clinical, epidemiological, research	OP	PB	PC, SPC, DC,TC	yes	ICD-10, MKC, LMC, MDSTFC	Active
	Spain, Local (Girona)	Registry of Dementias of Girona (ReDeGi), 2007 (10)	Clinical, epidemiological, surveillance	OP/IP	CR	PC, SPC, DC, TC	Yes	DSM-IV, MKC, LMC, MDSTFC, NINDS-SPSP	Active
	Denmark, Local (Copenhagen)	Danish dementia assessment quality database, 2005 (39)	Clinical, epidemiological	OP	CR	PC, DC, TC	Yes	NP	Active
	Italy, Local (Tuscany)	The Tuscany experimental registry for Alzheimer disease and other dementias, 1999 (40)	Clinical, epidemiological	OP/IP	CR	PC, DC, TC	Yes	ICD-9	1999 - 2005
	UK, Local (Camberwell)	The Camberwell Dementia Case Register (CDCR), 1992 (23)	Clinical, epidemiological	OP/IP	CR	PC, SPC, DC	NP	NINCDS-ADRDA	1993 - 1995
North America (n = 13)	USA, State (Georgia)	Georgia 's Alzheimer Disease Registry, 2014 (41, 42)	Clinical, epidemiology, research	OP/IP	PB	PC,SPC, DC	Yes	NP	Active
	USA, State (West Virginia)	The West Virginia Alzheimer Disease Registry, 2008 (43, 48, 49)	Clinical, epidemiological	OP	PB	P PC, SPC, DC, TC	NP	ICD-10, ICD-9	Active
	Canada, local (Toronto)	Canadian dementia care registry, 2004 (44)	Clinical, epidemiological	OP/IP	PB	PC, SPC, DC	NP	NP	Pilot
	USA, National	National Alzheimer Coordinating Center (NACC) Database, 1997 (45, 46)	Research	OP	PB	PC, SPC, DC, TC	Yes	NP	Active
	USA, State (South Carolina)	The South Carolina Alzheimer Disease Patient Registry, 1988 (14, 50)	Clinical, epidemiological	OP/IP	PB	PC, SPC, DC	Yes	ICD-9	Active
	USA, State (Florida)	The Florida Dementia Registry, 1987 (15)	Clinical, epidemiology, research	OP	CR	PC, SPC, DC	NP	NP	NP
	USA, State (New York)	New York State dementias registry, 1986 (11, 13)	Clinical, epidemiological, surveillance	OP/IP	PB	PC, SPC, DC, TC	Yes	ICD-9	Active
	USA, local (Rochester)	Mayo Clinic Alzheimer Disease Patient Registry, 1986 (16)	Clinical, epidemiological,	OP	PB	PC, DC	Yes	NINCDS-ADRDA	Active
	USA, Local (Seattle)	The University of Washington Alzheimer Disease Patient Registry, 1986 (17)	Clinical, epidemiological	OP/IP	PB	PC, DC	NP	DSM-III-R, NINCDS-ADRDA	Active

	USA, Local (Pittsburgh)	The University of Pittsburgh Alzheimer Disease Patient Registry, 1986 (18)	Research	OP	PB	PC, DC	NP	DSM-III-R	NP
North America (n = 13)	USA, Local (East Boston)	The East Boston Alzheimer Disease Registry, 1986 (19)	Clinical, epidemiology, research	OP	PB	PC,SPC, DC	NP	DSM-III-R, NINCDS-ADRDA	NP
	USA, Local (Iowa)	Iowa Alzheimer Disease Registry, 1986 (20)	Clinical, epidemiology	OP/IP	PB	PC,SPC, DC	NP	ICD-9, NINCDS-ADRDA	Prototype
	USA, National	Consortium to Establish a Registry for Alzheimer Disease(CERAD), 1986 (21, 22, 47)	Clinical, epidemiological	OP	PB	PC, SPC, DC, TC	NP	NINCDS-ADRDA	Active
South America (n = 1)	Cuba, National	Cuban Registry of Cognitive Impairment and Dementia (ReCeDemCu), 2015 (12)	Clinical, epidemiological	OP/IP	PB	PC, SPC, DC, TC	NP	ICD-10, MKC, LMC, MDSTFC, NINCDS-ADRDA, NINDS-SPSP	Pilot

Abbreviations: C, completeness; CR, central registry; DC, diagnostic characteristics; DCV, diagnostic criteria validity; DSM-III-R, diagnostic and statistical manual of mental disorder, 3rd edition; DSM-IV, diagnostic and statistical manual of mental disorder, 4th edition; ICD-10, the 10th revision of the international classification of diseases; IP, inpatient; LMC, the Lund-Manchester; criteria; LRH, local registry hospital; MDS, minimum data set; MKC, the McKeith criteria; MDSTFC, movement disorder society task force criteria; NINDS-ADRDA, national institute of neurological and communicative disorders and Stroke, and Alzheimer disease and related disorders association; NINDS-SPSP, clinical research criteria for the diagnosis of progressive spranuclear palsy; NP, No published data available; OP, outpatient; PB, population-based; PC, patient characteristics; SPC, service provider characteristics; TC, treatment characteristics.