

Categorizing the world of registries

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Abstract

The term *registry* is widely used to refer to any database storing clinical information collected as a byproduct of patient care. Despite the use of this single characterizing term (registry), these databases exist in various forms and support functions ranging from biomedical informatics and clinical research, to public health, epidemiology and evidence-based clinical practice. This ambiguous terminology impacts the ability to locate and learn about specific types of registries; the goal of this research project was to develop a more useful categorization scheme for registries. We thoroughly analyzed peer-reviewed publications related to registries. From our findings, we created a detailed definition for registries in healthcare (medical data registries, or MDRs) and outlined a set of characteristics common to all such MDRs. This framework, MDR-OK, comprises five distinguishing features of registries, and is intended to provide a clear understanding of MDRs as a functional variety of databases, as well as to provide a framework for evaluation and categorization of registries and other data systems.

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1. Introduction

Recent reports by the Institute of Medicine demonstrate the potential impact of clinical data analysis as a method to improve our healthcare system and to establish quality benchmarks [1,2]. Indeed, databases are important and widely used tools in science—including modern medical practice and clinical research [3]. A database has been defined as a structured repository of data that allows for ongoing data collection, modification, and retrieval [4,5]. Articles using the term database abound in the literature—with more than 88,000 title hits on MEDLINE as of July 2007.

In many cases, researchers with a desire to assess a group of patients want a “registry” of these patients. A PubMed search for the term “registry” in July 2007 returned almost 43,000 hits. A well-cited operational defi-

inition for the term “registry” is not easily accessible. According to MeSH, registries are the “systems and processes involved in the establishment, support, management, and operation of registers [*sic*], e.g., disease registers.” This definition appropriately expands the notion of a registry (synonymous and used interchangeably with register by MeSH) to involve both the environment (through systems and processes that must be managed) and the interaction of that environment with a specific disease or therapy. However, it does not adequately articulate the specific differences between simple databases and more sophisticated databases around which systems or processes can be constructed to improve their use for benchmarking or outcomes research [6,7]. It is these more sophisticated databases (and the systems that support them) that are often designated registries.

The ambiguity regarding the unique requirements of registries is fueled by the variety of data repositories described using this single term. The history of registries is centuries old [8], and though modern computerized reg-

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istries have evolved significantly from those handwritten and manually tabulated systems, the terms used to describe them have not changed significantly. The definition of a registry, most recently described in 2002 by Arts et al. [3], is based on work dating from 1949 to 1991 [9–12]: “a systematic collection of a clearly defined set of health and demographic data for patients with specific health characteristics, held in a central database for a predefined purpose.” Although Arts’ definition characterizes important features of registries, there are several reasons to pursue a more thorough definition and understanding of these data systems. Arts’ definition does not distinguish a database from a registry [13–15], nor does it adequately elucidate all important registry traits including those characterized in the MeSH definition of the term. For example, data collection approaches and data models vary widely among databases; however, the use of a registry to store patient data should imply at a minimum the need for a standard set of procedures to appropriately manage security and data privacy. Such procedural requirements may be pre-specified, as is the case with the privacy and security rules specified by the Health Insurance Portability and Accountability Act (HIPAA), under United States Federal Law [16,17], or they may be less stringent in other countries. How these procedures are implemented also may vary among registries, but the functional endpoint should be the same.

Numerous computerized registries have been presented, but not reproducibly characterized in the literature, beginning in the 1970s with the trauma registry at Cook County Hospital [18,19] and the total joint arthroplasty registry at the Mayo Clinic [20]. Since then, projects described as registries have greatly increased in number. For example, Sweden saw nearly a twofold increase in national registries in just 4 years, jumping from 40 to 70, between 2001 and 2005 [21–23]. The goal of this project was to devise a framework for defining and functionally characterizing registries of the type now prevalent in the literature under that heading. Such a framework will allow researchers to better describe, design, and understand data systems, and eventually to conduct more accurate literature searches if our terms become standard. Likewise, physicians and health-care administrators can apply this framework to evaluate registries for use in medical practice or in hospital settings.

2. Methods

This project was conducted in three phases, largely following the immersion/crystallization process used in qualitative research [24]. This process features “the analyst’s prolonged immersion into and experience of the text and then emerging, after concerned reflection, with an intuitive crystallization of the text.”

In the first phase, we constructed a reference list of medical data registry (MDR)-related papers from the peer-reviewed literature. In the second phase, we reviewed each paper to determine how well it fit the definition of registry that had been proposed by Arts in 2002 [3]. During this

immersion phase, we also noted the presence and absence of characteristics identified as important by the authors, including processes for data collection, storage, retrieval, and specific constraints based on the type of data. In the final step (crystallization), we developed a framework consisting of a distilled or summarized set of frequently cited characteristics described in manuscripts about registries. We used this framework to construct an inclusive definition for what we term a *medical data registry* (MDR), which is a subset of registry as previously discussed but specific for medical data. We also generated our scoring and categorization framework. Each phase of this project is described in detail below.

2.1. Phase I: identification of references

Published studies potentially related to registries were identified in MEDLINE using PubMed and Ovid search engines. We also used Google Scholar for broad Internet searches. A title search was run using “registry OR register OR regist#.” This query was modified independently and grouped using AND “medical”, “clinical”, “disease”, “database”, “data repository”, and “computerized” to create our initial reference set (IREF). Using the original search query and independently including the keywords “evaluation”, “implementation”, “design”, and “review”, we identified a second set of articles. These primary reference sets were limited to English articles that had been published in peer-reviewed journals with available online abstracts. Subsequently, we expanded the references to include papers from relevant citations. These cited sources were retrieved and manually entered into the IREF.

2.2. Phase II: preliminary review

One of the authors (BCD) initially read the abstracts of the review articles to identify papers not directly related to the registry (e.g., an article that used a registry to assess immunization compliance but did not describe the characteristics of the registry). We reviewed the remaining articles completely and identified 15 papers (Table 1) that reviewed and discussed general registry characteristics, as well registry construction and development. From this review set (REV), we identified an initial group of “registry” characteristics from which we created a working framework for an objective, qualitative evaluation of the IREF.

We then reviewed the abstracts from the IREF and excluded any article not clearly discussing a registry or registries. Each remaining article in the IREF was reviewed by both authors in face-to-face meetings to determine the presence or absence of the initial characteristics identified in the REV. In cases where an IREF article did not describe the registry in any detail, we actively searched for this information in MEDLINE or from the Internet. If no further information could be found, we excluded the paper and the registry from further review. This process identified 96 papers describing 42 specific “registry” projects.

Table 1

Articles referenced for general discussion of medical data registry design, evaluation and implementation

Title [citation]	Author	Year
Evaluation and Implementation of Public Health Registries [9]	Solomon, D.J.	1991
Immunization Registries in the United States: Implications for the Practice of Public Health in a Changing Health Care System [56]	Wood, D.	1999
Building a patient registry from the ground up [57]	White, B.	1999
Clinical data repositories: an overview	Guyer, S.	2000
National and regional registries: what good are they? [13]	Dyke, C.K.	2000
Are data from clinical registries of any value? [14]	Alpert, J.S.	2000
Defining and improving data quality in medical registries: a literature review, case study and generic framework [3]	Arts, D.G.	2002
Improving Primary Care for Patients with Chronic Illness [27]	Bodenheimer, T.	2002
Using Computerized Registries in Chronic Disease Care [25]	Metzger, J.	2004
Using Clinical Information Technology in Chronic Disease Care: Expert Workshop Summary [26]	Mittman, R.	2004
Using Computerized Medical Databases to Measure and to Improve the Quality of Intensive Care [58]	Rubinfeld, G.D.	2004
Database Production and Maintenance [59]	Engh, C.A.	2004
Introduction/overview on clinical registries [15]	Gladman, D.D.	2005
Critical Features for a Successful Implementation of a Diabetes Registry [28]	Gabbay, R.A.	2005
The rationale for a spine registry [51]	Roder, C.	2006

2.3. Phase III: framework construction and evaluation

Based on the 15 review papers (REV) that discussed design, implementation, and utilization of MDRs, the two authors developed a candidate set of MDR characteristics. We subsequently reviewed the 96 papers discussing the 42 data projects and iteratively refined (crystallized) our set of characteristics. In this process, we used software (Excel) to label articles based on the registry characteristics identified or omitted. We generalized some characteristics (e.g., *able to support a unified, centralized data storage approach* became *mergeable*) or added new characteristics that were not initially generated from the REV papers. Every reference was reviewed at least two times by the first author, and at least once by the second author. The REV articles were reviewed twice because they did not discuss specific registry projects, and therefore the presence or absence of “new” characteristics was not identified by further review. On the other hand, the remainder of IREF articles were reviewed four times to assess for the presence or absence of characteristics identified through subsequent iterations of the crystallization protocol. We grouped characteristics, ultimately arriving at six—five for definition and one for categorization—that appeared frequently in the IREF. We created a detailed definition of each of the six composite characteristics based on all referenced papers. We assigned descriptive and numerical values to each MDR characteristic to create the framework, as shown in Table 2. Finally, we evaluated each of the 42 data systems for these six characteristics to test our framework (Table 3).

3. Results

3.1. MDR framework details

Our initial query in phase I returned a total of over 500 references. In phase II, this number was reduced significantly by review of abstracts for immediate relevance, fol-

lowed by exclusion of articles with incomplete data. Ultimately, 96 references (Table 3) remained for 42 unique clinical data systems (multiple references were used for most data projects). During phase III, we evaluated these data systems looking for the six registry characteristics previously discussed (Table 3). Four clinical data projects did not contain all five characteristics in our definition (Table 4a). These four projects collected a cross-section of data without an association of these data over time. The remaining 38 registries possessed the five critical characteristics, which appear to uniquely distinguish registries from simple databases or other non-registry data repositories. These characteristics relate to key design principles underlying MDRs as discussed below. For a database to meet our definition of a registry, all five of the following MDR characteristics must be present (i.e., score of one or greater for each trait):

- (*M*)*ergeable data*: Data from multiple users and from all patients in the database are combined to create an aggregate set of data. An aggregate dataset supports numerous functions including assessment of procedural utilization and outcomes, physician performance and patient health trends. The ability to merge data into a centralized dataset can be either present {1} or absent { \emptyset }.
- (*D*)*ataset standardized*: The same set of characteristics is collected for each patient in the repository. This process establishes a well-populated data matrix of the aggregate dataset. If all patients contribute data for the same variables, comparisons between patients and to the aggregate population will be possible. A standardized dataset can be either present {1} or absent { \emptyset }.
- (*R*)*ules for data collection*: A systematic and prospective data collection protocol is established. Systematic collection optimizes standardization of the dataset, which is critical to functional data collection endeavors (like MDRs) as described above. Prospective requires pre-

Table 2
MDR-OK categorization protocol

Variable	Defined characteristic	Value
Mergeable data	M Data stored in format that allows a user/researcher to create a single aggregate and queryable dataset for research and patient care purposes	Ø. No 1. Yes
Dataset standardized	D The same data are collected for all patients/records in a registry	Ø. No 1. Yes
Rules for data collection	R A set of characteristics are defined prior to the collection of data. These data are collected in a systematic and prospective manner	Ø. No 1. Yes
Observations associated over time	O Database is designed so that each patient is identified in the registry as a single continuous record for storage of longitudinal data	Ø. No 1. Yes
Knowledge of outcomes	K Follow-up must be obtained to assess outcomes or manage patient care	Ø. None 1. Passive 2. Active
Inclusion principle	— The characteristic that is common to all patients in an MDR	DZ = chronic disease TH = acute/interventional

selection of patient characteristics and point-of-care collection of these data; this process minimizes data omission and confounding bias. These rules for data collection protocol can be either present {1} or absent {Ø}.

- *(O)bservations associated over time:* In the collection and storage of longitudinal patient data, a systems protocol links follow-up data for individual patients to their unique record in the registry. This is an important technical extension of the follow-up protocol required of MDRs. Without such a process, follow-up associations for individual patients and the aggregate are not possible. Observation associated over time for individual patients can be either present {1} or absent {Ø}.
- *(K)nowledge about patient outcomes:* Follow-up data are collected for all patients in the database. In order to provide useful data for any purpose, a registry should collect data that can evaluate the results of each case. For practitioners, these data can be used in self-evaluation of healthcare delivery and evaluation of patient health trends over time. For researchers, follow-up data are essential to evaluate the impact of therapy on both short and long-term outcomes. Knowledge of outcomes can be either active (e.g., computerized reminder system, patient outreach, etc.) {2}, passive (i.e., additional entries collected during subsequent encounters) {1} or absent {Ø}.

The sixth characteristic (inclusion principle) will be discussed in the next subsection.

3.2. MDR domains

A qualitative assessment of the 38 definitive registries disclosed two broad domains of MDR focus: chronic diseases, independent of therapy; and therapeutic interventions, such as treatment for acute coronary events or surgical procedures. The sixth component of our frame-

work, called inclusion principle (IP), describes the characteristic of a registry for grouping into either domain. The IP is the distinguishing feature of a registry; it describes the medical trait that is common to the patient population of an MDR (e.g., a diabetes registry only records data for diabetic patients). The inclusion principles of different registries were easily grouped by unambiguous inherent similarities, allowing us to categorize registries into two domains; either chronic disease (DZ-MDR) or therapeutic (TH-MDR) (Table 4b).

As the final component of our study, we examined numerous secondary design and functional characteristics of the 38 definitive registries. The design features are related to the data storage architecture and intended usage (e.g., outcomes research versus patient data management). The functional characteristics primarily involve the application of data stored in the registry (e.g., reminder system for follow-up appointments). Based on our qualitative assessment, we found that MDRs within each domain—DZ-MDR versus TH-MDR—had similar secondary characteristics. In general, chronic disease-specific MDRs were designed for integration into the workflow of the clinician and used for patient management. In contrast, therapy-based registries tended to have research goals and were not as integrated into clinic workflow. Table 5 summarizes important secondary characteristics and their presence or absence in several well-discussed registries from each domain.

4. Discussion

We have designed MDR-OK under the premise that certain data system features make a repository more functional for a chosen purpose (e.g., research, patient management, etc.). We define a medical data registry (MDR) as system functioning in patient management or research, in which a standardized and complete dataset including associated follow-up is prospectively and system-

Table 3
Defining characteristics of MDRs

Database name	Meets registry definition	Defining characteristics					Descriptive parameter Inclusion principle
		M	D	R	O	K	
ADHERE [34,41,60–62]	No	Y	Y	No	No	Passive	Hospitalized for acute heart failure
AWESOME [33,63–65]	Y	Y	Y	Y	Y	Passive	Cardiac revascularization
AVID [66–68]	Y	Y	Y	Y	Y	Passive	Antiarrhythmics drug treatment
AORI THA [59]	Y	Y	Y	Y	Y	Passive	Total hip arthroplasty
BRB [69,70]	Y	Y	Y	Y	Y	Passive	Pharmacologically treated rheumatological disease
COHERE [35,71]	Y	Y	Y	Y	Y	Passive	Carvedilol pharmacotherapy
CONCOR [54]	Y	Y	Y	Y	Y	Passive	Congenital heart defects or Marfans
CASS [32,72–74]	Y	Y	Y	Y	Y	Active	Coronary artery surgery
CRB [75]	No	Y	Y	No	No	Passive	Renal biopsy
DRSB [42]	Y	Y	Y	Y	Y	Passive	Breast surgery
ENACT [76,77]	No	Y	Y	Y	No	None	Acute coronary syndromes
ERA-EDTA [78,79]	Y	Y	Y	Y	Y	Passive	Renal replacement therapy
EVENT [80]	Y	Y	Y	Y	Y	Passive	Percutaneous coronary intervention (PCI)
FCN [57]	Y	Y	Y	Y	Y	Passive	Diabetes mellitus
Finnvasc [81–83]	Y	Y	Y	Y	Y	Passive	Vascular surgery
Finnish Arthroplasty [48,49,84]	Y	Y	Y	Y	Y	Passive	Surgical arthroplasty
GRACE [85–88]	Y	Y	Y	Y	Y	Passive	Acute coronary events
IRNR [36]	Y	Y	Y	Y	Y	Passive	Out-of-hospital cardiac arrest
Mayo Arthroplasty [20,46]	Y	Y	Y	Y	Y	Active	Arthroplasty
Mayo Diabetes [89]	Y	Y	Y	Y	Y	Active	Diabetes mellitus
MGH/DMA Diabetes [29,30]	Y	Y	Y	Y	Y	Passive	Diabetes mellitus
NA-PCM [53]	Y	Y	Y	Y	Y	Passive	Pediatric cardiomyopathy
NEBR [40,90,91]	Y	Y	Y	Y	Y	Passive	Epidermolysis bullosa
NEON [92,93]	Y	Y	Y	Y	Y	Passive	Cataract surgery
NIROO [94]	Y	Y	Y	Y	Y	Passive	Malignancy of bone
NPR [55,95]	No	Y	Y	Y	No	None	All patients, compulsory on hospital discharge
Norwegian Arthroplasty [44,96,97]	Y	Y	Y	Y	Y	Passive	Implant surgery
NorKar [22,98]	Y	Y	Y	Y	Y	Passive	Vascular surgery
NPTR [99,100]	Y	Y	Y	Y	Y	Passive	Pediatric trauma
NSN [37,101–103]	Y	Y	Y	Y	Y	Passive	Orthopedic spine disease
PREMIER [104,105]	Y	Y	Y	Y	Y	Passive	Myocardial infarction
Puget Sound Diabetes [106]	Y	Y	Y	Y	Y	Passive	Diabetes mellitus
REACH [107,108]	Y	Y	Y	Y	Y	Passive	45+ years old, three atherosclerosis risk factors
REIN [109]	Y	Y	Y	Y	Y	Passive	Renal replacement therapy (dialysis)
RIAT [110,111]	Y	Y	Y	Y	Y	Passive	Hypertension
SOJRR [45]	Y	Y	Y	Y	Y	Passive	Arthroplasty
Spine Tango [112–114]	Y	Y	Y	Y	Y	Passive	Orthopedic spine disease
Swedish Cataract [21,115–117]	Y	Y	Y	Y	Y	Passive	Cataract
Swedish Hip Replacement [43,47,50,118,119]	Y	Y	Y	Y	Y	Passive	Orthopedic spine disease
SwedVasc [120,121]	Y	Y	Y	Y	Y	Passive	Vascular surgery
Swedish Spine [23,39,122–124]	Y	Y	Y	Y	Y	Passive	Hip replacement surgery
UKBOR [52,125]	Y	Y	Y	Y	Y	Passive	Barrett's esophagus

Table 4a
Projects not satisfying MDR-OK criteria

Database name	Meets registry definition	M	D	R	O	K	Inclusion principle	MDR-OK score
ADHERE [60]	No	1	1	1	∅	1	Hospitalized for acute heart failure	4
CRB [75]	No	1	1	1	∅	1	Renal biopsy	4
ENACT [76,77]	No	1	1	1	∅	∅	Acute coronary syndromes	3
NPR [55]	No	1	1	1	∅	∅	All patients, on hospital discharge	3

atically collected for a group of patients with a common disease or therapeutic intervention. This definition builds upon that proposed by Arts [3], and makes the important distinction that registries are a functional subset of databases (i.e., all registries are databases, but not all dat-

abases are registries). In making this distinction we have described five registry-defining characteristics (MDR-OK), which when present will make a data system (registry by our definition) maximally functional for a variety of purposes. Therefore, it is not appropriate to use the terms

Table 4b

Evaluation of MDRs using MDR-OK scoring protocol and inclusion principle categorization

Database name	M	D	R	O	K	Inclusion principle	MDR-OK score and inclusion principle
Family Care Network [57]	1	1	1	1	1	Chronic disease	5, DZ
Puget Sound Diabetes [106]	1	1	1	1	1	Chronic disease	5, DZ
Mayo Diabetes [89]	1	1	1	1	2	Chronic disease	6, DZ
MGH/DMA Diabetes [29,30]	1	1	1	1	1	Chronic disease	5, DZ
NEBR [40]	1	1	1	1	1	Chronic disease	5, DZ
REACH [107,108]	1	1	1	1	1	Chronic disease	5, DZ
RIAT [110,111]	1	1	1	1	1	Chronic disease	5, DZ
AWESOME [33,63–65]	1	1	1	1	1	Therapeutic	5, TH
AVID [66–68]	1	1	1	1	1	Therapeutic	5, TH
AORI THA [59]	1	1	1	1	1	Therapeutic	5, TH
BRB [69,70]	1	1	1	1	1	Therapeutic	5, TH
COHERE [35,71]	1	1	1	1	1	Therapeutic	5, TH
CONCOR [54,126]	1	1	1	1	1	Therapeutic	5, TH
CASS [32,72–74]	1	1	1	1	2	Therapeutic	6, TH
DRSB [42]	1	1	1	1	1	Therapeutic	5, TH
ERA-EDTA [78,79]	1	1	1	1	1	Therapeutic	5, TH
EVENT [80]	1	1	1	1	1	Therapeutic	5, TH
Finnvasc [81–83]	1	1	1	1	1	Therapeutic	5, TH
Finnish Arthroplasty [48,49,84]	1	1	1	1	1	Therapeutic	5, TH
GRACE [85–88]	1	1	1	1	1	Therapeutic	5, TH
IRNR [36]	1	1	1	1	1	Therapeutic	5, TH
Mayo Arthroplasty [20,46]	1	1	1	1	2	Therapeutic	6, TH
NA-PCM [53]	1	1	1	1	1	Therapeutic	5, TH
NEON [92,93]	1	1	1	1	1	Therapeutic	5, TH
NIROO [94]	1	1	1	1	1	Therapeutic	5, TH
Norwegian Arthroplasty [44,96,97]	1	1	1	1	1	Therapeutic	5, TH
NorKar [22,98]	1	1	1	1	1	Therapeutic	5, TH
NPTR [99,100]	1	1	1	1	1	Therapeutic	5, TH
NSN [37,101–103]	1	1	1	1	1	Therapeutic	5, TH
PREMIER [104,105]	1	1	1	1	1	Therapeutic	5, TH
REIN [109]	1	1	1	1	1	Therapeutic	5, TH
SOJRR [45]	1	1	1	1	1	Therapeutic	5, TH
Spine Tango [112–114]	1	1	1	1	1	Therapeutic	5, TH
Swedish Cataract [21,115–117]	1	1	1	1	1	Therapeutic	5, TH
Swedish Hip Replacement [43,47,50,118,119]	1	1	1	1	1	Therapeutic	5, TH
SwedVasc [120,121]	1	1	1	1	1	Therapeutic	5, TH
Swedish Spine [23,39,122–124,127]	1	1	1	1	1	Therapeutic	5, TH
UKBOR [52,125]	1	1	1	1	1	Therapeutic	5, TH

database and registry interchangeably; and a registry has potentially more value to physicians, healthcare administrators, and researchers. In choosing a data system for research, patient management, or other functions, our scoring system and taxonomy can be a guide in shopping for a registry from private companies marketing proprietary data collection systems designed for practitioners or researchers. Likewise, registry developers may use this framework to model MDRs and associated policies/procedures. Finally, the literature should benefit from accurate and appropriate use of terminology and categorization of registries provided by the MDR-OK framework.

This manuscript represents the most thorough definition of a registry to date and describes the first published protocol for classifying and categorizing medical data registries based on design and functional characteristics. There are three implications of this work. First, as discussed above, a database should only be termed an MDR when all five MDR-OK characteristics are present. Second, all registry

and non-registry databases may be scored and classified using the MDR-OK protocol. Finally, an MDR's function and approach to data collection appear to be closely tied to what we have termed the inclusion principle (IP). This inherent characteristic requires little interpretation and appears to predict many secondary aspects of a registry. By grouping similar IPs, we have established two MDR domains and have demonstrated that registries within each domain tend to share similar secondary features.

In general, chronic disease-specific (DZ) MDRs focus on patient management and the use of treatment guidelines to improve quality of care by targeting high-risk patients and utilizing physician/patient reminder systems to improve follow-up care [25–27]. These registries may be useful for population-wide healthcare improvement by enabling hypothesis generation or retrospective (pre-post) studies. These registries can utilize outcomes data to assess disease status depending on the IP. For example, a physician using a diabetes MDR might look at a patient's

Table 5
MDR-OK, inclusion principle and secondary registry characteristics

Database name	Inclusion principle	M	D	R	O	K	Clinical support system	Physician feedback	Based on guidelines	Patient management	Reminder system	Outcomes research
<i>Chronic disease</i>												
Unspecified* [27]	Chronic disease*	X	X	X	X	X	X	X	X	X	X	
Unspecified* [25]	Chronic disease*	X	X	X	X	X	X	X	X	X	X	
Unspecified* [26]	Diabetes	X	X	X	X	X	X	X	X	X	X	
Mayo Diabetes[89]	Diabetes	X	X	X	X	X	X	X	X	X	X	
Puget Sound Diabetes[106]	Diabetes	X	X	X	X	X	X	X	X	X	X	X
MGH/DMA Diabetes [29,30]	Diabetes	X	X	X	X	X	X		X	X		X
Family Care Network [57]	Diabetes	X	X	X	X	X	X	X	X	X	X	X
RIAT [110,111]	Hypertension	X	X	X	X	X	X	X	X	X		
<i>Acute/interventional</i>												
Unspecified* [51]	Spine*	X	X	X	X	X						X
Unspecified* [58]	Intensive Care*	X	X	X	X	X	X	X				X
Swedish Cataract [21,115–117]	Cataract	X	X	X	X	X						X
Mayo Arthroplasty [20,46]	Arthroplasty	X	X	X	X	X	X	X			X	X
AORI THA [59]	Arthroplasty	X	X	X	X	X	X					X
NSN [37,38,101–103]	Spine	X	X	X	X	X	X	X				X
Swedish Spine [23,39,122–124,127]	Spine	X	X	X	X	X	X	X				X
Swedish Hip [43,47,50,118,119]	Arthroplastyssssss	X	X	X	X	X		X				X
Finnish Arthroplasty [48,49,84]	Arthroplasty	X	X	X	X	X						X
SwedVasc [120,121,128]	Vascular Surgery	X	X	X	X	X		X				X
Spine Tango [112–114]	Spine	X	X	X	X	X	X					X
GRACE [85–88,129]	Acute coronary events	X	X	X	X	X						X

* Indicates paper did not discuss a particular registry project, but rather general concepts or principles of registries.

HbA1c to assess health status [27–30]. By observing the frequency of HbA1c measurements performed by physicians; insurance companies, researchers, and administrators can assess physician compliance with standard guidelines (i.e., HbA1c measured every six months) [31]. Finally, long-term results of HbA1c measurements can be used as an outcomes measure to assess the impact of care [28]. Consequently, DZ-MDRs function in patient and physician assessment, and as healthcare management tools. Our findings for the functions real-world DZ-MDRs, when categorized as such by the MDR-OK protocol, are both consistent and expound upon those proposed by Wagner in his chronic illness model [27].

On the other hand, therapeutic (TH) MDRs collect data about patients who are acutely ill or are receiving a specific therapy. These registries evaluate the outcomes of acute illness and how therapies impact outcomes. Many TH-MDRs evaluating care for severe, acute events use mortality as the outcome measure (e.g., myocardial infarction) [32–36]. Numerous other measures are found in the cited references, including validated outcomes metrics (e.g., SF-36) [37–39], complications rates [21,40–43], or the need for revision surgery [44–50]. TH-MDRs serve as tools supporting the practice of evidence-based medicine, allowing researchers to identify therapies associated with the best outcomes. Indeed, TH-MDRs have been successfully used by oncologists to optimize chemotherapy for decades. Additionally, TH-MDRs can be used for assessment of diagnostic and procedural utilization [51], as well as ongoing demographic and epidemiological evaluations

[52–54]. Finally, TH-MDRs sometimes function in a patient management capacity. An example includes the Mayo Arthroplasty registry [46], which sends reminders to physicians to follow-up at appropriate intervals following surgery. However, many TH-MDRs may be unusable for this type of patient management because data entry occurs in batches long after treatment is complete, despite prospective collection of data. This storage approach limits the usefulness of the registry in clinic work-flow or short-term healthcare delivery, but does not compromise the registry for its intended outcomes research purpose.

Of note, this framework may also be useful for non-registry database classification, as demonstrated in Table 4a. Consider a non-MDR database like the self-described Norwegian Patient “Registry” (NPR) [55], which we scored as {TH – M1, D1, R1, OØ, KØ}. The NPR is a good example of an administrative database, which records discharge diagnoses and several other demographic features of patients, but no follow-up information. Although the NPR has an atypical inclusion principle—hospital discharge—it might still be categorized using MDR-OK as a therapeutic non-MDR database, with the inclusion principle as the “therapy” of “inpatient admission” regardless of treatment provided. When classified as such, the database should have some research functionality, which it does in population and disease epidemiology. However, a lack of follow-up precludes its significant use in clinical research. Using the MDR-OK framework to classify various database projects, both registry and non-registry, may serve many purposes. First, the framework may provide more

specific results from PubMed searches if our terminology becomes standard for authors. Second, it is likely that other aspects of MDRs, including data entry approaches, sustainability models, or analytic methods, may be tied to one or more of these characteristics; though this association has not been demonstrated in this analysis. Third, this framework may provide a better understanding of a particular MDR's capabilities and intended use—which will benefit other attempts at comparing MDRs or learning about the technical requirements for MDRs with specific design specifications.

We have noted similar design features and applications of MDRs within either of the two IP domains. As previously mentioned, there is some overlap in function, but the primary applications of each registry type are distinct. We note that there is a difference between the registry per se and the applications of a registry. Applications rely on data, and MDRs can be a great source for these data. In our secondary analysis, we have included several additional features of registries, which are most appropriately defined as peripheral applications because they make use of registry data but are not required of a registry by MDR-OK. Two applications in particular, a clinical support system and a clinician feedback protocol, were present in most proper registries (Table 5). We feel these applications represent important utilization of registry data; however, the presence of these applications is not necessary by definition for a data system to be defined as a registry. We believe that a good registry should function as a clinical support system: data collected for the registry should be distributed to staff and physicians as part of normal clinical workflow. Second, registries should provide data as feedback to physicians submitting information to the dataset. Physicians should be informed of their adherence to standard-of-care guidelines, their patients' outcomes; individual physician or office can also be compared to the aggregate dataset. Many of the registries we studied utilized these applications, and this additional feature is particularly useful in the practice of evidence-based medicine.

5. Limitations and future work

Our study has several limitations, primarily related to our methodology of gathering data regarding the specific registry projects. First, inter-rater reliability cannot be assessed from our immersion–crystallization protocol; though both authors contributed to the review process. Second, we did not conduct a systematic literature review. Thus, we may have omitted articles discussing registries that were only described as databases or other data systems. Since our review protocol focused on finding published descriptions of “registry” projects—specifically the design, evaluation and implementation of self-described registries—we did not include articles in the IREF discussing databases that may have been MDR-OK-consistent registries but were not self-described as a “registry.” Therefore, it is possible that characteristics of MDRs were

excluded in our scoring and categorization framework due to incomplete sampling of the literature. However, we believe that our thorough examination of the many registry projects included in the IREF made our examination broad enough that we have included all vital registry features. Moreover, our review protocol did include a single reading of manuscripts discussing database projects that we ultimately excluded from IREF as non-registry according to the authors' descriptions. Finally, we suggest that this limitation of our study, which is due to inexact or improper terminology prevalent in the literature, is precisely the problem that we try to resolve with the MDR-OK framework.

A third limitation of our research is incomplete data regarding the registries within our study. As mentioned in our methods, we conducted our evaluation based on information available in the literature and online regarding each individual MDR. We did not attempt to contact authors or registry coordinators in order to further examine the secondary characteristics of all MDRs in the IREF. However, data were available for the six MDR-OK characteristics for all 38 registries and four databases examined. Likewise, sufficient data regarding important secondary features were available to support our preliminary findings and warrant further investigation (Table 5). Future research will focus on more thoroughly evaluating these secondary characteristics and their association with either chronic disease or therapeutic MDRs. We will conduct literature review and directly contact registry projects to study prototype registries within each category of our framework. Now that we have defined important parameters and categorized MDRs, we would like to understand the features that make one registry more successful than another of the same variety. Lastly, there is little current research about how registries functioning as clinical support tools impact physicians and patients. We are in the process of adopting a registry and studying its effects on patient satisfaction, provider attitudes about the system, and long-term outcomes assessment to improve quality of care.

6. Conclusion

We have conducted a thorough review of the literature discussing medical data registries (MDRs). This review has resulted in a framework, MDR-OK, that may be used to better distinguish an MDR from a non-registry database, to define the term “registry”, and to score and categorize various data systems including MDRs. Our definition and categorization framework is the most thorough to date, and should provide clarity regarding choice of terminology in the literature. Researchers may be able to use this framework to better describe and understand their data systems, and eventually to conduct more accurate literature searches about MDRs. Although more useful to researchers and health information managers, physicians, and healthcare administrators can use our results to evaluate registries for use in medical practice or in hospital settings.

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