

International Journal of Population Data Science

Journal Website: www.ijpds.org



Swansea University
Prifysgol Abertawe

Challenges Associated with Cross-Jurisdictional Analyses using Administrative Health Data and Primary Care Electronic Medical Records in Canada

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Submission History

Submitted:	30/11/2017
Accepted:	16/07/2018
Published:	05/10/2018

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Abstract

Over the last 30 years, public investments in Canada and many other countries have created clinical and administrative health data repositories to support research on health and social services, population health and health policy. However, there is limited capacity to share and use data across jurisdictional boundaries, in part because of inefficient and cumbersome procedures to access these data and gain approval for their use in research. A lack of harmonization among variables and indicators makes it difficult to compare research among jurisdictions. These challenges affect the quality, scope, and impact of work that could be done. The purpose of this paper is to compare and contrast the data access procedures in three Canadian jurisdictions (Manitoba, Alberta and British Columbia), and to describe how we addressed the challenges presented by differences in data governance and architecture in a Canadian cross-jurisdictional research study. We characterize common stages in gaining access to administrative data among jurisdictions, including obtaining ethics approval, applying for data access from data custodians, and ensuring the extracted data is released to accredited individuals in secure data environments. We identify advantages of Manitoba's flexible 'stewardship' model over the more restrictive 'custodianship' model in British Columbia, and highlight the importance of communication between analysts in each jurisdiction to compensate for differences in coding variables and poor quality data. Researchers and system planners must have access to and be able to make effective use of administrative health data to ensure that Canadians continue to have access to high-quality health care and benefit from effective health policies. The considerable benefits of collaborative population-based research that spans jurisdictional borders have been recognized by the Canadian Institutes for Health Research in their recent call for the creation of a National Data Platform to resolve many of the issues in harmonization and validation of administrative data elements.

Introduction

While in the past there has been doubt about the ability of 'big data' to generate research findings that can impact health-care in a meaningful way, the value of administrative health data is now increasingly recognized in research, health services planning and evaluation, and clinical care (1,2). Administrative health data are routinely generated during the administration of the health care system, and include records from physician services, inpatient and emergency department care, long-term care, prescription medications, and health insurance registries. Recently, electronic medical records have emerged as an additional source of routinely collected clinical data. Although such data are intended for patient care, they are an efficient source of consistently collected information, and have enormous potential for use in disease surveillance, quality improvement, pragmatic clinical trials, and answering clinically relevant queries.

Many developed countries, including the US, the UK, Australia, and Canada, maintain administrative health datasets at

the state, provincial and/or national level, and use them as tools for population-based research (3). Researchers are increasingly drawing upon these data repositories to pose and answer research questions, and often use multiple datasets linked across jurisdictions to conduct sophisticated analyses. However, while the creation and maintenance of large datasets has enhanced and advanced research in population and public health fields, obtaining access to and approvals for using these resources remains cumbersome in many settings and often requires copious clerical effort (4,5). As early as the 1990s, there have been calls for streamlining of approval processes for access to and linkage of large datasets (6). And while there is recognition of a continuing need to safeguard data privacy, it must also be acknowledged that timely access to information is essential for conducting research using linked administrative and clinical data.

In Canada, universal health insurance creates an opportunity for health services researchers to conduct whole-population studies by harmonizing, linking and structuring data to help generate new knowledge (5). The fact that the

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Canadian health care system is administered at the provincial/territorial level can be viewed as an advantage, as it creates a rich laboratory of differences in policy and health care delivery within an over-arching pan-Canadian framework. At the same time, provincial/territorial responsibility for health care means each jurisdiction collects and stores its own administrative health data within different structures and definitions. Because of differing regulations and codes for patient confidentiality, information privacy, research ethics, and legal and social issues across the country, data from multiple jurisdictions cannot be aggregated directly, and so cross-jurisdictional studies are conducted as distributed analyses, with the aggregate results combined. That is, to conduct cross-jurisdictional research, each province obtains approvals for linking its own data and conducting the analyses, and the results are then compared among provinces. Gaining meaningful results from cross-provincial research, surveillance, and evaluation using administrative data therefore requires a great deal of experience and training with analytic techniques specific to large datasets and familiarity with how the data are collected and structured in each jurisdiction (7). There are also differences in the processes required to obtain data access across Canadian provinces (for example, in data governance, wait times and costs), often leading to frustration and outright avoidance of cross-jurisdictional research. Tapping the full potential of the rich administrative data resources available can be complex and time consuming, and many researchers decide that the potential reward of cross-provincial research is not worth the additional investment of time and resources. However, by sharing methodological approaches, establishing clear processes for multi-jurisdictional data access, and collaborating in other ways, we can streamline the process and expand capacity for insightful analysis of administrative data in Canada and other countries.

In this paper, we describe the challenges and successes of a collaboration spanning three Canadian jurisdictions, examining administrative health and primary care electronic medical record (EMR) data in pursuit of an algorithm for identifying frailty in community-dwelling older adults (Box 1 provides a brief overview of this cross-centre study). The three jurisdictions are represented by researchers at the Manitoba Centre for Health Policy (University of Manitoba), the University of Calgary in Alberta, and the Centre for Health Services and Policy Research (University of British Columbia). We then detail the data access processes in each of the three provinces and discuss how we addressed the major challenges we encountered in conducting this research.

Approaches to Data Access in Three Canadian Provinces

One of the most significant challenges to cross-jurisdictional research is enabling access to health data to conduct research that is in the public's interest while at the same time abiding by legislation that protects patients' right to privacy and maintains the confidentiality of their personal information (5). Access to health data for research carries with it the risk that personal information could be inadvertently or intentionally released. Provincial health ministries are responsible for protecting the administrative data they maintain when these data are used in research, and this is accomplished through robust gov-

ernance models and practices that provide access in a timely manner while preserving confidentiality in each jurisdiction. The following discussion characterizes the data access procedures in Manitoba, Alberta and B.C. A side-by-side comparison is provided in Table 1.

Manitoba

In Manitoba, researchers gain access to administrative health data through the Manitoba Centre for Health Policy (MCHP) at the University of Manitoba. MCHP houses the Manitoba Population Research Data Repository, a comprehensive collection of administrative, survey and registry data from the health care, social services, education and justice systems on virtually all residents of Manitoba. The data are routinely collected by several different government departments and agencies, community organizations, and First Nations governance bodies, and are transferred to the MCHP Repository in regular intervals. Personal identifiers (e.g., names, addresses and personal health numbers) are stripped from the data before they arrive at MCHP, but the data are linkable at the individual level across datasets and over time by use of a unique scrambled numeric identifier attached to each record. MCHP coordinates data access through the following steps:

1. **Feasibility Assessment and Cost Estimate.** MCHP reviews research proposals and conducts feasibility assessments for new projects. A data analyst with expert knowledge of the specific datasets required for the project examines the researcher's analysis plan, estimates the projected time to complete the analyses, and notes any inconsistencies, omissions or potential complications with the data requested or proposed methodologies. MCHP then produces a cost estimate for the data extraction and analysis work to be completed based on the scope and complexity of the project. Most often, MCHP analysts are contracted to conduct the analyses for external projects, but researchers may also hire their own analysts to do this work, in which case those individuals access the data through a hardwired remote access site or by secure virtual private network login.
2. **Data Access Accreditation.** Any individuals who will have direct access to the data or the MCHP computer network are required to attend an accreditation session. The 3-hour session provides basic information on the MCHP data holdings, the process for beginning and managing a research project using the Repository, the limits imposed on data access, use and publication, and time and cost estimates to execute a project. The session also provides an overview of the Personal Health Information Act (PHIA) requirements as they apply to data de-identification and disclosure at MCHP.
3. **Data Access Request, Ethics Approval and Other Permissions.** All projects using Repository data must be approved by the University of Manitoba Health Research Ethics Board (UM-HREB) and the Health Information Privacy Committee (HIPC), the provincial body responsible for personal health information. Approvals are generally granted within one month of submission if all requirements are met in the Data Access Request. In

Box 1. A Case Study: Identifying Frailty using Administrative Health and Electronic Medical Record Data

Frailty is a medical syndrome characterized by reduced strength, endurance and physiological function, which results in increased vulnerability to functional decline, dependence and/or death. The majority of the 250,000 individuals who die annually in Canada are considered frail (8). Independent of age, frailty is predictive of adverse health events including death, hospitalizations, institutionalization, falls, and decline in health status (9–11). In addition, a large proportion of each Canadian province's health care expenditure is for hospital care, which is due in part to a population of patients who are severely frail (completely dependent for personal care) to terminally ill (approaching the end of life) (12). Adverse health events associated with frailty translate to increasing costs both for the overall health care system and among frail individuals. Preventing, reducing or delaying frailty has the potential to reduce the burden on individuals and society (13). Yet the relevant intervention research needed to assess and reliably identify frailty is still in its infancy, and consequently there is a dearth of evidence to support individuals with complex health needs.

The **Frailty Study** was funded within the Strategy for Patient-Oriented Research (SPOR) Primary and Integrated Health Care Innovation Network initiative with the aim to identify frailty in seniors (aged 65+ years) by developing and validating algorithms in administrative data and electronic medical records (EMRs). This study builds on previous work using administrative data to define frailty by researchers at Dalhousie University (Nova Scotia, Canada) (14) and the B.C. Ministry of Health (15,16). Although research on identifying frail individuals is still preliminary, secondary sources of data are promising resources since identifying frailty in administrative data and EMRs is likely to be less time-consuming than carrying out periodic health assessments on individual patients. Frailty identification algorithms will ultimately be used to determine the natural range of frailty associated with the risk of hospitalization or other hospital-related events, and thus will inform clinical care and jurisdiction-level health services planning.

keeping with the various data sharing agreements, HIPC additionally requires that researchers obtain a letter of permission from each non-health data provider, stating their approval for use of their specific datasets in the proposed project. An agreement between the University of Manitoba, the data providers who have entered into Information Sharing and Protection of Privacy Agreements with the University, and the researcher is made, establishing the legal obligations of the researcher and their responsibilities under PHIA and the Freedom of Information and Protection of Privacy Act (FIPPA) legislation governing the use of MCHP data.

4. **Data Extraction and Analysis.** Once the researcher agreement is fully executed, the accredited data analysts have access to the pertinent datasets. Analysts can begin working with the data within the secure data environment at MCHP or through a remote access site. Temporary linkage of the requested datasets is performed on a project-by-project basis.

Alberta

In Alberta, administrative health data are routinely collected by the ministry for healthcare (Alberta Health) and the single health authority for the province responsible for delivering nearly all hospital-based care (Alberta Health Services; AHS). Since the formation of AHS in 2008, data access is most often facilitated through a branch within that organization called Health Research Methods and Analytics in partnership with the Alberta SPOR (Strategy for Patient-Oriented Research) Support Unit's Data Platform, who exclusively provide resource support, expertise, and advice to academic researchers seeking to use administrative health data. Alberta Health also makes data accessible through their Analytics and Performance Reporting Branch. Both AHS and Alberta Health have access to fully identifiable personal health information;

however, most data are de-identified prior to release. The process for accessing data is as follows:

1. **Feasibility Assessment and Cost Estimate.** This is currently not part of the Alberta process.
2. **Data Access Accreditation.** This is not currently part of the Alberta process.
3. **Data Access Request, Ethics Approval and Other Permissions.** The researcher obtains Research Ethics Board approval for their proposal from one of the three accredited research ethics boards in the province (Cancer, Clinical Trials, and Community Health), which typically takes up to one month. The ethics agreement describes the data that are to be released by the data custodian (AHS or Alberta Health), as well as outlining the secure storage and protection parameters for the extraction.

The researcher then submits a request for data access to the data custodian, including a research proposal, a description of the requested data, and the ethics agreement proposal. The staff at AHS Analytics examine the data analysis plan and work with the researcher to determine the details of the data extraction. This step may include identifying the best available datasets to answer the proposed research question(s) for the study period, agreeing on the specific variables to be released, and deciding on the degree of de-identification required

4. **Data Extraction and Analysis.** Upon approval of the data access application, AHS Analytics staff link the data from separate databases using identifiable information, and then de-identify the data prior to release, although they are still linkable through a study ID for analysis purposes. Data release to the researcher is generally done by use of a secure file transfer protocol by

the AHS Analytics staff in accordance with the specifications for data transfer, storage and access described in the researcher's ethics agreement.

The lead researchers of the Frailty Study intended to link administrative health data in each of the three provinces to the primary care EMR data held within the Canadian Primary Care Sentinel Surveillance Network. However, due to unforeseen circumstances, the mechanisms for linking administrative data and EMRs in Alberta were not yet fully developed when we began implementing the Frailty Study. Rather than delay the entire study while dealing with this complication, a decision was made to move forward using the Manitoba and BC administrative data to develop the frailty algorithm, and to use the Alberta EMR dataset to identify frail patients in Alberta. Thus, the majority of this paper focuses on the administrative health data that were obtained from Manitoba and B.C; the Alberta portion of the Frailty Study will be detailed in a future publication. This obstacle demonstrates the need for adaptability and flexibility when conducting cross-jurisdictional data projects: while it was our intent to include linked data from Alberta in the Frailty Study, we soon realized that waiting for the administrative challenges to be resolved would jeopardize the entire project, and chose to modify our research plan accordingly.

British Columbia

In B.C., researchers work with Population Data B.C. (PopData), a multi-university resource that facilitates research on the determinants of human health, well-being and development (17), to obtain access to administrative health data. PopData is the custodian of 19 linkable datasets of individual-level, de-identified, longitudinal data on B.C. residents in the domains of health services, population, vital statistics, demographics, life course, and occupation. Researchers are first required to obtain ethics approval, and then have a data access request approved by the data provider. PopData facilitates the completion of data access requests by reviewing requests before they are submitted to the provider. The data provider may request revisions before granting approval for the use of data in the proposed research.

1. **Feasibility Assessment and Cost Estimate.** PopData staff are available to answer questions about data availability and feasibility of research requests. A new tool developed (not yet available during this research project) called B.C. Data Scout enables researchers to find out how many study subjects meet criteria of interest, such as diagnoses, age groups, interventions.
2. **Data Access Accreditation.** All researchers must receive a passing score in an online privacy training module through PopData prior to receiving access to data. This training covers the legislative requirements and researcher responsibilities in gaining access to linked data.
3. **Data Access Request, Ethics Approval and Other Permissions** A current ethics approval certificate from an accredited research ethics board and a complete copy of the research proposal must be submitted with the data access request. PopData provides the researcher

with a detailed set of instructions for completing the request and reviews it for:

- (a) **Completeness:** ensure all sections are filled out and supporting documents - e.g., ethics approval, peer review documents, funded research proposal, data field list, consent forms - are included;
- (b) **Clarity:** ensure the study details - e.g., population, data linkages, research objectives - are clear and consistent with the funded research proposal; and
- (c) **Consistency:** ensure the analysis plan and investigators are consistent across all study documents.

4. **Data Extraction and Analysis.** Once the data access request is approved, PopData extracts the pertinent data according to the specifications in the request. Data are released without identifiers, but can be linked through a study-specific ID. Data release to the researcher is generally done into PopData's virtual secure research environment (SRE) (18). Authorization to house research extracts outside the SRE need to meet additional security requirements. PopData keeps an audit trail of transfers in and out of the SRE and of the explicit actions required by the researcher to minimize the potential for a data breach. The log information is reviewed by PopData regularly and upon request by the applicable data custodian to ensure conformity with the research agreement(s).

Challenges in Data Governance and Architecture: Lessons Learned

While administrative data centres like MCHP and PopData have established procedures for facilitating data access in a way that minimizes information privacy concerns, challenges for researchers collaborating on multi-jurisdictional studies still exist in how the data are governed and structured. These challenges affect the quality, scope, and impact of work that can be done, and have important downstream effects on the time and financial expenditures needed to conduct the planned analyses (5). Data governance (the ownership of the data and how it affects ease of gaining access to datasets) varies across Canada. Laws on sharing data are not harmonized across provinces and territories, or may be lacking entirely; as a result, data providers and custodians may make cautious and conservative interpretations of allowable access in many Canadian organizations. However, adoption of good data governance practices are bringing about a shift from a 'data custodianship' model, in which holding and securing data are emphasized to the exclusion of other considerations, to a 'data stewardship' model, in which enabling access is a core institutional objective that is balanced with the need to protect information privacy (5).

In Manitoba, for example, analysts employed by MCHP have ready access to the data in the Repository once ethics approvals are in place, and amendments to analysis plans (e.g., to include additional variables or a longer timeframe) are facilitated through HIPC in a timely manner, often a matter of days. The analyst can access the new variables or years

of data immediately at no additional cost. In B.C., however, data access requests result in a single data extract from the greater PopData resource, which means that when an amendment is submitted, the researcher is required to wait for and pay the associated costs to receive that new data extract. Manitoba's more flexible data stewardship model also offers the potential for exploring new research questions with little 'red tape'. New variables can be explored in a 10% sample of the population without first obtaining permissions. Should this investigation produce findings of interest, an amendment submitted to HIPC grants full access to additional variables within a short timeframe. At the time of the Frailty Study, no equivalent mechanism for exploring new research directions existed in B.C., although the new B.C. Data Scout tool offers researchers some insight into the characteristics of their study population of interest.

Our work on the Frailty Study has highlighted the importance of the requirements for research projects and data access requests to be approved in advance, often through separate processes. The time needed to obtain ethics and data access approvals varies widely across organizations and jurisdictions in Canada, ranging from months to years. Ethics approvals for research projects that involve more than one centre, province or territory can be particularly time-consuming and duplicative. Our work within the more restrictive custodianship model of data governance in B.C. has also underscored the need to communicate data access requests clearly and completely to avoid delays and unnecessary expenditures.

Another major challenge we encountered in this research was the difference in data architecture (or how the data were structured, arranged or coded) between Manitoba and B.C. While some administrative health datasets, like the Hospital Discharge Abstract Database, are national and can thus be used to draw comparisons across the country, many provincial centres hold data that are organized or defined in a province-specific way. For example, there were differences in diagnostic code specificity for physician billings between provinces. For the time period used in the Frailty Study, Manitoba physicians used 3-digit diagnostic codes, while B.C. physicians used up to 5 digits to describe more specific conditions. Tariff codes or fee items, which specify the main reason for the physician visit, tended to be province-specific with no overlap between Manitoba and B.C. We addressed these issues by having the analysts from each jurisdiction code each variable of interest in sequence, such that the SAS code defining the variables was first developed in B.C., then shared with the analyst's counterpart in Manitoba and adapted to reflect differences in the variable definitions. Not all variables were available in both provinces, requiring the analysts to be creative in using variables from different datasets to write code for the same concept (see also Table 2). For example, B.C. data differentiated between three separate constructs in defining palliative care: 'palliative care planning', 'terminal care', and 'facility visits'. Manitoba does not have a palliative care variable, so we instead used data from the Manitoba Drug Program Information Network (prescription drugs), from which we could identify drugs for terminally ill patients.

In cross-jurisdictional studies, differences in data architecture can compound the very real difficulties of working with administrative health data. Coding variables for the Frailty Study required careful attention to the similarities and differ-

ences between provinces, and expert knowledge of the available datasets in Manitoba to compliment or replace the B.C. variable definitions. Regular communication between two analysts with experience in cross-jurisdictional work helped to ensure that this part of the analysis went smoothly. Having local expertise and knowledge of the data quality of individual datasets also helped to compensate for data that were poor quality or missing entirely, as we were able to 'fill in the gaps' with information from alternative sources.

The considerable challenges associated with use of administrative health data for research has been recognized by the Canadian Institutes for Health Research, which put out a call for developing a National Data Platform as part of Canada's Strategy for Patient-Oriented Research (SPOR) in late 2017 (19). The Data Platform is intended to address major barriers and inefficiencies in accessing and using multi-jurisdictional data that cannot be addressed by individual provincial/territorial units by: (i) establishing a single access portal for multi-jurisdictional service requests; (ii) harmonizing and linking national/multi-jurisdictional cohort clinical trial data to population-based clinical, administrative and social data; and (iii) developing national standards for data access and privacy protection across SPOR units. This collaborative coordinated approach should not only shorten the time required for researchers to access administrative data, but support the development of a virtual data platform for sharing tools and best practices for data linkage and harmonization. Ultimately, efforts to harmonize and validate datasets to make them comparable across provinces will advance multi-jurisdictional population health and health services studies on priority topics and build capacity for impactful Pan-Canadian health policy research.

Conclusion

Administrative health data are powerful resources that can offer insight into prevention, planning and evaluation of health services and systems. With increasing access to large-scale, high quality administrative health and clinical datasets, Canada's diverse health systems and policies are fertile ground for comparative analyses and sharing of best practices in research using these data. The key to cross-centre data working is to build capacity for detailed-oriented analytic staff who have ground-level familiarity with the data that are available, to develop strong communication skills for working across jurisdictional borders, and to foster expertise in adapting code and variable definitions to work around the barriers. Ongoing efforts to harmonize data across Canada will maximize the impact of evidence-informed research and help shape future health and health care policy decisions.

Acknowledgments

Funding for the Frailty Study was provided by the Canadian Institutes of Health Research (Funding Reference Number 145182) and the Michael Smith Foundation for Health Research.

Statement on Conflict of Interest

The authors declare that there are no conflicts of interest.

Abbreviations

AHS	Alberta Health Services
DAD	(Hospital) Discharge Abstract Database
DPIN	Drug Program Information Network
EMR	Electronic Medical Record
FIPPA	Freedom of Information and Protection of Privacy Act
MCHP	Manitoba Centre for Health Policy
MSP	Medical Services Plan
HIPC	Health Information Privacy Committee
PHIA	Personal Health Information Act
PopData	PopulationData B.C.
SPOR	Strategy for Patient-Oriented Research
UM-HREB	University of Manitoba Human Research Ethics Board

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Table 1: Comparing Administrative Data Access in Three Canadian Provinces

	British Columbia	Alberta	Manitoba
Data Steward	PopData B.C.	Alberta Health and Health Services	Manitoba Centre for Health Policy
Feasibility Assessment and Cost Estimate	As part of a feasibility assessment, PopData provides a cost estimate for the data extract.	n/a	As part of a feasibility assessment, MCHP provides a cost estimate for the analysis work to be completed by in-house analysts.
Data Access Accreditation	All researchers must complete an online data privacy training module.	n/a	All individuals requesting line-level access to the data complete an accreditation session.
Data Access Request, Ethics Approval and Other Permissions	Data access request is submitted to PopData through a Researcher Liaison for review; must be approved by the appropriate data steward(s). Research ethics approval is obtained from an accredited Research Ethics Board in B.C.	Data access request is submitted to Alberta SPOR Support Data Platform. Research ethics approval is obtained from University of Calgary or University of Alberta.	Data access request is submitted to and reviewed by the Health Information Privacy Committee (HIPC). Research ethics approval is obtained from University of Manitoba. Permission to use data is obtained from data providers.
Data Extraction and Analysis	PopData prepares the data extract using a common study ID to enable researchers to link data sets. The data extract is most often made available to researchers within the secure PopData virtual research environment.	Alberta Health/AHS releases the linked and de-identified data extract to the researcher via secure file transfer in accordance with the ethics agreement.	Access to the de-identified data is provided to accredited analysts in the secure MCHP environment or through a remote access site. Linkage of the requested datasets is then performed on a temporary project-by-project basis.



Table 2: Administrative Health and Clinical Datasets Used in the Frailty Study

	Dataset Name	Description
Manitoba	• Canadian Primary Care Sentinel Surveillance Network (CPCSSN)	EMR data from primary care providers
	• Hospital Discharge Abstracts Database (DAD)	Administrative, clinical and demographic information on hospital discharges
	• Medical Claims/Medical Services	Physician billing claims
	• Manitoba Health Insurance Registry	Demographic information for Manitoba residents
	• Drug Program Information Network (DPIN)	Prescription drugs dispensed by community pharmacies, emergency departments, hospitals, and primary care practices
	• Home Care	Home care client assessment, utilization and health status
	• Long Term Care	Assessment, utilization and health status of residents of personal care homes (nursing homes)
British Columbia	• Canadian Primary Care Sentinel Surveillance Network (CPCSSN)	EMR data from primary care providers
	• Hospital Discharge Abstracts Database (DAD)	Administrative, clinical and demographic information on hospital discharges
	• Medical Services Plan (MSP) Payment Information File	Physician billing claims
	• Consolidation File (Registry & Demographics)	Demographic Information for B.C. residents
	• PharmaNet	Prescriptions for drugs and medical supplies dispensed from community pharmacies and hospital outpatient pharmacies Note: Physicians may also record medications provided to patients during an office, clinic or emergency department visit. The recording of medications by physicians is not mandatory at this time; therefore this data is not complete.