

# Challenges of Medical Record Abstraction in a Long-Term Follow-up Study

Muhammad F. Ahmed, MBBS, MPH<sup>a,b</sup>; Andrea Galfo, MPH<sup>a,b</sup>; Wendy Huggins, BS<sup>a,b</sup>; Lisa E. Paddock, PhD, MPH<sup>b,c</sup>; Antoinette M. Stroup, PhD<sup>b,c</sup>; Jyoti Malhotra, MD, MPH<sup>b</sup>

**Abstract:** Medical records are a rich source of information and have tremendous value in epidemiological research. Nevertheless, the process of obtaining and abstracting medical records for a long-term follow-up study is complicated, time-consuming, and resource intensive. We identified the following major challenges during this process. First, widely varying infrastructure of electronic health record systems used by different organizations makes it difficult to ensure that all medical charts from all sources for a particular patient have been received. Second, extensive use of free text by health care providers requires a manual line-by-line search for relevant information, which may result in some missing data due to human error. Third, there are often discrepancies between patients' provided lists of health care providers and the registry data, which may affect the data-collection process. Fourth, providers have varied requirements for medical record release of their patients, which might entail multiple patient contacts. This, in turn, can frustrate patients and discourage them from participating in current or future research studies. Fifth, the use of inconsistent medical terminology by different providers complicates conversion of unstructured text into categorical data for analysis. We have the following recommendations for any future study with similar design to overcome the above challenges. First, the source of medical records best suited for the research objectives should be identified from the beginning. Second, the abstractors should be appropriately trained to accomplish research-specific tasks. Third, a quality data-tracking system for the abstracted elements should be employed to ensure data integrity. Fourth, the abstracted cases should be reviewed by one other abstractor. We also recommend a pilot study with a smaller number of patients to evaluate the required resources before any large-scale study.

**Key words:** chart abstraction, electronic health records, long-term study, medical record abstraction

## Introduction

Medical records are rich in information and can be an invaluable resource in epidemiological research.<sup>1-3</sup> They are considered complementary to randomized controlled trials and health services research because of the availability of detailed clinical information on diagnosis, disease course, and treatment that may not be found elsewhere.<sup>4-6</sup> The US Food and Drug Administration has formally incorporated the electronic health record (EHR) as a source of real-world data to be used in research and has provided comprehensive guidelines for its use.<sup>7</sup> The enormously increased and remarkably improved use of computers in health care has furthered the use of medical records in research.<sup>6,7</sup>

The medical record abstraction (MRA), also known as *chart review*, is a process in which a human manually searches through an electronic or paper medical record to identify data required for a secondary purpose.<sup>8</sup> Notwithstanding the improvements, this process in a long-term study is complicated, time-consuming, and resource intensive.<sup>6</sup> The medical records are primarily collected for clinical purposes and are largely unstructured.<sup>8,9</sup> Subjective human inferences are often necessary when converting this raw data into categorical information for analysis. In this article, we will discuss the observations and challenges our

team experienced during the collection and abstraction of medical records in a long-term follow-up study.

## Method

We conducted MRA as a part of an observational study, "Identifying Racial Disparities in Follow-up Care in a Diverse Population of Lung Cancer Survivors (The Diversity Study)." The purpose of the study was to measure any racial differences among lung cancer survivors in receipt of the recommended posttreatment follow-up care, such as regular surveillance scans.

We identified 552 lung cancer survivors (189 males, 363 females) through the New Jersey State Cancer Registry (NJSCR) who met the study eligibility criteria. Each patient was mailed a research packet that included a cover letter explaining the purpose of the contact, a brochure of frequently asked questions about the study, a paper-based survey, a medical record release form to sign, and a form for providing a list of health care providers involved in the patient's lung cancer care.

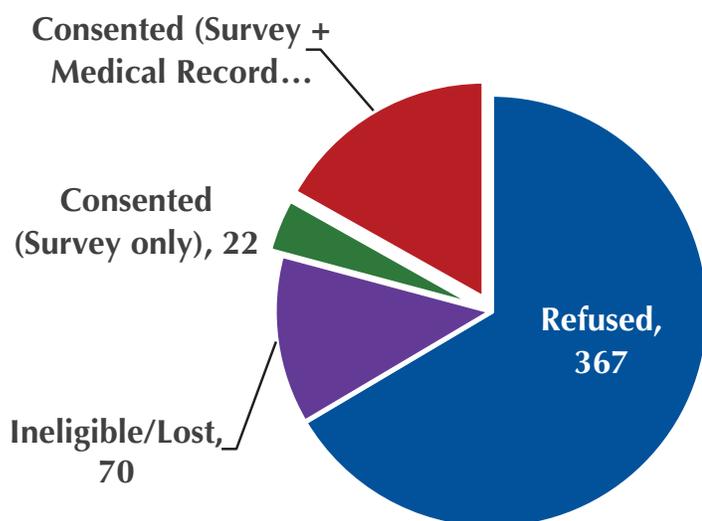
A total of 115 participants (20.8%) completed the paper-based survey. Of these, 93 (80.9%) returned a signed medical record release form (Figure 1). We then reached out to the physicians of the consented participants through mail to

<sup>a</sup>New Jersey Department of Health, Trenton, New Jersey. <sup>b</sup>Rutgers Cancer Institute of New Jersey, New Brunswick, New Jersey. <sup>c</sup>Rutgers School of Public Health, Piscataway, New Jersey.

Address correspondence to Muhammad F. Ahmed, MBBS, MPH. Email: Muhammad.Ahmed@doh.nj.gov.

Cancer Epidemiology Services, including the New Jersey State Cancer Registry, receives support from the National Program of Cancer Registries, Centers for Disease Control and Prevention under cooperative agreement NU58DP006279-02-00, the State of New Jersey, the National Cancer Institute, and the Rutgers Cancer Institute of New Jersey.

Figure 1. Outcome of Patient Contact



obtain the patients' medical records. A total of 261 records (an average of about 3 records per patient) were received, containing 5 years of posttreatment follow-up data for the 93 patients. These records were obtained from 150 facilities and 111 physician offices, following procedures compliant with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Although the original charts were in electronic format, the charts received by the research staff were either mailed in a paper-based format or electronically faxed in a PDF format directly to the registry. In both situations, they required page-by-page or screen-by-screen manual review of data. We estimated that more than 25,000 pages were received and abstracted in total, for an average of about 300 pages of records per patient. A predesigned form was used to identify the data elements required for the study. These data were then entered in a Microsoft Access database that was created for this purpose. Additional data were collected from the NJSCR and patient-administered surveys (Table 1).

#### Quality-Control Measures

A team of 3 trained investigators abstracted data from the medical records. To ensure consistency, the investigators initially abstracted 3 cases together. Another combined session was held after 5 to 7 individual case abstractions to adopt the best practices from our respective experiences. Data from the first 5 cases were also reviewed by the principal investigator to ensure that we were capturing complete and accurate data using the medical record abstraction form. Thirty-five percent of the medical records (33 cases) were reabstracted by different staff for quality control.

#### Observations and Challenges

MRA for research studies may pose widely different challenges depending on the study objectives. For the diversity study, our team had to collect posttreatment follow-up data such as radiological tests, including chest radiographs, computed tomography (CT) scans, positron emission tomography (PET) scans, and magnetic resonance

Table 1. Sources of Information for the Diversity Study

Data type	Source
Basic demographic characteristics	NJSCR
Tumor characteristics	NJSCR
Health and social behaviors	Patient-administered survey
Comorbidities	Patient-administered survey
Treatment procedures and sequence	Medical records and NJSCR
Testing procedures, including radiographs and CT/PET scans	Medical records

CT, computed tomography; NJSCR, New Jersey State Cancer Registry; PET, positron emission tomography.

imaging (MRI). We analyzed the data as it was abstracted and tailored our model accordingly until the study objectives were achieved. This approach has also been evaluated and recommended by Polnaszek et al, who recommended a phase-based approach to find a "fit-for-use" framework for MRA.<sup>10</sup> The paragraphs below describe the major observations and challenges our team experienced during this process and the approach we took to succeed.

Ensuring a complete medical record is challenging with the complexity of EHR systems. The EHR landscape in health care is complex and subject to continuous and rapid changes.<sup>11,12</sup> Providers use a myriad of EHR systems with diverse configurations. This widely varied system of medical record repositories makes it difficult for researchers to determine if all required medical records from all years of follow-up for a particular patient have been received. To ensure complete records, our team requested and obtained an EHR from all possible sources for each patient, unless we determined that the already-received records had sufficient information for the study objectives. Although this required more resources, it provided a more accurate picture of post-treatment care.

Medical record release authorization: rigorous documentation requirements can frustrate patients. Providers have varied and rigorous requirements for the release of their patients' medical records, which often requires study staff to make multiple patient contacts throughout the recruitment process. This can frustrate patients and can discourage them from participating in current or future research studies. One possible solution to this issue is to provide a comprehensive medical records release form that includes language that is required by several providers. Additionally, the research staff should complete as many fields on the form as possible and leave blank only those requiring direct participant input before mailing it to them for a signature. This will not only save the participants from filling in the painstaking details required by many providers, but will also reduce the chance of errors.

Large/long medical records are time consuming and cumbersome to abstract. Large medical records can make data collection more difficult. We estimated that it took 1 abstractor approximately 1 hour to abstract 100 pages of free text. Therefore, large medical records ( $\geq 500$  pages) posed a

substantial challenge to the abstractors. Due to the tedious and monotonous nature of the abstraction work, human factors like fatigue can affect the process. The legibility of some records is also compromised during photocopying and faxing, which may further complicate abstraction procedures. For the diversity study, we prioritized abstracting records related to testing procedures that were recorded over several years, because we found that they were more likely to represent the needed follow-up data rather than the extensive surgery-related notes.

Obtaining medical records specific to the study objectives needs careful consideration. Medical records contain different sets of information depending on their source, such as general hospitals, specialty centers, primary care providers, or subspecialty clinics. Determination of the sources that are best for the study objectives may require early abstraction and careful analysis of the first few records that are received. This should be reviewed with a provider before abstraction begins so that MRA goals are realistic. For instance, medical records from a hospital might be easier to obtain compared to a physician office.

Reporting bias: discrepancies in the list of physicians. We found that the patient-provided lists of physicians who treated their lung cancer were different from data in the NJSCR in 42% of cases. In the diversity study, we used patient-provided information with the NJSCR data in 89 out of 93 patients (95.7%). In the remaining 4 patients (4.3%), NJSCR data were used alone because the patients had not provided the lists. Although we expect minimal reporting bias in our study, this factor might affect the studies that use a single source for data collection.

Inconsistent medical terminology and extensive use of free text by providers. The use of inconsistent medical terminology by different providers complicates the conversion of unstructured text into categorical data for analysis. Furthermore, the providers extensively use free text, which requires a manual line-by-line search for relevant information. This may result in missing some data due to human error.

Obtaining a large number of medical records – 2-step strategy: Obtaining medical records from many sources requires a substantial amount of time, effort, and careful coordination. In our estimate, a single medical record from 1 source may take 8 to 10 hours of deliberations involving phone calls, faxing, and follow-ups, as well as receiving and scanning the records. We divided the process into 2 stages. In the beginning of the project, we conducted a mass mailing to all the health care providers that were identified by study participants. We were successful in receiving almost half of the records through this process. In the second stage, we reached out to the “nonresponding” health care providers through a more involved process, including individual phone calls and faxing. We received medical records of all 93 consented participants by the end of the study period.

## Recommendations

We have the following recommendations for any future study involving MRA on long-term follow-up outcomes.

- *Source of research data:* Different sources of research data,

such as medical records from various providers, registry data, and survey questionnaires, will provide different sets of information. The source that is best suited for the most complete and accurate outcome data should be determined early in the study. For instance, self-reported data is considered the reference standard for demographic information; however, registry data may be more accurate for clinical information.

- *Abstractor training:* To have consistency in the abstraction procedures, all staff should receive sufficient training from an experienced abstractor before starting the process. Other studies have also shown significant reduction in errors following a didactic training prior to the start of MRA.<sup>13,14</sup>
- *Tailoring the abstraction to research objectives:* Medical records often contain a tremendous amount of information. The researchers might be tempted to collect more information than required while designing the study or during the abstraction process. However, we recommend that the abstractors focus on the relevant data to save time and effort.
- *Data-collection tool:* By involving an experienced researcher, clinician, or medical records abstractor, a useful data-collection tool can be designed. This tool should be well tested before using it for the MRA.
- *Data abstraction audit:* A quality data tracking system for the abstracted elements might be required to ensure data integrity. Detailed reporting tools are helpful for tracking and organization.
- *Data quality-control measures:* We found that the cases abstracted by 2 abstractors independently had on the average 12.4 testing procedures per patient compared to 11.5 testing procedures per patient for the cases abstracted by 1 abstractor only. Therefore, we recommend that more than 1 abstractor separately review some or all charts depending on the available research resources. If possible, metrics like interrater reliability might also be used to measure the quality of abstracted data.<sup>15</sup>
- *Pilot study:* A pilot study with a smaller number of patients is strongly recommended to evaluate the required resources before any large-scale study is conducted.

## Conclusion

Despite being a rich source of information, several factors can affect the data-collection process from medical records and thus bias research results. These include receiving incomplete medical records, inaccurate coding, and missing important information during abstraction. In our experience, the process can be improved by using multiple sources to identify the providers, adding a second abstractor for MRA, and analyzing the abstracted data early. It is also recommended to appropriately train the staff to obtain and abstract data, employ firm data auditing procedures, and allocate sufficient time and human resources to collect quality data to achieve the research objectives.

## Acknowledgment

We would like to acknowledge the support of Rutgers Cancer Institute of New Jersey and the American Cancer Society for providing the funding for this study. We also thank all the hospitals and physician offices who provided the medical records for this study. A special thanks to all the hospital and central registry staff for their hard work in collection of cancer information.

## References

1. Eder C, Fullerton J, Benroth R, Lindsay SP. Pragmatic strategies that enhance the reliability of data abstracted from medical records. *Appl Nurs Res*. 2005;18(1):50-54.
2. Gareen IF, Sicks JD, Jain AA, Moline D, Coffman-Kadish N. Identifying and collecting pertinent medical records for centralized abstraction in a multi-center randomized clinical trial: the model used by the American College of Radiology arm of the National Lung Screening Trial. *Contemp Clin Trials*. 2013;34(1):36-44.
3. Cook EA, Schneider KM, Robinson J, et al. Field methods in medical record abstraction: assessing the properties of comparative effectiveness estimates. *BMC Health Serv Res*. 2014;14:391.
4. Townsend JS, Jones MC, Jones MN, Waits AW, Konrad K, McCoy NM. A case study of early-onset colorectal cancer: using electronic health records to support public health surveillance on an emerging cancer control topic. *J Registry Manag*. 2021;48(1):4-11.
5. Ramagopalan SV, Simpson A, Sammon C. Can real-world data really replace randomised clinical trials? *BMC Med*. 2020;18(1):13.
6. Kim E, Rubinstein SM, Nead KT, Wojcieszynski AP, Gabriel PE, Warner JL. The evolving use of electronic health records (EHR) for research. *Semin Radiat Oncol*. 2019;29(4):354-361.
7. Real-world data (RWD) and real-world evidence (RWE) are playing an increasing role in health care decisions. US Food and Drug Administration website. Accessed August 3, 2021. <https://www.fda.gov/science-research/science-and-research-special-topics/real-world-evidence>
8. Zozus MN, Pieper C, Johnson CM, et al. Factors affecting accuracy of data abstracted from medical records. *PLoS One*. 2015;10(10):e0138649.
9. Allison JJ, Wall TC, Spettell CM, et al. The art and science of chart review. *Jt Comm J Qual Improv*. 2000;26(3):115-136.
10. Polnaszek B, Gilmore-Bykovskiy A, Hovanec M, et al. Overcoming the challenges of unstructured data in multisite, electronic medical record-based abstraction. *Med Care*. 2016;54(10):e65-e72.
11. Jiancaro T, Jamieson GA, Mihailidis A. Twenty years of cognitive work analysis in health care: a scoping review. *J Cogn Eng Decision Making*. 2014;8(1):3-22.
12. St-Maurice JD, Burns CM. Modeling patient treatment with medical records: an abstraction hierarchy to understand user competencies and needs. *JMIR Hum Factors*. 2017;4(3):e16.
13. Zozus MN, Young LW, Simon AE, et al. Training as an intervention to decrease medical record abstraction errors multicenter studies. *Stud Health Technol Inform*. 2019;257:526-539.
14. Mi MY, Collins JE, Lerner V, et al. Reliability of medical record abstraction by non-physicians for orthopedic research. *BMC Musculoskelet Disord*. 2013;14:181.
15. Roth CP, Coulter ID, Kraus LS, et al. Researching the appropriateness of care in the complementary and integrative health professions part 5: using patient records: selection, protection, and abstraction. *J Manipulative Physiol Ther*. 2019;42(5):327-334.