A Feasibility Assessment to Improve the Reporting of Hematopoietic Diseases

Final Report

The Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Contents

1. PROJECT OVERVIEW AND TIMELINE

As a part of the Agency for Toxic Substance and Disease Registry's larger initiative to understand the etiology of polycythemia vera, this project was led by the Centers for Disease Control and Prevention's (CDC's) Division of Cancer Prevention and Control. The overall goal of the project was to develop and implement methodologies to increase the reporting of hematopoietic diseases from physician offices to state and central cancer registries (CCRs). All reportable hematopoietic diseases (RHDs) except Hodgkin and non-Hodgkin lymphomas were targeted for this project.

Cancer registries are usually notified of new cases when they receive reports from hospitals, radiation treatment centers, or pathology laboratories that diagnose or treat cancer patients. There may be the potential underreporting of RHDs because these patients are not always treated in hospitals or radiation treatment centers or definitively diagnosed by pathologists; often they are diagnosed or treated (or monitored) by physicians in outpatient settings. The objective of this project was to work with CCRs to increase their outreach to physician offices that may treat these diseases and to encourage physicians to report to CCRs. It was hypothesized that increased physician reporting would increase: (1) the number of cases ascertained, (2) the incidence of some RHDs calculated by the CCRs, and (3) the quality of the information available.

The Kansas Cancer Registry (KCR), the New York State Cancer Registry (NYSCR) and the South Carolina Cancer Registry (SCCR) were selected to participate in the project. CCR staff were provided with a training manual to guide them when preparing training tools for physician practices. Each CCR used available data sources to develop a list of eligible physicians that care for patients with RHDs, develop methods select physicians for participation in the project, provide training to physicians or their staff on reporting, conduct quality control, and process and consolidate the data received. The CCRs staff evaluated the methods used and the data obtained and provided this feedback to CDC. In this report, we will review the approaches for provider identification, recruitment, and training that the CCRs developed, along with lessons learned. The analysis of the final submitted data will also be presented.

2. METHODOLOGY

Each CCR developed their own methodology for the project that included plans for identifying potential physicians that treated patients with RHDs, recruiting them for the project, establishing reporting methods, and training them to report cases. The methods used by the three CCRs and the basic differences in their approaches are summarized in Table 1. SCCR conducted their project throughout the state. KCR also conducted the project throughout the state for hematologists and oncologists, but then took a sample of primary care physicians to include in the project because the care of patients with RHDs may be provided by primary care physicians in rural areas of the state where access to hematologists or oncologists is limited. NYSCR focused their efforts on hematologists and oncologists in 30 of the state's 62 counties surrounding Albany, which represents approximately 25 percent of the state population.

All three CCRs used state licensing agencies, the National Provider Identifier (NPI) registry, and hematology and oncology societies to identify eligible physicians. As part of registry's routine activities, KCR and SCCR sent eligible physicians an information package, including the state reporting law, about the project and requested their participation. Rather than utilizing a voluntary participation approach, NYSCR provided practices with packets that contained an introductory letter explaining the mandatory reporting laws and information about the Web-based reporting application. Training by all three CCRs was conducted through initial information packages that were supplemented by telephone contact, Web-based training, and in-person training as needed.

The three CCRs used different reporting mechanisms. KCR had their providers report cases via AbstractPlus (http://www.cdc.gov/cancer/npcr/tools/registryplus/ap.htm), if they had the software available. Providers that were not already using AbstractPlus were instructed, based on expected case counts, to either install AbstractPlus or to send components of paper medical records to the registry for abstracting. Clinics in Kansas sent a medical record disease index (MRDI) to the CCR and only the cases that had not been previously reported by other providers were abstracted. NYSCR created a new RHD reporting mechanism by developing its own Web-based application. The application contained data entry forms for physicians to complete. Resulting RHD information was submitted directly and securely to the CCR production database tables. SCCR requested that physician offices give the registry access to their electronic medical record (EMR) so that registry staff could remotely login and abstract the cases. Providers in South Carolina who could not grant remote access to their EMR system, or that lacked EMR capability, reported via WebPlus (http://www.cdc.gov/cancer/npcr/tools/registryplus/wp.htm).

Table 1: Summary of recruitment methodologies—Kansas Cancer Registry, New York State Cancer Registry, South Carolina Cancer Registry

	Kansas Cancer Registry	New York State Cancer Registry	South Carolina Cancer Registry
Geographic area	Entire state	30 counties surrounding Albany	Entire state
Providers	Hematologists, oncologists, and a sample of primary care physicians	Hematologists and oncologists	Hematologists and oncologists
Identification			
State licensing agencies	✓	✓	✓
National Provider Identifier (NPI)	✓	✓	✓
Society memberships	✓	✓	✓
Registry database	✓		
Recruitment	Information packages with telephone follow-up	Information packages explaining mandatory reporting laws	Information packages and in-person site visits

	Kansas Cancer Registry	New York State Cancer Registry	South Carolina Cancer Registry
Training	Information packages, and in-person or webinar trainings	Telephone and e-mail contacts, information on Web site, physician manual, quality assessment of new reporter cases	Information packages and conference calls
Reporting	Providers reported via AbstractPlus or sent paper files to registry for abstraction	Provider offices reported via registry-designed web application	Registry staff abstracted cases via remote access to provider EMRs or providers used WebPlus

2.1. PHYSICIAN IDENTIFICATION AND RECRUITMENT

The initial step for each CCR was to identify physicians or medical practices in the project area that might be responsible for diagnosis or treatment of patients with hematopoietic malignancies. The following outlines the data sources used by each state.

Kansas Cancer Registry

- Provider database based on provider information reported to the registry
- NPI registry (downloadable; maintained by the U.S. Department of Health and Human Services)
- Kansas State Board of Healing Art provider database (licensing agency)
- Internet searches
- KCR staff contact with providers

New York State Cancer Registry

- New York State Education Department (NYSED; most complete list of New York-licensed physicians)
- NPI registry
- Internet searches, including the American Society of Hematology site
- NYSCR staff contact with physician practices and hospital reporters

South Carolina Cancer Registry

- South Carolina Labor and Licensing Regulatory List (LLR)
- NPI registry
- American Medical Association Web site
- South Carolina Oncology Society member roster
- Telephone directory

The CCRs pooled information from these various sources and removed any duplicates to obtain the most complete list of physicians. Identified physicians or practices were usually contacted to verify final eligibility.

Once the CCRs developed the comprehensive list of physicians, they verified eligibility by contacting providers. Once the initial list was developed, each CCRs identified physicians that were determined to be ineligible for recruitment. All three CCRs identified ineligible physicians that were retired, no longer practicing, or practicing entirely outside of the project's catchment area (out of state for Kansas and South Carolina, or out of the 30-county area for New York). For KCR and NYSCR, identified physicians were determined to be ineligible if they were practicing at a hospital, since the hospital's cancer registry already reports their cases. Finally, NYSCR determined that a number of physicians were ineligible because they were not in patient-related service or were duplicates of other entries on the list.

2.1.1. Physician Identification and Recruitment—Lessons Learned

Overall

- No single data source was sufficient for obtaining a comprehensive list of physicians.
- Telephone follow-up was necessary to verify the accuracy of information in the data sources.
- Physicians were concerned about the staff resources required to report.

Kansas Cancer Registry

- The NPI included non-physicians and most physicians had multiple specialties listed.
- Detailed information on physician specialty is not captured on the lists. One radiation oncologist only treated patients with solid tumors, so this physician did not participate in the project.
- Education on the reporting laws and the extent of required information is needed.

New York State Cancer Registry

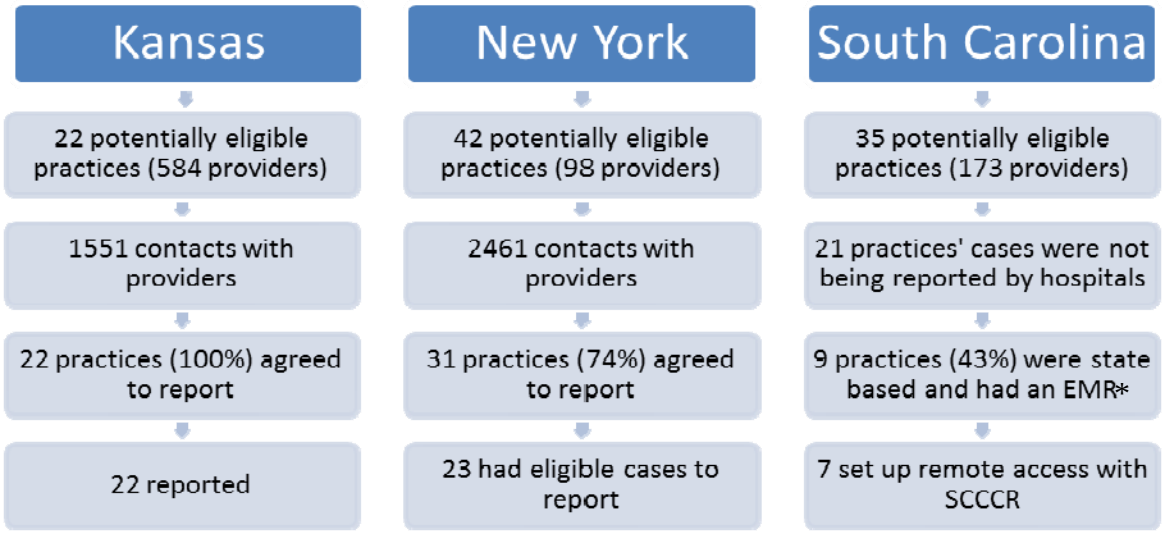
- The NYSED data file was a good initial source of information and was improved by the addition of the NPI.
- Additional resources were required to consolidate data from NPI and NYSED with available information on the Internet.
- Telephone follow-up may become a burden when expanding this project to include multiple physician specialties in the entire state.
- Education on the reporting laws and the extent of required information is needed.
- Weekly contact with physicians was needed for the project, which would not be sustainable if the project included all targeted physicians in the state.
- The creation of a tracking database was helpful to monitor outreach and contacts with providers.
- New York requires a notarized signature from every individual applying for access to the Web-based reporting system. This requirement may have delayed the start of reporting for some practices and affected the timeliness of some reports.

South Carolina Cancer Registry

- It was practical to develop a regional approach to identify physicians and facilities because local CCR staff members were familiar with the medical community.
- The LLR was the most inclusive data source, followed by the review of the AMA Web site and the local phone directory.

- Education on the purpose of project for staff was important.
- All physicians at each facility were contacted and multiple follow-up calls and conversations were needed in some cases.
- In-person site visits were needed to get reluctant facilities to participate.

Figure 1: Summary of physician recruitment —Kansas Cancer Registry, New York State Cancer Registry, and South Carolina Cancer Registry



*EMR: Electronic Medical Record

SCCR focused on practices rather than individual physicians; therefore, the number of contacts with individual physicians was not applicable to their effort. SCCR focused its effort on gaining access to each practice's EMR system so that the CCR could abstract cases from all physicians at the practice.

2.1.2. Physician's follow-up—Lessons Learned

KCR and NYSCR sent follow-up information to practices during the physician identification and recruitment process to determine whether they were already reporting and what their capacity would be for reporting electronically to the CCR; SCCR did not send this out since it focused on practices. KCR and NYSCR conducted follow-up in slightly different formats, but they found that it took multiple contacts with each provider to get completed information. In general, follow-up response rates of 88 percent or higher were obtained from the hematologists and oncologists, but the CCRs concluded that the value of information collected might not outweigh the effort required to get completed responses.

Kansas Cancer Registry

- Hematologists and oncologists responded to the follow-up more often than primary care physicians.

- Physicians preferred telephone communication compared to mailed information.
- Physicians preferred questions being asked requiring only Yes or No responses.
- It was challenging to identify outpatient physicians because many physicians practiced in multiple locations, such as hospital settings and private clinics.

New York State Cancer Registry

- Follow-up feedbacks did not appear to provide any benefit, especially given the amount of time needed to encourage completion and return.

2.2. PHYSICIAN TRAINING

Each state selected or developed the materials and methods of training that would be most effective. KCR included case ascertainment and audit procedures in their project and NYSCR included multiple quality control steps. Below is a summary of training methodologies along with some lessons learned.

Kansas Cancer Registry

- Training efforts encompassed the office or clinic as a whole, not just the physicians.
- Physician offices were provided with updated 2010 ICD-9-CM codes for reporting.
- Packets with detailed information were sent to new reporters (i.e., reporting law, reportable cancers and codes, required data items, reporting frequency, acceptable media) and a training session was conducted for them.
- Electronic training was prepared for new reporters (Elluminate, Microsoft PowerPoint, and Camtasia).
- KCR worked with current reporters' IT staff to add the new hematopoietic codes to existing facility casefinding lists.
- Physician offices that already use AbstractPlus were trained in how to capture the JAK-2 mutation variable and how to use the collaborative staging fields.
- All facilities were required to submit a MRDI for the 2010 dates of service to KCR. KCR de-duplicated and linked these with the central registry database to determine whether the case had been previously reported. Non-matches were sent to the clinics for reporting and were used to compute expected case counts.
- Based on the expected case counts, some facilities were instructed to install AbstractPlus and transmit non-matched cases to the central registry; facilities with smaller case counts were told which portions of the medical record to copy and submit to KCR.
- A casefinding and data accuracy audit was performed on the two largest volume reporters and two of the lowest volume reporters.

New York State Cancer Registry

- Training tools for physicians and their staff were developed and placed on the New York State Department of Health's (NYSDOH's) public web site. These tools included the following documentation:
  - *Overview of Physician Reporting—NYS Cancer Registry (NYSCR)*: Introduces the NYSCR, explains reporting laws, describes reporting system, and describes how to conduct casefinding and determine reportability

- *NYSCR Physician Reporting Manual:* Contains information similar to the overview document and includes web forms and specific fields that will be encountered during reporting
- *Casefinding Guide for Physician Medical Practices:* Introduces concept of casefinding, explains how to determine which patients to report, when to report and how to use the *Physician Practice Cancer Case Tracking Log* template.
- *Guide to Determine Reportability for Physician Medical Practices:* Specifies conditions, with ICD-9-CM codes, that are reportable to the NYSCR
- *Physician Cancer Reporting Using the NYSDOH Health Commerce System:* Provides step-by-step instructions with screenshots of forms encountered, application features, and tips for successful use
- *Guide for Physician Medical Practices to Obtain Commerce System Accounts:* Instructions for physicians and designated office staff to obtain Health Commerce System accounts

- Two cancer registry staff members were designated to assist physicians and their staff in any area of cancer reporting
- Four processes were put in place for quality control:
  - Non-physician reporters were asked to send copies of medical records for the first five cases submitted. This information was compared to their submission data and feedback was given if necessary.
  - Cases submitted by physician practices were reviewed weekly. Reporters were contacted to resolve any potential discrepancies or problems.
  - In September 2011, reporting practices were approached to conduct casefinding audits; 25 participated in the review process.
  - In the spring of 2012, quality reviews were performed on 167 cases submitted by 11 practices; 6 of these reviews were conducted at the reporting practice and 5 were paper audits.

South Carolina Cancer Registry

- Information packets were sent to providers being recruited (i.e., reporting law, exemption of SCCR from the Health Insurance Portability Accountability Act, track record for SCCR's North American Association of Central Cancer Registries (NAACCR) certification, project description, number of SC facilities that report).
- Options were provided for SCCR to remotely access records (i.e., access via EMR software; access only a certain queue of records from the casefinding list; access to only hematology and oncology physician records for practices with multiple specialties).
- Hematology/Oncology providers were divided into 4 categories:
  1. Providers that had already allowed remote access to EMRs were briefed on the 2010 RHD cases. A virtual private network client or internet connection was set up for RHD project abstractors.
  2. Providers with remote access capability were provided with information packets. Options were discussed for remote access and provider commitment was established.
  3. Providers without remote access capability were trained to use WebPlus. SCCR gave them information packets and held conference calls with them.
  4. Some providers have yet to be recruited.

- South Carolina did not provide information on the non-EMR providers that were instructed to submit abstracts via WebPlus.

2.2.1. Training—Lessons Learned

Kansas Cancer Registry

- Working with the outpatient clinics was time consuming and challenging.
- Many of the outpatient clinics do not have an EMR.
- All outpatient facilities were able to provide a MRDI, although formats varied.
- The casefinding and data accuracy audit indicated that:
  - Only 2.5 percent of cases were missed by the facilities.
  - However, 54 percent of records had at least one data field error.
  - The variable most likely to have been coded erroneously was JAK2 (24 percent of cases).

New York State Cancer Registry

- NYSCR received very few calls about questions or problems using the Web application for reporting.
- Follow-up training and feedback were required to teach reporters to use bone marrow instead of blood for primary site and to correct reporters' selection of behavior.
- Physicians and their staff are not familiar with casefinding procedures, have competing priorities.
- Implementation of a casefinding audit program of physician's office reporting requires understanding and cooperation of the physician's office as well as time and effort by the central registry staff.

South Carolina Cancer Registry

- It was difficult for smaller facilities to get technical support from vendors to set up SCCR's remote access. SCCR was also unsuccessful in getting responses from the vendors.

3. DATA SUBMISSION

The data on all 2010 diagnoses included all reportable RHD cases diagnosed in 2010, regardless of whether a case was submitted by a provider recruited specifically for this project, reported by a hospital or other facility already reporting, or not recruited for the purposes of this project. We also requested all 2009 RHD cases for comparison. KCR and SCCR submitted data on the entire state; NYSCR only submitted 2010 and 2009 data for the 30 counties included in the project. The data were submitted as a text file based on NAACCR layout version 12.2.

The following standard NAACCR variables were included:

- Patient ID Number [Item 20]
- Addr at DX—State [Item 80]
- County at DX [Item 90][1]
- Race 1 [Item 160]
- NHIA Derived Hisp Origin [Item 191]
- Race—NAPIIA [Item 193]
- Sex [Item 220]
- Age at Diagnosis [Item 230]
- Occupation Code [Item 290][2]
- Industry Code [Item 300][2]

- Text—Usual Occupation [Item 310][2]
- Text—Usual Industry [Item 320][2]
- Sequence Number—Central [Item 380]
- Year and Month of Diagnosis [Item 390]
- Primary Site [Item 400]
- Grade [Item 440]
- Diagnostic Confirmation [Item 490]
- Type of Reporting Source [Item 500]
- Histologic Type ICD-O-3 [Item 522]
- Behavior Code ICD-O-3 [Item 523]
- CS Site-Specific Factor 1 [Item 2880][3]

[1] County of residence is requested if a registry can legally release it.
[2] If available
[3] SSF #1 should be included for 2010 data only.

Some additional state-specific variables were developed for the purposes of this project. Some of the project-specific variables applied to all three CCR and some were CCR-specific. The project-specific variables and their coding are outlined in Table 2. The project-specific variables were necessary because none of the current NAACCR variables allowed us to tease out information about who reported the case. Typically, NAACCR item 500, Type of Reporting Source, is used to describe the source of the information used to prepare the case abstract. In theory, this could allow us to determine the type of institution that reported the case; however, the hierarchy rules for coding that variable prevented its use in this project. For example, cases abstracted with more than one source should be coded as "hospital" regardless of whether abstracts were also received on that patient from physicians' offices, while cases abstracted by a hospital tumor registrar using medical records from a staff physician's office would be coded as "physician office". These case reports cannot be distinguished from reports that came from a physician's office as a result of this project, were triggered by follow-up requests by the central registry, or were from self-initiated reporting.

To address this issue, we created the Source of Case variable to determine which cases were reported only by a targeted physician and can therefore be considered to have been reported as a result of this project. The Source of Provider reporting variable was included to determine which case reporting was initiated by targeted providers and which cases were reported as a result of the registries' routine follow-up with physicians.

As a result of this project's efforts, additional cases prior to 2010 were also reported. For example, targeted physicians who initiated reporting as a result of this study project were likely to report on follow-up requests for 2009 cases, which were sent in 2010. The Source of 2009 Data variable indicates 2009 cases that were collected as a result of this project. Each state also used its own collection methodologies, so a state-specific variable was created. For NYSCR, the variable indicated whether all of a patient's treatment occurred within the 30-county catchment area. For KCR, the variable indicated the specialty of the reporting physician, and for SCCR, the variable indicated whether the abstract was done by the registry or the provider.

Table 2: Description of additional project-specific variables

Project-Specific Variable	Variable Categorization
Source of case	4 = Case provided by non-targeted physician and any other source 3 = Case reported by targeted physician and any other source 2 = Case reported by non-targeted physician office only 1 = Case reported by targeted physician only 0 = Case reported by one or multiple non-physician sources
Source of provider reporting	9 = Case not reported by provider 1 = Case report initiated by provider office 0 = Case reported by provider as part of registry follow-up
Source of 2009 data	9 = 2010 case 1 = Case obtained through project-initiated processes 0 = Case obtained through standard registry processes
NYSCR—Catchment area	9 = Patient treatment location unknown (death certificate only cases for 2009) 2 = Received treatment (reported by facilities/providers) both inside and outside of the project catchment area 1 = Received treatment (reported by a facility/provider) in project catchment area 0 = Treated (reported by a facility/provider) outside project catchment area
SCCR—Method of reporting	1 = Obtained by registry certified tumor registrar (CTR) via remote access 0 = Reported by facility
KCR—Type of provider	1 = Primary care 0 = Hematologist

4. DESCRIPTION OF SUBMITTED DATA

A review of the submitted data for 2010 is displayed in tables 3–6. In total, the three CCRs collected 3,640 cases diagnosed in 2010 for this project. As a result of a quality control audit performed by NYSCR, 14 cases that were reported as eligible were found to be ineligible (i.e., 7 cases that were out of state, and 7 that were within New York but outside of the 30-county project area). These cases are included as initially reported in the tables below because comparable audits were not performed in all three CCRs. Overall, the vast majority of cases were residents of one of the three CCRs involved in the project; the main exceptions were Missouri residents who received treatment in Kansas. This project targeted physicians, so residents from outside the catchment area who were reported by targeted physicians practicing within the catchment area were included in the data collection effort.

RHDs are typically diagnosed at older ages, with 85 percent of cases diagnosed among those aged 50 and older and nearly 25 percent of cases among patients aged 80 and older. In KCR and NYSCR, nearly all cases was white, while there were 27 percent African-American in SCCR. Almost all cases were non-Hispanic. Just over half the cases were males. The race and ethnicity distributions for NYSCR reflect the distributions in the 30-county catchment area that were included in the project; unlike KCR and SCCR, they do not accurately reflect the overall distributions of the state because the catchment area did not include New York City.

Table 3: Demographic information of 2010 Reportable Hematopoietic Diseases—Kansas Cancer Registry, New York State Cancer Registry, and South Carolina Cancer Registry

	Total N (%)	Kansas Cancer Registry N (%)	New York State Cancer Registry N (%)	South Carolina Cancer Registry N (%)
State resident				
Yes	3517 (97)	862 (88)	1780 (100)	875 (100)
No	123 (3)	116 (12)	7 (0)	0
Age at diagnosis (years)				
<30	239 (7)	79 (8)	100 (6)	60 (7)
30–39	95 (3)	23 (2)	37 (2)	35 (4)
40–49	219 (6)	62 (6)	104 (6)	53 (6)
50–59	536 (15)	132 (14)	258 (14)	146 (17)
60–69	788 (22)	207 (21)	376 (21)	205 (23)
70–79	893 (25)	240 (25)	435 (24)	218 (25)
80+	870 (24)	235 (24)	477 (27)	158 (18)
Race				
White	3028 (83)	814 (83)	1582 (89)	632 (72)
African-American	384 (11)	57 (6)	95 (5)	232 (27)
Other*	62 (2)	16 (2)	37 (2)	9 (1)
Missing	166 (5)	91 (9)	73 (4)	2 (0)
Ethnicity				
Non-Hispanic	3536 (97)	938 (96)	1740 (97)	858 (98)
Hispanic	104 (3)	40 (4)	47 (3)	17 (2)
Sex				
Male	2058 (57)	553 (57)	1024 (57)	481 (55)
Female	1582 (43)	425 (43)	763 (43)	394 (45)

*Other includes the Asian and Pacific Islander (API) and American Indian and Alaska Native (AIAN).

The cancer characteristics of all cases reported are presented in table 4. Twenty-two percent were previously diagnosed with cancer; twelve percent in SCCR and 25 percent in both KCR and NYSCR. Grade was included in the data submission requirements but this data is not shown because the value was coded as non-applicable for all non-leukemia cases. Just under half the cases were leukemia and 166 cases were polycythemia vera. Seventy percent of all cases were diagnosed by a positive histology with very few cases having an unknown value for their method of diagnostic confirmation.

Table 4: Cancer information for 2010 Reportable Hematopoietic Diseases—Kansas Cancer Registry, New York State Cancer Registry, and South Carolina Cancer Registry

	Total N (%)	Kansas Cancer Registry N (%)	New York State Cancer Registry N (%)	South Carolina Cancer Registry N (%)
Multiple primary				
None	2854 (78)	738 (75)	1349 (75)	767 (88)
1 or more	786 (22)	240 (25)	438 (25)	108 (12)
Primary site				
C421	3460 (95)	891 (91)	1717 (96)	852 (97)

	Total N (%)	Kansas Cancer Registry N (%)	New York State Cancer Registry N (%)	South Carolina Cancer Registry N (%)
All others	180 (5)	87 (9)	70 (4)	23 (3)
Diagnostic confirmation				
Positive histology	2539 (70)	720 (74)	1100 (62)	719 (82)
Positive cytology, no positive histology	134 (4)	36 (4)	49 (3)	49 (6)
Positive histology and positive immunophenotyping or genetic studies	446 (12)	87 (9)	327 (18)	32 (4)
Positive microscopic confirmation, method not specified	24 (1)	1 (0)	23 (1)	0
Positive laboratory test/marker study	296 (8)	90 (9)	170 (10)	36 (4)
Radiography and other imaging techniques without microscopic confirmation	12 (0)	3 (0)	5 (0)	4 (0)
Clinical diagnosis only	103 (3)	28 (3)	56 (3)	19 (2)
Unknown whether or not microscopically confirmed	86 (2)	13 (1)	57 (3)	16 (2)
Histology group				
Plasma cell tumors	776 (21)	184 (19)	342 (19)	250 (29)
Immunoproliferative diseases	43 (1)	7 (1)	35 (2)	1 (0)
Mast cell tumors	5 (0)	2 (0)	3 (0)	0
Histiocytosis	17 (0)	6 (1)	8 (0)	3 (0)
Leukemia	1701 (47)	481 (49)	798 (45)	422 (48)
Chronic myeloproliferative disorders	488 (13)	131 (13)	264 (15)	93 (11)
Polycythemia vera	166 (34)	47 (36)	77 (29)	42 (45)
Essential thrombocythemia	193 (40)	51 (39)	115 (44)	27 (29)
Primary myelofibrosis	31 (6)	12 (9)	18 (7)	1 (1)
Other	98 (20)	21 (16)	54 (20)	23 (25)
Myelodysplastic syndrome	610 (17)	167 (17)	337 (19)	106 (12)

Coding NAACCR item 500, Type of Reporting Source, according to NAACCR guidelines indicated that 61 percent of cases were reported by hospitals and 12 percent of cases were reported by physicians' offices. Using the variables created specifically for this project, the data indicate that among all reported cases, 14 percent were provided only by a targeted physician while an additional 6 percent were provided by the targeted physician and another reporting source. In South Carolina, cases abstracted by the cancer registry for this project are considered to have been provided by a targeted physician since the reports were abstracted by the central registry.

Table 5: Reporting sources for 2010 Reportable Hematopoietic Diseases—Kansas Cancer Registry, New York State Cancer Registry, South Carolina Cancer Registry

	Total N (%)	Kansas Cancer Registry N (%)	New York State Cancer Registry N (%)	South Carolina Cancer Registry N (%)
Type of reporting source				
Hospital inpatient	2207 (61)	781 (80)	889 (50)	537 (61)
Treatment centers	412 (11)	11 (1)	269 (15)	132 (15)

	Total N (%)	Kansas Cancer Registry N (%)	New York State Cancer Registry N (%)	South Carolina Cancer Registry N (%)
Laboratory	179 (5)	44 (4)	93 (5)	42 (5)
Physician's office	431 (12)	118 (12)	220 (12)	93 (11)
Other	411 (11)	24 (3)	316 (18)	71 (8)
Source of case				
Case reported by one or multiple non-physician sources	2254 (62)	714 (73)	1540 (86)	0
Case reported by targeted physician only	495 (14)	175 (18)	142 (8)	178 (20)
Case reported by non-targeted physician office only	3 (0)	3 (0)	0	0
Case reported by targeted physician and any other source	230 (6)	84 (9)	105 (6)	41 (5)
Case provided by non-targeted physician and any other source	658 (18)	2 (0)	0	656 (75)
Source of provider reporting				
Case reported by provider as part of registry follow-up	0	0	0	NA
Case report initiated by provider office	506 (14)	259 (27)	247 (14)	
Case not reported by provider	3134 (86)	719 (74)	1540 (86)	

The state-specific variables indicated that 25 percent of SCCR cases were abstracted remotely by a CCR certified tumor registrar. Ninety percent of NYSCR cases were diagnosed or treated inside the project's catchment area but may also have been diagnosed or treated by a physician outside the project area. Seven percent of the cases from KCR were reported by primary care providers.

NYSCR and SCCR were able to provide the county of residence for each of their cases. For NYSCR, the number of cases per county ranged from 30 to 752 for counties in the project catchment area. While NYSCR selected 30 contiguous counties, patients from counties both adjacent and non-adjacent to the catchment area were treated by physicians within one of the selected counties, and therefore those cases were included in the project. A number of the counties with very low case counts are present in the data. These were not counties in which the physicians were directly targeted; rather, patients from these counties were diagnosed or treated by physicians within the 30-county catchment area used for this project. For SCCR, cases by county ranged from 4 to 175.

A secondary interest of this project was to examine the completeness of JAK-2 testing for patients diagnosed with chronic myeloproliferative disorders. Table 6 displays the results for three specific histology codes for which JAK-2 testing is clinically indicated. The cases that NYSCR found to be ineligible during their audit have been excluded from this table. Of the 186 cases with a known JAK-2 test result, 122 (66 percent) were positive for a JAK-2 mutation. For the cases where the JAK-2 was not done 44 percent were diagnostic by a positive histology, 34 percent were diagnosed by a positive laboratory test or marker and the remainder diagnosed via other methods.

Table 6: Results of JAK-2 testing among patients diagnosed with polycythemia vera (9950), myelosclerosis with myeloid metaplasia (9961), and essential thrombocythemia (9962)—Kansas Cancer Registry, New York State Cancer Registry, South Carolina Cancer Registry

	Totals N (%)	Kansas Cancer Registry N (%)			New York State Cancer Registry N (%)			South Carolina Cancer Registry N (%)		
Histology Codes		9950	9961	9962	9950	9961	9962	9950	9961	9962
Total (number)	379	47	12	51	70	18	111	42	1	27
JAK-2 negative	64 (17)	4 (8)	4 (33)	12 (24)	10 (14)	3 (17)	16 (14)	7 (17)	0	8 (30)
JAK-2 positive	122 (32)	24 (51)	4 (33)	19 (37)	25 (36)	4 (22)	20 (18)	19 (45)	0	7 (26)
Ordered, results unavailable	7 (2)	1 (2)	0	1 (2)	2 (3)	0	2 (2)	1 (2)	0	0
Test not done	59 (16)	4 (8)	1 (8)	8 (16)	12 (17)	4 (22)	18 (16)	6 (14)	1	5 (19)
Unknown	127 (34)	14 (30)	3 (25)	11 (22)	21 (30)	7 (39)	55 (50)	9 (21)	0	7 (26)

We also examined the 725 cases that were specifically reported as a result of this project. These are cases that were reported by targeted physicians who were not reporting cases prior to this project. First, we examined whether the distribution of cases by histology group was different for this subset of cases. Overall, nearly half the cases were leukemia and 21 percent were plasma cell tumors. In contrast, among the subset of cases reported as a result of this project, 36 percent were leukemia, 24 percent were myelodysplastic syndromes, and 15 percent were plasma cell tumors. When we look specifically at the cases with histology codes of 9950, 9961, and 9962, JAK-2 reporting from the subset of cases reported as a result of the project is more complete. Of the 143 cases in this category, only 17 percent have a value of Unknown, a decrease from 34 percent in the project overall.

Table 7: Distribution of histology group and JAK-2 testing among the subset of cases reported as a result of this project—Kansas Cancer Registry, New York State Cancer Registry, South Carolina Cancer Registry

	Total N (%)	Kansas Cancer Registry N (%)	New York State Cancer Registry N (%)	South Carolina Cancer Registry N (%)
Histology group (all cases)	725	259	247	219
Plasma cell tumors	111 (15)	11 (4)	44 (18)	56 (26)
Immunoproliferative diseases	7 (1)	3 (1)	3 (1)	1 (0)
Mast cell tumors	1 (0)	1 (0)	0	0
Histiocytosis	0	0	0	0
Leukemia	261 (36)	82 (32)	100 (40)	79 (36)
Chronic myeloproliferative disorders	172 (24)	71 (27)	58 (24)	43 (20)
Polycythemia vera	78 (45)	29 (41)	29 (50)	20 (47)
Essential thrombocythemia	67 (39)	29 (41)	20 (34)	18 (42)

	Total N (%)	Kansas Cancer Registry N (%)	New York State Cancer Registry N (%)	South Carolina Cancer Registry N (%)
Primary myelofibrosis	9 (5)	9 (13)	0	0
Other	18 (10)	4 (6)	9 (16)	5 (12)
Myelodysplastic syndrome	173 (24)	91 (35)	42 (17)	40 (18)
JAK-2 result (only for histology codes 9950, 9961 and 9962)	143	67	38	38
JAK-2 Negative	33 (23)	15 (22)	10 (26)	8 (21)
JAK-2 Positive	63 (44)	28 (42)	22 (58)	13 (34)
Ordered, results unavailable	2 (1)	1 (1)	0	1 (3)
Test not done	20 (14)	9 (13)	5 (13)	6 (16)
Unknown	25 (17))	14 (21)	1 (3)	10 (26)

Overall, KCR, NYSCR, and SCCR recruited and trained non-hospital providers in reporting specific hematopoietic diseases. The benefits included 725 additional cases collected, improved JAK-2 test result reporting, and an increase in the number of reports of specific hematopoietic diseases, e.g, the myelodysplastic syndromes, that otherwise might not have been reported to the CCRs.

5. SUMMARY AND DISCUSSION

The goal of this project was to develop and implement methods to identify, recruit, and train non-hospital physicians to report to CCRs. While this project specifically targeted RHD, the approaches and techniques used by each CCR are broadly applicable to other CCRs. Each CCR developed, implemented, and evaluated the methods that they used. The results of this project showed that a substantial amount of effort and staff resources on the part of the registry is needed to educate physicians' practices, to provide the training necessary for case reporting, and to actively follow up to ensure they are reporting cases consistently and in a timely way.