

Opportunities for Improving the Use of Cancer Registry Data in Drug Safety Studies: Factors Influencing Interview Response Rates

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Presentation Objectives

- **Provide background on the study and source of data used for analysis**
- **Assess the impact of various factors on successfully completing a patient interview**
 - Lag time
 - Differing patient access pathways
 - Access and availability of updated contact information
- **Identify opportunities to improve the interview rate**

Background:

US Adult Osteosarcoma Surveillance Study

- In a preclinical rat toxicology study, Forteo (teriparatide), a drug used to treat osteoporosis, caused an increase in the incidence of osteosarcoma
- No such signal has been seen in clinical experience
- FDA required a postapproval surveillance study as a condition of drug approval
 - A 15-year study was initiated in 2002 and is currently ongoing

Study Background, Continued

- **Primary objective**
 - Identify approximately 33% of newly diagnosed cases of osteosarcoma among men and women aged 40 years and older
 - Determine incident osteosarcoma cases, if any, who have a history of Forteo treatment
- **15 cancer registries are currently providing data for the study**
- **Cases include 12 ICD-O-3 codes for osteosarcoma plus 5 additional ICD-O-3 codes for sarcoma, NOS and other specified cancers where site equals bone**
- **Interview patients (or proxies if patient is deceased) regarding prior exposure to Forteo**

Methods

- We assessed the impact of various factors on completing a successful patient interview:
 - Lag time between diagnosis and reporting to RTI-HS
 - Complexity of patient-access pathways
 - Access and availability of updated contact information

Methods Cont'd

- Lag time is defined as time between date of diagnosis and date reported to RTI-HS with contact information
- Factors impacting lag time:
 - Time for complete case ascertainment
 - Patient access pathway
 - Year the registry joined the study
- The longer the lag time, the more difficult it becomes to interview:
 - Greater chance the patient has died
 - Patient or proxy has moved from address at diagnosis
 - Patient or proxy may no longer remember specifics about medication usage or cancer diagnosis

Impact of Lag Time on Interview Rate

Interview Rate by Lag Time

Lag Time	Total Identified	Total Interviewed	Interview Rate ^a
0-1 Year	486	229	47%
1-2 Years	430	149	35%
2-3 Years	171	53	31%
3+ Years	196	50	26%

^a Interview rate = (number interviewed)/(number identified by participating registries). Data as of March 31, 2011, for cases diagnosed 2003-2009.

Interview Rate by Year Registry Added

Year Registry Added (No.)	Total Identified	Total Interviewed	Interview Rate ^a
2004 (4)	654	263	40%
2005 (3)	434	181	42%
2006 (3)	421	172	41%
2007 (2)	222	83	37%
2008 (2)	239	55	23%
2009 (2)	151	45	30%

^a Interview rate = (number interviewed)/(number identified by participating registries). Data as of March 31, 2011, for cases diagnosed 2003-2009.

Impact of Patient-Access Pathway on Interview Rate

Patient-Access Pathways

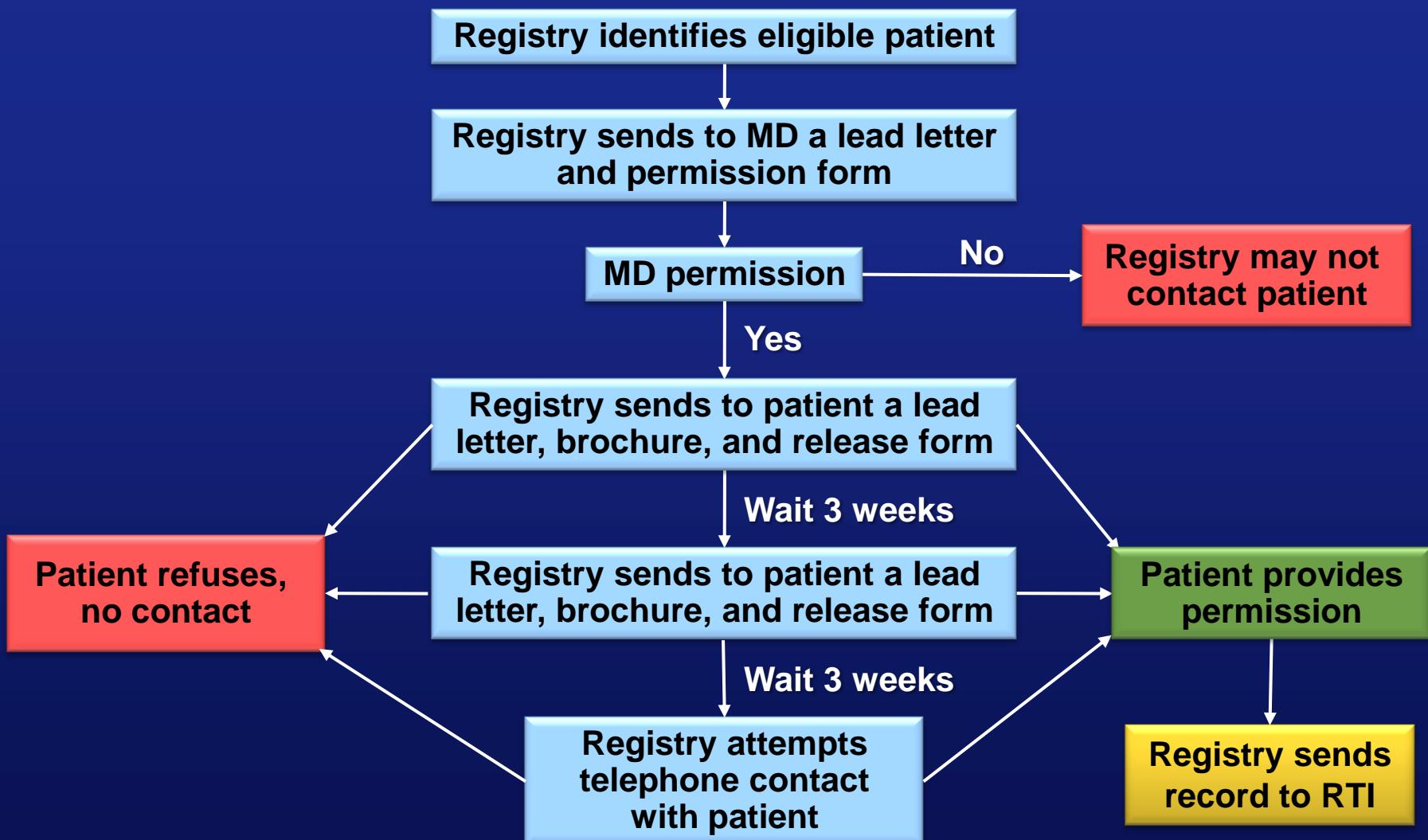
- **General Types**
 - MD notification required
 - Patient release required
 - MD notification and patient release required
 - MD permission to contact patient required
 - MD permission to contact patient and patient release required

Example: Simple Patient-Access Pathway, Physician Notification

Registry identifies eligible patient

Registry sends record to RTI;
RTI contacts MD and patient directly

Example: More Complex Patient-Access Pathway, Physician Permission and Patient Release



Patient-Access Pathways

Process Required to Obtain Patient Information	Number of Registries
MD notify only	4
Patient release only	4
MD notify and patient release	3
MD permission	4
MD permission and patient release	1
Total	16

Includes MD Anderson Cancer Center separately because it has a pathway different from that of the Texas Cancer Registry. Note that Texas Cancer Registry is categorized as 'MD Permission'; recently in Dec. 2010 the pathway changed to 'MD Notify only'.

Patient-Access Pathway and Interview Rate

Registry	Type of Patient Access Pathway	Total Identified	Total Interviewed	Interview Rate ^a
North Carolina	MD notify only	121	71	59%
New York	MD notify and patient release	231	108	47%
CA - LA SEER	MD notify only	81	36	44%
California (exc. LA)	MD notify only	323	141	44%
Michigan	MD notify and patient release	122	51	42%
Pennsylvania	Patient release only	183	70	38%
Arizona	MD notify only	36	13	36%
Harvard & Hopkins	MD permission	111	40	36%
MD Anderson	Patient release only	154	51	33%
Missouri	Patient release only	63	21	33%
New Jersey	MD permission and patient release	67	22	33%
Florida	Patient release only	269	86	32%
Ohio	MD permission	100	32	32%
Minnesota	MD notify and patient release	88	24	27%
Texas	MD permission	172	33	19%

^a Interview rate = (number interviewed)/(number identified by participating registries). Data as of March 31, 2011, for cases diagnosed 2003-2009.

Access and Availability of Updated Contact Information

Qualitative Factors Affecting the Ability to Complete an Interview

- **Missing or out-of-date contact information**
 - Patient
 - Proxy
 - Physician
- **Limited access by some registries to commercial databases to update contact information**
- **Some registries are unable to send RTI cases if they were unable to contact MD or patient**

Conclusions

- **Interview rates decrease as complexity of the patient access pathway increases**
 - Interview rates trended lower at registries where MD permission was required
- **Interview rates decrease as lag time increases**
 - Year registry began participating appeared related to interview rate; however, registries with less complex requirements were recruited first (confounds lag time)
- **Missing or out-of-date contact information can adversely affect interview rates**

Collaborative Efforts to Improve Interview Rates

- **RTI-HS met with 10 participating registries in November 2010 to discuss ways to increase interview rate**
 - Registries shared efforts undertaken to improve data
 - Registries shared what processes they can and cannot change
- **Since meeting with the registries three amendments were submitted in two states resulting in simplification of patient access pathway**

Thank You!

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