Q&A Session for National Data Exchange Agreement

Friday, May 21, 2010

Q1: Is there any clarification about whether interstate exchange should include source records or consolidated records?

A1: Documentation on records to use for data exchange was found in the Procedure Guidelines for Cancer Registries, Series I: Interstate Data Exchange. It states:

Series I Interstate Data Exchange; Edited by the Registry Operations Committee 1/2001 (Page 5) *Number of records for each tumor*.

The sending and receiving registries should determine whether they want all source records for each tumor or only the consolidated record. This should be defined clearly in the exchange agreement. Nonconsolidated records will require significantly more time for the receiving registry to process and clean up; however, use of nonconsolidated records may permit exchange in a more timely fashion. If only consolidated records are exchanged, the exchange file should be checked for duplicate records, and all duplicates should be deleted.

Because of the age of this document and the fact that there were a number of questions about the process of data exchange, the Registry Operations Committee will be asked to consider updating this document or creating a best practices document for data exchange.

Q2: Legally, how can a terminated agreement maintain force after termination? I am thinking of the requirement for confidentiality after the agreement terminates. Obviously, registries will maintain confidentiality, but the legal logic needs to be clarified.

A2: This is an agreement or understanding among participating state cancer registries. It is not a binding, legally enforceable document. In all cases, the laws and regulations of the sending state will apply.

Q3: What if a case is first reported via this agreement, then the receiving registry gets another source record for the case from an in-state reporting source? Who governs permissions/restrictions?

A3: Once the case is reported to the state in which the case resides, by an in-state institution, the state laws of that state take precedence. They are now the custodian.

Q4: Could a FACILITY sign on to this agreement?

A4: This agreement is designed for central registries.

Q5: Can the agreement include that text documentation should be required?

A5: NAACCR strongly encourages the inclusion of text information to document any case.

Per Standards Volume III, Section 2.2.5.1-The shared information SHOULD include confidential and non-confidential data and abstracted text summaries as described in the current NAACCR Standards for Cancer Registries Volume II: Data Standards and Data Dictionary.

Q6: Will there be a new NAACCR variable to track the origin of the record - which sending registry sent the record?

A6: NAACCR does not anticipate adding a new variable at this time. Some registries track cases of their residents diagnosed out-of-state via the Reporting Facility [540] field or Registry ID [40] — a unique code that represents the data transmission source.

Q7: If state confidentiality law differs from provisions in the agreement, how might this affect confidentiality after termination?

A7: The National Data Exchange Agreement is an agreement among participating states to follow certain procedures related to sharing confidential data. It is not a contractual document and should not be interpreted as legally binding. In all cases, state laws and regulations will take precedence over any terms specified in the data exchange agreement. If state confidentiality laws differ from the provisions of the agreement, the provisions in the state law will apply.

Q8: Will Federal Facilities such as VA and Military be included in this agreement?

A8: This agreement will need to comply with the provisions of the VA agreements with states. VA and military cases cannot be exchanged if that exchange would violate VA agreements with States.

Q9: Is there any clarification on what kind of edit(s) is allowed before sending?

A9: Documentation on data editing and data exchange was found in the Procedure Guidelines for Cancer Registries, Series I: Interstate Data Exchange.

Series I Interstate Data Exchange; Edited by Registry Operations Committee 1/2001 (page 6)

Standards: Outgoing

4. Run the NAACCR EDITS metafile and correct errors before sending the disk to the sharing state, province, or territory.

Standards: Incoming

4. Screen the data submitted for completeness and accuracy using the NAACCR EDITS metafile.

Because of the age of this document and the fact that there were a number of questions about the process of data exchange, the Registry Operations Committee will be asked to consider updating this document or creating a best practices document for data exchange.

Q10: Does CDC endorse this agreement?

A10: CDC-NPCR supports the use of this national interstate exchange agreement

Q11: Item #3 indicates that the data should be sent using "the current NAACCR data exchange record layout." I think that, given our current experience with version 12, perhaps it should be loosened to say "...an appropriate NAACCR data exchange record layout."

A11: At the present time we feel that the National Data Exchange Agreement should remain as is. Registries should always strive to be in compliance with the latest formats. Registries can always negotiate with each other regarding the NAACCR data exchange record layout.

Q12: Does section 4 cover Force Majeure?

Section #4. From the proposed NAACCR Agreement

"...Trading Partners shall make every reasonable effort to forward all cancer case reports within 18 months of the end of the diagnosis year."

(Wyoming's language as our data sharing agreement now stands):

"Force Majeure. Neither party shall be liable for failure to perform under this Agreement if such failure to perform arises out of causes beyond the control and without the fault or negligence of the nonperforming party. Such causes may include, but are not limited to, acts of God or the public enemy, fires, floods, epidemics, quarantine restrictions, freight embargoes, and unusually severe weather. This provision shall become effective only if the party failing to perform immediately notifies the other party of the extent and nature of the problem, limits delay in performance to that required by the event, and takes all reasonable steps to minimize delays. This provision shall not be effective unless the failure to perform is beyond the control and without the fault or negligence of the nonperforming party."

NOTE: It was stated at the Webinar that the "any reasonable effort" should cover this but let us know for sure, please.

A12: A force majeure clause is not necessary or appropriate for this agreement. This is not a contract and the time frames specified are not legally binding. The agreement clearly says that "reasonable efforts" should be made. In the case of a force majeure event, no one will fault a registry for delays.

*SEE QUOTED Sections 13 and 14 of NAACCR agreement below for both following questions.

Q13: Does the NAACCR Agreement address Sovereign Immunity? Wyoming data sharing references our statues as well as the state we are exchanging data with the following: "Sovereign Immunity. The State of Wyoming and the State of (State name) do not waive sovereign immunity by entering into this Agreement and specifically retain immunity and all defenses available to them as sovereigns pursuant to Wyo. Stat. '1-39-104(a) or (State name and law of that state)."

A13: It is not necessary for states to make an explicit statement regarding sovereign immunity since states retain that immunity unless they waive it and since this is an agreement among states, not a legally binding contract. If any state wants to include a specific statement like Wyoming suggested, they could do so in the Addendum.

Q14: Does the NAACCR Agreement address Indemnification?

"Indemnification- Each party to this agreement shall assume the risk of any liability arising from its own conduct. Neither party agrees to insure, defend, or indemnify the other."

*Your Section #13: "That in the event that the Receiving Registry receives a subpoena or other compulsory legal process compelling disclosure of confidential data, the Receiving Registry agrees to notify the Sending Registry within 2 working days (48 hours) of receipt of the subpoena or other compulsory legal process. Additionally, should the Receiving Registry receive

such a subpoena or other compulsory legal process, it shall take all legal steps reasonably necessary to oppose the subpoena or other compulsory legal process."

*Your Section #14: "That the Receiving Registry shall bear liability for loss, expense, attorneys' fees or claims, for injury or damages arising out of acts or omissions in the performance of this agreement related to data provided by the Sending Registry."

A14: An indemnification clause was added during a previous round of edits to the agreement (see section 14). Language regarding one state indemnifying another should not be in this agreement since it is not a contract. Some states, including Massachusetts, may have a problem agreeing to such language. I am not opposed to a statement that "each party shall assume the risk of any liability arising from its own conduct. Neither party agrees to insure, defend, or indemnify the other."

NAACCR recommends that each central registry have its legal department review the National Data Exchange Agreement prior to signing.