Breeze Session
November 3, 2006
Introduction : Multiple Primary and Histology Coding Rules

Slide 1
Hello and welcome to the first in a series of Breeze Webcasts for multiple primary and histology coding rules that become effective in January 2007.

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The first session of the series is actually teaching you a little about: why we did the rules;

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why the actual change was needed; who developed the rules; how they were developed;

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teaching you about the equivalent terms and definitions, the multiple primary rules, the histology coding rules and the rule formats. So, it is a general overview telling you why the project was undertaken, how it was done; then giving you broad information about how the new rules look and how you will use them.

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Now, we did have a number of indicators for change. We saw actual problems with the previous rules. When we did our casefinding, re-abstracting and reliability audits we found a consistent problem with coding histology and we saw people were confused about coding multiple primaries.

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When we looked through our question and answer software—the SEER SINQ and the Commission on Cancer (CoC) I & R, we saw that there were a huge number of questions on how to code and also on whether or not a certain case was a multiple primary. There were a lot of requests for workshops on coding complex histologies and also on making decisions on whether a case was a multiple primary or a recurrence. We also noticed that there were differences in rules between the agencies. There were differences in reportability rules and differences in how cases were coded.

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We all know that both the multiple primary decisions and the histology coding are critical elements for data quality. So it became quite apparent that we would have to do something.

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What happened? It's really not that registrars became unable to code. There were a lot of medical advances throughout the years--everything from electronic

microscopy to immunohistochemistry. Because of those medical advances we saw changes in the pathology reports that we use to code cases. There were suddenly more descriptors and more histologic types noted. Along with those additional descriptors and histologic types there was a non-standard use of nomenclature. Terms did not mean the same written by one physician as they did when they were written by another.

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Let me give you an example of a pathology report where we see multiple histologic types. This is the pathology report from an actual case. It reads: "Left Lung: Moderately differentiated adenocarcinoma, mucin secreting cells, mixed acinar, papillary and bronchioalveolar features." The result of these more complex diagnoses was that the registrar had difficulty choosing which of these histologic terms should actually be coded and abstracted.

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Then things were happening in the field to cope with these advances in technology and with the changes we were seeing in pathology reports. Our 25 year old rules saw a lot of add-ons. There were also a lot of exceptions that were added to the rules to be able to cope with the differences we were seeing in pathology reports. The result of those changes was that we could not flow-chart the old rules. We did try flow-charting them and there was no way we could get a logical start, path and completion. The old rules were very difficult to teach to new registrars. The logic was not clear. The choice of which rule to use was not clear. So again, we had a lot of problems.

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ICO-O-3 also underwent some changes to cope with advances in the medical field. There were additional histologic terms added to the volume and there were additional combination codes added.

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Let me give you an example: One of the combination codes that was added is 8255: Adenocarcinoma with mixed subtypes. Well, the result of the addition of codes was that registrars were confused about when and how to use these codes. Adenocarcinoma with mixed subtypes was interpreted very differently from region to region and from registrar to registrar.

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Who developed the actual rules? There was a task force and it was called the Multiple Primary and Histology Task Force. It was a collaborative effort. The major cancer data collection organizations were involved. There were pathologists, registrars, statisticians.
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The organizations that were involved included: The American College of Surgeons' (ACOS) Commission on Cancer (CoC), The American Joint

Committee on Cancer (AJCC), The Canadian Cancer Registries (CCR), The North American Association of Central Cancer Registries (NAACCR), the National Cancer Registrars Association (NCRA) and of course the SEER group from the National Cancer Institute (NCI). The result of having this collaboration by all of these organizations is that we now have the same data collection and coding rules for everyone whether you are a hospital registrar or a central registrar.

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We also had *ad hoc* consultants. They included the AJCC Site Teams for each of the major sites such as lung, digestive system, etc. They reviewed all of those rules for the specific sites. The CBTRUS Executive Committee reviewed the rules for malignant brain and CNS. The ICD-O-3 Editors were on call throughout the entire length of the committee to lend us advice, to interpret rules. We had NCI statisticians who were part of the actual Task Force and also worked with an interpretation on how the rules would affect the incidence count. We had specialty physicians who were involved *ad hoc* for their specific sites and as a result of all of the *ad hoc* consultations we really did have an excellent Quality Control (QC) on the actual codes and coding instructions and also on the effect that these codes would have on our incidence count.

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After the actual codes were written we went through a series of testing. We did reliability testing first during the beta phase and used those results to make changes and improvements in the rules. Then we did reliability testing during the field test just prior to the distribution of the rules. The reliability testing gave us a chance to see how actual registrars in the field could read the rules and code cases using the rules. We also did a re-abstracting field study that was done immediately prior to the release of the rules. We had a hospital component and a central registry component. The re-abstracting they did was on actual cases in the database. We thought this was a practical exercise at both the hospital and the central registry levels to see if: first, people would be able to use the rules without an extremely long learning curve; secondly, that they could apply them to cases in their registries; and third, to evaluate how well they could do the actual coding.

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The Task Force itself made the decision that they would develop site-specific rules rather than having just one set of general rules as we had had in the past. The sites were chosen using the QC principles of: quantity and high risk. By “quantity,” we mean sites with high incidence. In other words, the most frequent sites. “High risk” are the sites where there is a risk for errors when the case is abstracted; so, in other words, they are problem sites.

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Sites that were called both quantity and high risk were breast, colon and lung. We know these three sites comprise a very high percentage of the database, but they also have certain problems that also make them high risk. There is risk of errors as folks abstract these cases.

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The rest of the site specific rules were developed for head and neck, melanoma of the skin, kidney, bladder-renal pelvis-ureter and malignant tumors of the brain.

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So in all we have eight sets of site-specific rules. Then we have a set of rules that are for all of the other sites other than hematopoietic-- meaning lymphomas, leukemias and immunoproliferative diseases-- and benign brain.

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The structure of each of these sites is that there is a document called the Equivalent Terms and Definitions. Then, there are documents for the multiple primary coding rules and also documents for the histology coding rules.

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The site-specific Equivalent Terms and Definitions may include a short informational paragraph or instructions for problem areas. For example, for Head and Neck it [the introductory section] talks about how you code the primary site, i.e. what do you choose as the primary site? Then, the second part of this document is the Equivalent or Equal Terms. There we list those terms that for these rules will be equivalent or equal—they will mean same thing. Then, there are site-specific definitions. For all sites, that includes very frequent histologies or problematic histologies; it defines them. For some sites there is also specific information in these sections, for example, for multiple myelomas it defines reportability. You will see a term such as “evolving melanoma” that will have a definition, then there will be a statement: “reportable” or “not reportable.” That is because reportability was identified as one of the bigger problems that registrars have with malignant melanoma of the skin.

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The site-specific Equivalent Terms and Definitions may also have histology charts or tables. This is a new concept for registrars. The charts or tables will, in some cases, give you lineages showing you which codes are related-to or are more specific codes and you will learn how to use these charts and tables as we progress into teaching you the site-specific rules. For some sites there are also combination code tables. So for a combination code such as 8255, adenocarcinoma with mixed subtypes, it would tell you that these are the exact histologies that must be present in the tumor in order to code 8255. This, again, is a new concept. We will go over this as we go into the site-specific rules.

For each of the sites there is a set of graphics to orient you to that specific site and to give you a little help as you are coding and abstracting, particularly multiple primaries.

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22 For each [set] of the multiple primary rules there are three modules. They are called:

Unknown if single or multiple tumor; Single tumor; and Multiple tumors.

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The histology rules have only two modules called: “Single tumor” and “Multiple tumors.”

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Let me tell you about the module structures and how you actually use the modules. First of all, the modules are set up to be stand-alone. What that means is that you start with the first rule in a module and you use only one module. The rules within each of the modules are hierarchical. When you reach the rule that fits the case that you are abstracting, you stop. Go no further.

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How do you actually apply the rules?

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First of all, the 2007 multiple primary rules do replace all previous multiple primary rules for cases diagnosed in 2007 and later. So it is really important that when you abstract and code a case that was diagnosed in 2007 or later that you do not use the previous rules. You will end up with some pretty bad results if you try to combine or mix and match these rules with the previous rules.

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You use these rules for determining multiple primaries and for coding histology. You don’t use them for casefinding. You don’t use them for coding tumor grade. You don’t take these rules and use them for any data items other than histology or for any use other than determining multiple primaries.

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Again, remember that you are going to use them for cases or tumors that are diagnosed January 1, 2007 and after. And these rules will help you determine whether a new tumor is a recurrence or a new primary. In other words, if you have a case diagnosed prior to 2007 and that patient has a new tumor in 2007 you would use these rules to decide whether that new tumor was a recurrence or whether it was a new primary.

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There are General Instructions. You do need to read those General Instructions and also the site-specific Equivalent Terms and Definitions before you use the rules. It is very important. There is information in the General Instructions that applies to all cases that you code. That information is not repeated in the site-specific rules. Next, you will see Notes and Examples. Those Notes and Examples are actually put in to highlight key points or to add clarify to the rule. But it is really important to remember that they are not exclusive. In other words, they don't give you every example of how this rule will be used and they don't replace the rules themselves. You can't use Notes and Examples in place of the rule.

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You will use these rules to determine whether the patient has a recurrence or a new primary. This is a change for most people. We tell you to use the physician's statement only when the pathologist compares the present tumor to the original and states that the tumor is a recurrence from the original primary. This is a change. I do want to remind you that we did talk about this change with the CoC representatives and with the CDC representatives. We also spoke with the AJCC physicians and they were all in agreement that this was the better way to handle recurrences and the new primaries. We will get on to a definition that shows you why we have changed this rule. As we go through each site and we say, "This is a new tumor after a year," or "This is a new primary after five years," for example, we will give you the data behind this decision and we will also remind you that the AJCC site-specific physicians and the pathologists all agreed this was a very good way of handling recurrence versus new primary.

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Another thing that you need to know about the new rules is that there are no "negative" lists. So, for example, we have a list that says, "The ambiguous terms are…

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…apparently, appears, compatible with…" But what you will not see is a list that says, "These are not ambiguous terms," or "These are terms that are not coded as ambiguous terms." The reason we have done that is because registrars were quite confused by having an ambiguous terms list and then another list that said "Do not code these as ambiguous terms," because they would come up with a term that was not on either list and they really weren't sure what to do with it. So we have given you one list. We are telling you, "This is the list you do use. Anything that is not on this list you do not use."

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Remember that for hematopoietic malignancies you use the pre 2007 rules; that is the lymphomas, leukemias, the immunoproliferative and myeloproliferative diseases and the benign brain. They all use the pre 2007 rules.

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Let's look at some of the information that is in the General Instructions and in the Equivalent Terms and Definitions. First of all, we are saying that the terms "multicentric" and "multifocal" are equivalent. We went through a lot of time and a lot of physician discussion on these two terms. In the end, the physicians are saying, "These terms are so similar that trying to draw any line between them and figure out the difference between multicentric and multifocal is really not worth the time nor the effort. For all practical purposes these two terms are equivalent."

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Next, in the Definitions: Look carefully because the term "focal" actually means "limited to one area or organ." So a tumor described as focal could be either microscopic or macroscopic. The term focal is not to be updated with the term "foci" or "focus." The term "focus" is a group of cells only visible by microscope. This is the group of cells, for example, that you code as 001 if that is all the information you have. Don't confuse the two. "Focal" does not necessarily mean that it is microscopic or that the disease is limited to a small group of cells that's only visible by microscope.

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Another definition that is very important in these rules is the definition called "most representative specimen." You will see this term used throughout the rules. The definition is: "The pathologic specimen from the surgical procedure that removed the most tumor tissue." In other words, if the patient had a needle biopsy of a breast lesion followed by a lumpectomy, the lumpectomy would have the most representative specimen. It is the surgical procedure that removed the most tumor tissue. By contrast, if the patient had a lumpectomy followed by a mastectomy that showed only a microscopic residual, in that case the lumpectomy would be the most representative because, again, it had the most tumor tissue.

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This is where we come into the definition of recurrence. The problem we have had in the past with coding recurrence from a chart and taking a physician's statement from notes, or it may have been taken from the consult, but any time the word "recurrence" was mentioned the registrar would automatically code this case as a recurrence. However, the term has two meanings. The first meaning is "the appearance of a disease that was thought to be cured or inactive or in remission." So we saying that the patient had cancer and all of a sudden there is a recurrence of that disease caused by the same cells as the original disease. The second definition is "a new occurrence of cancer arising from cells that have nothing to do with the earlier (or first) cancer." Why is this called a recurrence? Let's say for example that a patient had breast cancer in the right breast and years later she has breast cancer in the left breast. A physician may say the

patient has a recurrence of breast cancer, which, indeed, she does. The physician is talking about the fact that the patient once had breast cancer and she now has breast cancer again. The physician is not saying that the second breast cancer is caused by the first breast cancer cells. The term “recurrence” did have some inherent problems. The physicians did agree that they used these terms meaning both of these types of recurrence and had never really known that we were coding literally from that word.

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Now the next instruction says, “Use the site-specific rules for malignant brain and CNS tumors, breast, colon, head and neck and kidney….

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…lung, malignant melanoma of skin, renal pelvis-ureter-bladder-and other urinary. Use the Other Sites for solid tumors of all other sites.”

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Now, the first instruction says, “Code the histology for each primary on a separate abstract.” That is quite familiar to registrars. “Use rules for all reportable, solid, malignant tumors.

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But the next instruction is very new for registrars. It gives you a priority order for coding histology. The first priority is to code histology from the pathology report. The second, if you do not have a pathology report, code from the cytology. Third, if you don’t have either the pathology or the cytology, code from the medical record documentation that references either the pathology or the cytology. In other words, if you see documentation in the medical record that says the patient had a biopsy in the office prior to admission and that biopsy showed adenocarcinoma, they are referencing the pathology. The fourth priority is a medical record mention of the type of cancer. This might be, for example, in the history and physical it mentions this patient is known to have adenocarcinoma of the left lung. So they are mentioning the type or histology of the cancer, but they are not referencing the pathology report or the cytology report.

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Using the pathology report: The first instruction is that you use the pathology from the most representative specimen. Remember we described the most representative specimen as being the pathology with the most tumor tissue. Secondly, you code from the final diagnosis. This is a change for registrars. In the past they were told to code the most specific histology so they would look through the microscopic and try to find something that was more specific. Now you are told to code from the final diagnosis. You may use associated addenda and comments. You use the microscopic only when instructed in the site-specific rules. The reason that this instruction is in the rules is that the pathologists stated that when they code microscopic they are talking about what they see from slide

to slide to slide. When they have finished looking at all the slides they put together the information that they gathered and using their expertise and their experience they come up with a final diagnosis. Their comment was that there may be a more specific diagnosis in the microscopic but it may have been a small part of a sample seen only in one slide. Because of that they have chosen not to put it into the final diagnosis because it is not representative. They would never call a final diagnosis based on such a small area. So the new rules will instruct you to code only from the final diagnosis and use associated addenda if the pathology was sent out to a specialty lab and the information from the specialty lab was added in an addendum, you would code that addendum. When the path report says, “See the comment for more information,” you would go to the comment and code the information from that comment.

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How do you choose which of the multiple primary modules you will use? We talked about the fact that the multiple primary modules are called “Unknown if single or multiple tumor,” “Single tumor,” and “Multiple tumors.” So first of all you have to have a reportable tumor. These rules do not cover our case reportability. You use the case reportability rules as you have always used them. Once you determine that this case is reportable, you then count the tumors not identified as metastatic. We are not counting metastases. You also count, of course, tumors that are separate. One would never count a large tumor that extended into another organ as two tumors. So, of course, if they have multiple tumors, they must be separate.

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You will use the module called, “Unknown if single or multiple tumors,” when there is no information about how many tumors the patient had. Perhaps you are coding a case based only on a pathology report and you really have absolutely no idea whether that patient has single or multiple tumors. Sometimes you don’t have enough information for example: If you had a patient who came to you in a hospital setting and you did an excisional biopsy of the tumor, and there was a note on the chart saying the patient had had a needle biopsy elsewhere and you didn’t know whether the needle biopsy was from that same tumor that was excised or from a different tumor; you don’t have enough information. At the central registry level you may get a report from hospital A about a needle biopsy on the right lung then a report from hospital B or just a pathology report showing an excisional biopsy from the right lung and you don’t know whether this is the same tumor. You don’t have enough information so you go to the “Unknown if single or multiple tumors” module. If you have multicentric or multifocal tumors and the number is unknown, you would go to the “Unknown if single or multiple tumors” module.

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Use the “Single tumor module.” You will use this, of course, when you have a known single tumor but you would also use it if you had a single tumor with

separate, microscopic foci. “Multiple tumors”: if you have multicentric tumors with the numbers of tumors identified; if you have multiple tumors with separate foci, you would use the “Multiple tumors” module.

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In choosing the histology module you are going to count the number of tumors that you are abstracting as a single primary. You do that because if you have multiple primaries, you prepare two abstracts and you code each separately. So you count just the number of tumors that you are abstracting on one abstract as a single primary.

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Multiple primary and histology formats.

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We have given you three different formats. They are called text, matrix and flowchart. The content is exactly the same in all of the three formats; it is only the appearance that is different.

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We have done that because people have different learning styles. One of the best examples is when you get a new piece of furniture; some people automatically go to the picture and put the entire piece of furniture together using the picture. Others turn to the text and read each of the instructions and put the piece of furniture together reading the instructions. That’s because you have different learning styles. You will understand things much better if they are presented to you in your own learning style. As you start to use these rules and as we finish up this particular presentation, we will be showing you the different types of styles in which the rules are presented and we will ask you to choose your learning style or choose the type of rules that really make sense to you. You will look at them and you will see that they are really easy in this format; that’s the style that you should use. You always pick the style that works for you. It doesn’t matter what someone else in your office uses. It doesn’t matter what your best friend uses. You want to pick the style that makes the most sense and that works for you.

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I will show you the three different styles of rules and I am going to show you two different rules in those styles. The first style is the one you are most familiar with; it is the text style. It says: **“Code the** most **specific** histologic **term when** the diagnosis is:
● Carcinoma, NOS (8010) and a more specific carcinoma or
● Adenocarcinoma, NOS (8140) and a more specific adenocarcinoma or
● Duct carcinoma, NOS (8500) and a more specific duct carcinoma (8022, 8035, 8501-8508) or
● Sarcoma, NOS (8800) and a more specific sarcoma.”

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Then there is a note and it says: “Note: The specific histology may be identified as type, subtype, predominantly, with features of, major, with _____differentiation. “ Then there is a very important note that says: “The terms architecture and pattern are subtypes only for in situ cancer.”

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This is the second style. This is the matrix style and you can see it divides up your information into certain categories. So if you are a person who likes groupings and categories you will like to look at this. You can immediately see that this rule is all about histology. This may be the style for you. If you look at this rule H12: we are talking about histology. If you have carcinoma, NOS and a more specific carcinoma or adenocarcinoma, NOS and a more specific adenocarcinoma or duct carcinoma, NOS and a more specific duct carcinoma, or sarcoma, NOS and a more specific sarcoma-- these are the histologies that are in question. The instructions are in the very last column to the right. It says: “Code the most specific histologic term.” The notes and examples are displayed in the middle column and it says: “The specific histology may be identified as type, subtype, predominantly, with features of, major, or with _____differentiation.” As you can see, you are getting exactly the same instructions but presented in a different format.

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The third format is the flow chart format, which asks questions as opposed to stating a rule. The first one says: “Is there a carcinoma, NOS and a more specific carcinoma?” If the answer is, “No,” it directs you down to the next question. “Is there adenocarcinoma, NOS and a more specific adenocarcinoma?” As you can see whenever your answer is, “Yes,” it directs you to the “Action” and it says: “Code the most specific histologic term.” That’s a stop sign. Stop. You are done. You don’t have to do anything else. The “Notes and Examples” are again in the flowchart format and it says again: “Histology may be identified as….” So as you can see the rules are exactly the same but they are presented to you in very different formats.

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Let’s do the next rule: H13. It says: “Code **8530** (inflammatory carcinoma) only when the final diagnosis of the **pathology** report specifically **states inflammatory carcinoma.**” And there is a **Note** that says: “Record dermal lymphatic invasion in Collaborative Staging.” Now this is saying, don’t code it here; you record that information in Collaborative Staging.

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Let’s look at the same rule in matrix format. It says again this is about histology: “Final diagnosis of the pathology report specifically states inflammatory carcinoma.” In the right column it says you code 8530 (inflammatory carcinoma). Notes and Examples are again there in the middle.

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Here is the same rule in flow chart. The question is asked: “Does the final diagnosis of the pathology report specifically state inflammatory carcinoma?” If you answer is, “Yes,” it instructs you to code 8530. If your answer is, “No,” you go on to the next rule.

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By this time you have seen these two rules presented in all three formats. You have probably noticed that one of them just makes more sense to you. You read it and it is very easy for you to use and that is the format that you will want to use from now on. I do want to give you a warning: Do not attempt to use all three formats at the same time. We noticed during beta testing that some registrars thought that they had to use the rules in text format, then go back and use them in matrix format then go back and use them in flowchart format. Don’t do that. You don’t have to; they really are the same rules. You will come to the same conclusion no matter what format you use.

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Our last slide shows you visually all of the different organizations who participated in making these rules a reality.

Questions

1. You said the terms “architecture” and “pattern” were used only for in situ cancers. Does that apply to all sites?

Yes, actually it does. The example that I used in the slides was for breast, but the terms architecture and pattern describe the histologic type only for in situ cancers. When those terms are used for an invasive histology they actually describe the way the tumor looks and it does not describe an actual histologic type so they are not coded for invasive histologies for any of the sites.

2. If the medical record contains documentation that slides were compared is that enough to code recurrence or do you have to have the actual pathology report?

That’s a good question. You don’t have to have the actual pathology report but you do need a statement that the pathologist looked at the two slides, compared them and stated that the new tumor definitely matches the previous tumor, that it is definitely a recurrence. If it is documented in that manner you can use that information and code it as a recurrence.

3. If a case is diagnosed prior to 2007 and the patient has a new tumor in 2007 do you use the 2007 rules to determine if it is a multiple primary or a recurrence?

That's a good question, too. We talked so much about these being the 2007 histology and multiple primary coding rules. A better way of thinking of them is the rules that you would apply to any tumor diagnosed on or after January 1, 2007. So if you have a case that was diagnosed in 2006 or in any year prior to 2007 and that patient now has a new tumor, you use the 2007 rules to decide whether that new tumor is a recurrence or if it is a new primary.

4. In a hospital registry a patient can be diagnosed in 2006 by a biopsy, seen in the hospital for the first time in 2007 in surgery. The hospital will assign a 2007-year for when the patient was seen. So, do you use the 2007 rules?

You do put that patient into your 2007 grouping because the date they were seen was 2007 but you still have to look at when the tumor was diagnosed, when they saw the tumor, when they did the biopsy. And the year of diagnosis for this tumor is 2006 so even though the patient first comes into your hospital in 2007 you would not use the 2007 rules. You would go by the date of diagnosis of that tumor which was 2006 and you use the previous rules.

5. Will we ever need the old rules after 2007?

We talked a lot about getting rid of old rules because we wanted to make sure people understand that they can't use them in tandem; they are not going to go together. But you need to hang onto the old rules. We were kind of burning them in effigy, not really. You need to understand that the rules that we used prior to 2007 need to be available if you find a case that you are adding to your database that was diagnosed before 2007. You need the old rules if you are going to go back and do some Quality Control work on your pre-2007 cases. So you can't actually just get rid of them. We just don't want you using them on any tumors that are diagnosed in 2007 and after.

Are there any other questions?

If not, thank you very much. I wanted to tell you today was an introduction to a new format, a new way of using rules and you will understand more and more as we start to present the site specific rules. There are things that certainly won' t be clear during the first presentation. As you use them over and over during the site-specific presentations you will become more familiar with them. It will be quite easy for you to understand. I just encourage you not to worry if you feel like you don't understand everything at the end of this particular presentation. This was intended as an introduction, a way for you to get started looking at the rules and be ready for your first training on how to actually use one of the site-specific rules. I want to thank you very much and definitely invite you to watch the rest of the series of presentations. Thank you.