Universal Data Collection Project

UDC Update

Fall 2005

Inside this issue

HTC Reports Available on the Web

Ever wonder if the patients you see in your HTC differ from other patients in your region or the rest of the HTC network? If so, we have added a new status report to the Universal Data Collection (UDC) HTC Reports feature in the UDC Project Database to provide each HTC with a way to compare your UDC data with that of other HTCs in your region and nationally. The HTC report contains summary demographic and clinical information about all the patients seen during a chosen year and is available from 1998, the beginning of the UDC project, through 2004.

To create your HTC Report:

- Go to the UDC Project Database at http://www2a.cdc.gov/ncbddd/htcweb/index.asp.
- Choose View and Print HTC Summary Reports.
- Log in. (Once you have logged in, the UDC HTC Reports page will appear.)
- Select HTC Reports (you can create a report for patients with hemophilia or VWD).
- Choose the year from the drop down box.

Hit the submit button to create the report.

If your UDC Contact does not have the UserID and password for your center, please ask them to contact Mike Soucie at msoucie@cdc.gov.

A Closer Look at UDC Data

Do you have a question about UDC data? As you know, you can review UDC summary data by using the UDC Surveillance Report (http://www.cdc.gov/ncbddd/hbd/surveillance.htm#UDC) or by using the online UDC report feature on the web. However, we welcome your questions about the data. When requests come in, we analyze the pertinent data to answer the research questions as thoroughly as possible. Following are highlights of the data requests we have received recently from researchers in the bleeding disorders community.

Blood Safety

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Males with severe hemophilia who have mild clinical characteristics

Deborah Brown, a pediatrician at the Gulf States Hemophilia and Thrombophilia Center in Houston, Texas, noticed that some of her patients who have severe disease seem to have fewer complications than others. She asked that we look at males with hemophilia in UDC to see if we could find an empirical basis for a clinical phenomenon she sees in her patients.

Using the UDC database, we compared a group of males with severe hemophilia (factor activity less than 1%) who had the lowest 10% of range of motion (ROM) loss from normal scores (Group 1) with the remaining severes who had the upper 90% ROM loss from normal scores (Group 2) and with males whose factor activity was between 1% and 2 % and who had a moderate course of disease (Group 3). Everyone in these three groups was between 2 and 20 years of age, was on episodic treatment, and did not have inhibitors. We hypothesized that the patients in Group 1 would have characteristics similar to the more moderate patients in Group 3, rather than the severe patients in Group 2. To test our theory, we compared risk factors (factor product use, target joints, invasive procedures, activity restriction, cane or wheelchair use, number of bleeds, age, age at first bleed, age at first HTC visit, and age first diagnosed) among the three groups.

Our results found no differences between Groups 1 and 2 and no similarity between Groups 1 and 3, which countered both parts of our hypotheses. We repeated this comparison using the lowest 5% of ROM loss from normal scores as the cut-off and found results similar to the 10% cut-off. We concluded that ROM loss does not appear to be a sensitive indicator of patients who have a milder course of hemophilia among those with severe disease. It is possible, however, that although the number of patients who experience this mild course may be very small, they are quite memorable to clinicians because of their uniqueness.

Joint infections in UDC data

Dr. Nigel Key, University North Carolina, Chapel Hill, NC, has proposed that we use UDC data to study joint infection. To begin our examination, we looked at all UDC participants with hemophilia in 2004. We compared those who had joint infections with those who did not have an infection across the following risk factors: age, treatment type, hemophilia type, severity, having an inhibitor, IVAD use, number of joint bleeds, and HIV and HCV status. We found that participants with joint infections were more likely to have used an IVAD, had 2–4 joint bleeds in the past 6 months, be HIV or HCV positive, and be between 25 and 44 years of age. We are now going back and compiling a cohort from the UDC data to further study the joint infection question. We will look at the data from all people with joint infections having at least two visits, no more than a year apart, where joint infection was not present on the first visit but had developed by the following visit. The purpose of the study is to determine rates of and risk factors for joint infections and to assess how infections affect joint ROM measurements. As part of this study, we are asking the HTCs who have patients in the database with qualifying joint infections to verify those infections and to collect some additional important information about the infections. If you are contacted about this study, we ask that you help out by providing the information requested.

Laboratory Update

In October 2004, the Division of Hereditary Blood Disorders Laboratory took over the hepatitis serology testing from Baylor. New equipment has been installed to process the additional specimens, and the transition is going smoothly. We have been catching up on the backlog of hepatitis testing that occurred during the change-over, and with a few exceptions, the testing of specimens received from September to December 2004 has been completed and reports have been sent to you. We have also completed testing and reporting of most specimens received from January through August 2005, and

testing of specimens received during September has begun.

Please let us know if you are missing reports on specimens collected between September 2004 and June 2005. Also, please continue to let us know if you find any discrepancies in your patients' results. If you missed the e-mail in June outlining the changes in the testing methods, or if you have additional questions, please contact Meredith Oakley at 404-498-2801 or moakley@cdc.gov.

Changes to the QOL Survey

The quality of life (QOL) questionnaire will be incorporated into the UDC in the next few months. A few changes have been made regarding how the questionnaire will be administered and how the data will be sent back to CDC. Because experts in QOL advised that self-administered assessment is the best method to obtain honest, unbiased responses from participants on their sense of well-being and health, the QOL will be self-administered. This means that UDC participants will complete the survey themselves, unassisted by HTC personnel. Upon completion, each participant will place the questionnaire in an envelope, seal it, and give it to an HTC staff member to be mailed back to CDC. When received at CDC, it will be entered into the QOL database.

We have revised the questionnaire; if you have any of the previous versions of the QOL questionnaire, please discard them. We will be sending paper questionnaires and complete instructions to the UDC Contact at your center soon. Thank you for your patience while we enter this new phase of data collection. If you have any questions about the QOL survey, please contact Vanessa Byams at 404-498-2723 or ver0@cdc.gov.

Lab Tracker Update

As you may know, all 12 regions have selected Lab Tracker software as the clinical tool the HTCs will use to collect data for the UDC. The software makes it possible to submit UDC data electronically. The newest version of Lab Tracker was launched at the end of May. Over the last three quarters, 45% of all forms have been received electronically. To date, more than 6,000 electronic forms have been submitted from the 40 sites already using Lab Tracker. We are working with other sites to bring them on board. We look forward to helping those sites make the transition to electronic form submission. If you are one of centers who will be using Lab Tracker, please call Evett Hunt at 404-498-280 before you transmit your first form to be sure that you have no outstanding validation errors in the system. For new users, we appreciate all the work you have done to make the transition to Lab Tracker in your facility a success! In future newsletters we will highlight improvements the latest version of Lab Tracker brings to database functionality.

UDC Working Group

On June 27–28, 2005, the UDC Working Group met in Atlanta, Ga., to review the progress of enrollment in the UDC project, to review the data being collected as part of the project, to advise on possible additions to data collection activities, and to provide feedback to CDC about the progress of UDC efforts in the group members' institutions or regions. The Working Group also meets monthly via teleconference and will hold its next meeting January 9–10, 2006, in Atlanta. We would like the welcome the newest members of the Working Group: John Drake, Nancy Duffy, Barbara Konkle, Ed Kueblerand, and Brenda Neilson. And, of course, we thank those who finished their terms last year: Steve Arkin, Ann Forsberg, Sue Geraghty, Marilyn Gradowski, Margaret Warner, and Gilbert White.

Welcome to Our New Supplies Coordinator

Please join us in welcoming Collette Lucas, our new supplies coordinator for UDC! She is responsible for maintaining supplies for the project and filling your supply requests. If you have any questions, you can reach her at 404-498-2716 or lua4@cdc.gov.

Data Entry Corner

Validation Errors

Mistakes are a fact of life. It is the response to error that counts. ~Nikki Giovanni

We receive approximately 150 paper forms per week to enter into the UDC database, which demonstrates how hard you are working to ensure UDC has the most current data. However, if the forms have validation errors, the process to enter the forms can slow significantly, depending on the number of errors per form. This delays our ability to give you feedback and results from your UDC data. We are asking for your help to minimize validation errors and the resulting delays. Here's what you can do:

- Send in your corrections to validation errors as soon as possible.
- Use the most current version of the annual form—the white one. If you still have the older (grey) form with 08/97 on the bottom of the form, please dispose of this form.
- Submit the registration form. When you send in an annual visit form, you may receive a notice that we are missing the registration form. This could mean 1) you have sent in the form for a new participant and we do not have a registration form; or 2) for some reason, a new study ID number has been generated for this participant, and we have no way of knowing that he or she has previously been enrolled and has a registration form in the system with a different ID number (in this case, we'll ask that you verify the ID and let us know which number to use).

We're here to help with your validation errors. By following these suggestions and responding right away when you receive notice of an error, you can help make the process more efficient for everyone. As always, we thank you for your assistance and your dedication to the UDC project.

Cha—cha—changes!

The UDC is changing to improve our data collection efforts. We have completed work and received CDC IRB approval on the following UDC-related items:

- The updated UDC protocol.
- The QOL forms and materials.
- The updated annual visit form.

The next step is getting local IRB approval. We will be sending a packet of these materials to the regional coordinators, and they will be working with you to get all these materials submitted to your IRB.

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