



ALABAMA STATEWIDE CANCER REGISTRY

http://www.adph.org/cancer_registry/

Data Transfer Link Access to WebPlus



Web Plus Training Manual
for
Alabama Cancer Reporting Sources

Version 2.0.16
2010

Funded by NPCR Grant 5U58DP000825

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INTRODUCTION

The Web Plus Reporting Manual has been created to assist non-hospital reporting sources in reporting cancer cases to the central cancer registry, and for all users to send and receive confidential information to/from the Alabama Statewide Cancer Registry (ASCR)

NPCR requires central registries to:

- ◆ Collect incidence data on residents of Alabama,
- ◆ Have legislation mandating the reporting of cancer cases by all facilities that diagnose and/or treat cancer,
- ◆ Provide training for state personnel, hospital registry and non-hospital reporting facility staff,
- ◆ Follow a standard data set when collecting cancer cases,
- ◆ Publish an annual report within 24 months of the end of the diagnostic year, Alabama meets this requirement by providing an on-line system.
- ◆ Conduct case finding and quality assurance audits to determine the completeness and quality of all cancer cases being submitted to the registry.

In 1995, the Alabama Board of Health mandated cancer as a reportable disease in the State of Alabama. The reference date for the Alabama Statewide Cancer Registry is January 1, 1996.

There has been a shift toward outpatient diagnosis and treatment, which has caused cases not to be reported to the central registry. **This is an attempt to assist you in collecting and submitting data on those cases that are diagnosed and treated entirely in your office or clinic.** Without this data, the burden of cancer in Alabama cannot be accurately measured. The ASCR staff is available to assist with any questions and/or provide in-services to better prepare you for the process.

GENERAL INSTRUCTIONS

The following information provides some basic rules regarding cancer reporting to the state central cancer registry.

For clinics this includes:

- ◆ Cases initially diagnosed at your facility and
- ◆ Cases treated at your facility, without having any treatment performed at a hospital.

Some examples (not intended to be all inclusive):

- 1) A prostate case diagnosed on biopsy in the office and placed on hormones or “watchful waiting”. The patient does not go to the hospital for any further treatment.
- 2) A melanoma completely excised in the office that may or may not go to the hospital for wide excision. The case must be reported if the wide excision is negative. Such a case would not be picked up by the hospital.

The completed case should be submitted to the central registry monthly for ambulatory surgery centers, freestanding cancer clinics, treatment centers and physician clinics and offices.

After the information has been recorded and reviewed for completeness and accuracy, please make a list of patients at your facility. Keeping a list of patients that have been reported to the ASCR may assist you in the future to verify that the patient has been reported. This list should include:

- a. Patient Name
- b. Social security number
- c. Date of birth
- d. Date of diagnosis
- e. Primary site
- f. Date case was submitted to the ASCR

REPORTABILITY

All facilities are required to report cancer cases to the ASCR. The following requirements are listed below:

Patients diagnosed and/or treated at your facility (physician's office, freestanding clinics and ambulatory surgery centers, etc)

- a. Diagnosis might be clinical (X-rays, CT scans, clinical exam, etc)
- b. Diagnosis might be pathological (biopsy, cytology, bone marrow, etc)
- c. Treatment given inside your institution (Chemo, hormonal, immunotherapy, etc)
- d. Surgery is performed inside of your institution (TURP, TURBT, Shave, Punch or Excisional Biopsies, etc.)
- e. No treatment is given (supportive care, watchful waiting or “observation” only). This includes palliative treatment.

What information is required?

Any details related to the **diagnosis, treatment and staging of this cancer**. We need any information you have, even if the data items are unable to be completed. Providing the name of the physician or hospital in which the patient was treated, will enable us to retrieve more accurate information. This information may be found in the facility history and physical, discharge summaries, pathology reports, etc. Please include the date of death.

WEBPLUS USER GUIDELINES

Web Plus is a web-based application used to collect cancer data securely over the Internet. It is most suited for physicians' offices and other low volume reporting sources that do not have facility-based cancer registries.

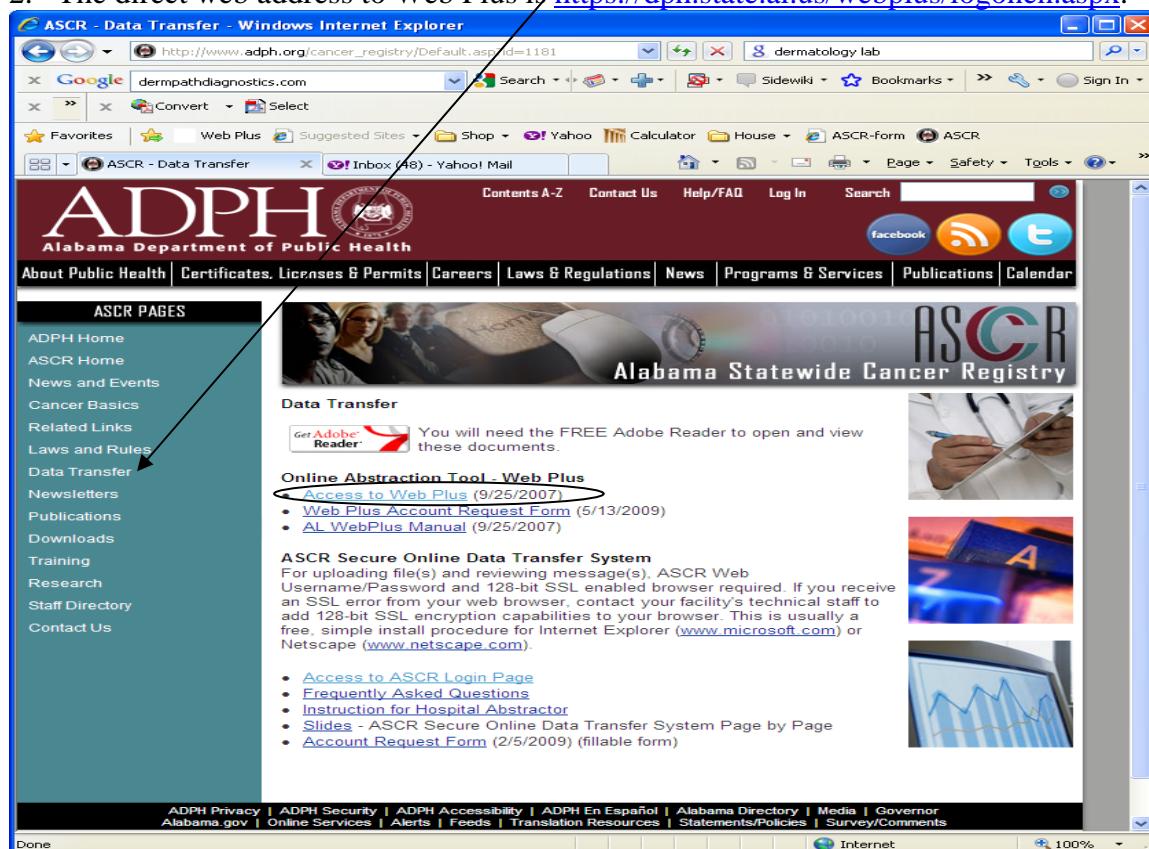
Records are saved in a database at the Alabama Statewide Cancer Registry and cases entered by one facility or office is not visible to other facilities. Data entered is validated by the CDC EDITS Engine running on a web server. User display types and edit configurations are managed at the ASCR. Web Plus is hosted on a secure web server that has a digital certificate installed; the communication between the client and the server is encrypted with Secure Socket Layer (SSL) Technology.

Requirements for Web Access

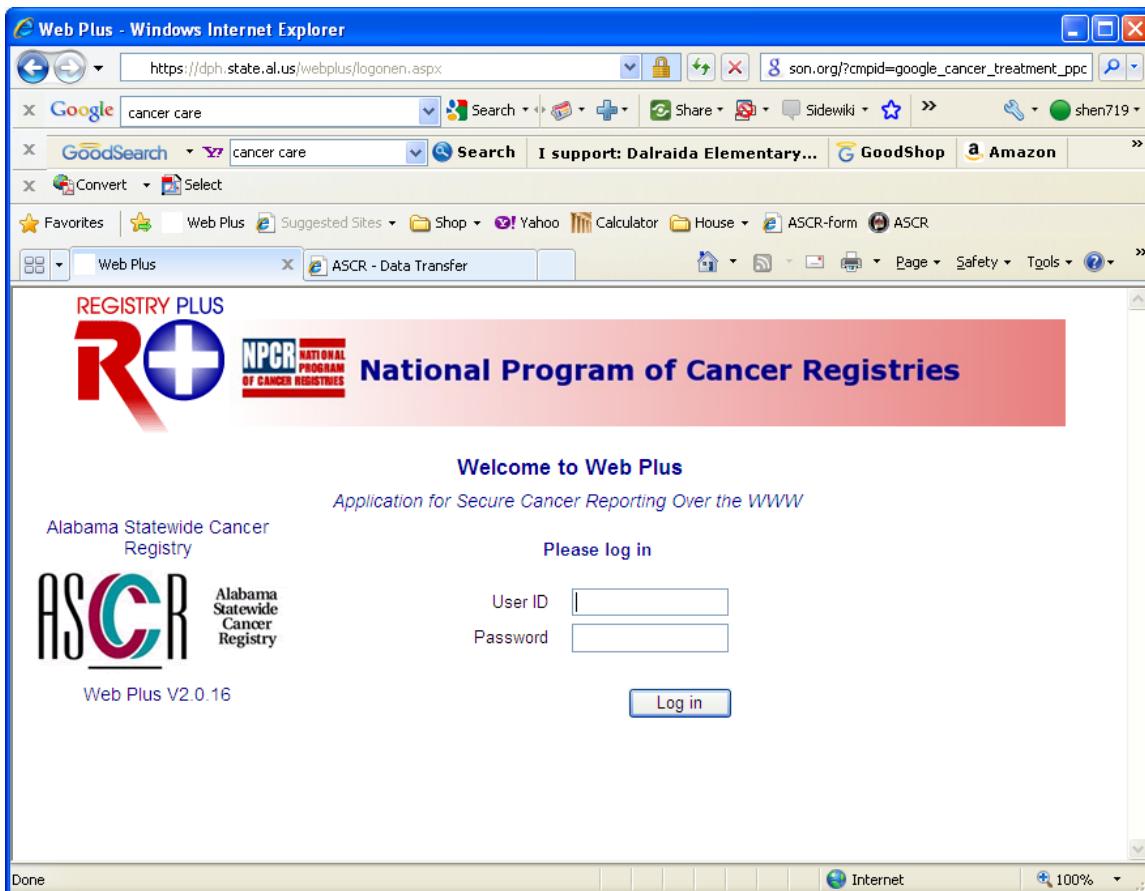
Web Plus requires Microsoft Internet Explorer version 5.0 or later or a Mozilla browser to operate the system fully. Although Web Plus works at 800 X 600 resolution, it can be best viewed at 1024 X 768 or higher resolution.

Detail Instruction for Using WebPlus to Abstract

1. Open by typing the following web address http://www.adph.org/cancer_registry/ into your Internet Browser and choose the “Data Transfer” link to [Access to Web Plus](#).
2. The direct web address to Web Plus is <https://dph.state.al.us/webplus/logonen.aspx>.



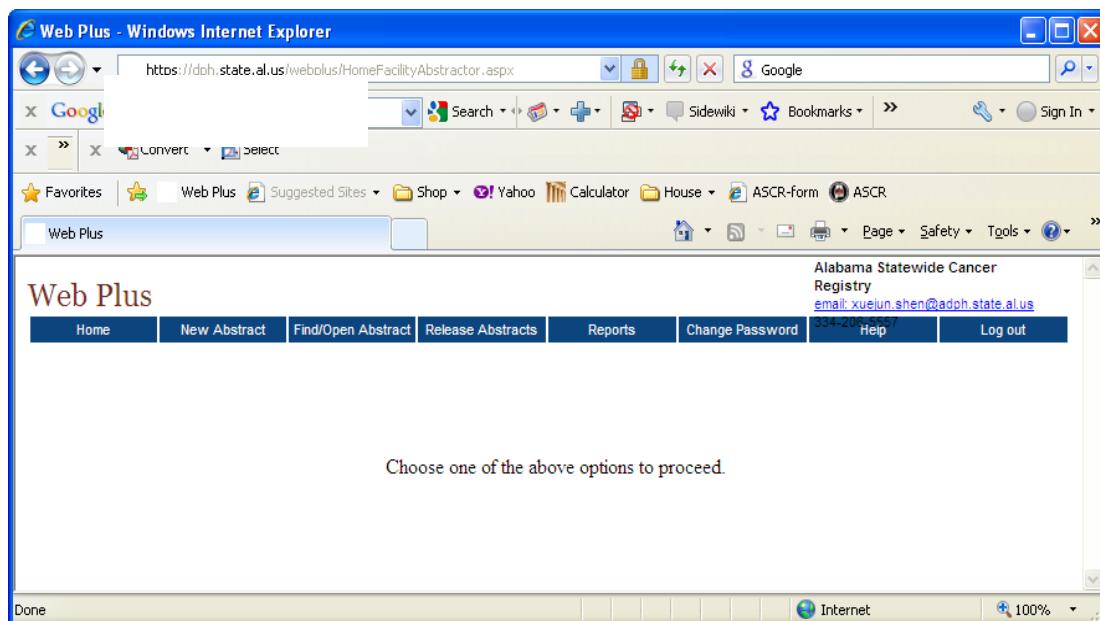
3. At “Data Transfer” page, click on “Access to Webplus” to get to the Webplus login window.



4. Save this website to your “Favorites” folder for easy access. To do this **click on Favorites** at the top of your Internet browser page and **click Add to Favorites...** give this web address a name you can remember (i.e. State Reporting, AL Cancer Reporting, etc.)
5. To login to Web Plus, enter _____ in the User ID field and _____ in the Password field.
* Password is case-sensitive.
6. Click **Log in**. The Web Plus home page displays your facility names, if you abstract for two or more facilities.



7. Click on the abstract type under facility name that you will enter cases for (like ASCR FULL or DEMO in the screen shot above). To upload a file, click on File Upload under the facility name.



8. To enter a new abstract, click on the tab labeled **New Abstract** and begin entering patient information. Your facility ID should appear in the Reporting Hospital field automatically. The cursor may be used to scroll through the fields. The **Tab** key may be used to move down and **Shift+Tab** keys to move up.

Web Plus - Windows Internet Explorer

https://dph.state.al.us/webplus/dataentrytype1.aspx?absrefid=0

Google

Web Plus

Alabama Statewide Cancer Registry
email: xuelun.shen@adph.state.al.us

Web Plus

Home New Abstract Find/Open Abstract Release Abstracts Reports Change Password Help Log out Add/View Comment

Enter new abstract

All data items marked with an asterisk (*) are required.

HOSPITAL SPECIFIC

Reporting Hospital 

Med Rec No. 

Date 1st Contact 

DEMOGRAPHIC

Last Name * 

First Name 

Middle Name 

Help

Enter an Abstract and click on Save at the bottom of the page to save it to the database. The abstract is edited each time you save. Edit errors, if there are any, will be shown in this message area. All your changes will be saved to the database even if there are edit errors.

Data entry Help Icons

Special Code Lookup  icon to the left of the data item links to a searchable listing of terms and coded values for the data item. When a specific code in the list is clicked, it is automatically filled into the abstract for the data item.

Save Click to save the abstract and run data Edits. See the box to the right for Edits results each time the abstract is saved.

Done

9. Most data fields have prompt boxes with specific instructions to help guide the user through the data entry. The prompt box will be displayed when the data entry box is clicked. Read each prompt carefully to learn the data entry rules.

Web Plus - Windows Internet Explorer

https://dph.state.al.us/webplus/dataentrytype1.aspx?absrefid=0

Google

Web Plus

Alabama Statewide Cancer Registry
email: xuelun.shen@adph.state.al.us

Web Plus

Home New Abstract Find/Open Abstract Release Abstracts Reports Change Password Help Log out Add/View Comment

Enter new abstract

All data items marked with an asterisk (*) are required.

Reporting Hospital 

Med Rec No. 

Date 1st Contact 

DEMOGRAPHIC

Last Name * 

First Name 

Middle Name 

Social Security No. 

Birth Date 

Birthplace 

AddrDx-No. and St. 

AddrDx-City 

Date of 1st Contact

Valid Date Entry Format: MMDDYYYY

Enter an Abstract and click on Save at the bottom of the page to save it to the database. The abstract is edited each time you save. Edit errors, if there are any, will be shown in this message area. All your changes will be saved to the database even if there are edit errors.

Data entry Help Icons

Special Code Lookup  icon to the left of the data item links to a searchable listing of terms and coded values for the data item. When a specific code in the list is clicked, it is automatically filled into the abstract for the data item.

Calculate Field Value  icon to the left of a data item is clicked to automatically calculate the value for the data item from information that has been entered for other data items.

Save Click to save the abstract and run data Edits. See the box to the right for Edits results each time the abstract is saved.

Done

10. The User may also click on the “?” mark to the right of each field to access more detailed help and instructions from Registry Plus Online Help.

Web Plus

Enter new abstract

All data items marked with an asterisk (*) are required.

Reporting Hospital: 0370003105

Med Rec No:

Date 1st Contact:

DEMOGRAPHIC

Last Name*

First Name

Middle Name

Social Security No

Birth Date

Birthplace

AddrDx-No. and St.

AddrDx-City

AddrDx-State

AddrDx-Zipcode

County at DX

Age at Diagnosis

Sex

Race 1

Race 2

Race 3

Race 4

Save Click to save the abstract and run data Edits. See the box to the right for Edits results each time the abstract is saved.

Date of 1st Contact - Windows Internet Explorer

REGISTRY PLUS ONLINE HELP

NAACCR Standards for Cancer Registries Volume II: Data Standards and Data Dictionary

Source: NAACCR Standards for Cancer Registries Volume II: Data Standards and Data Dictionary, Seventh Edition, 03/2002

DATE OF 1ST CONTACT (Revised)

Alternate Name | Item # | Length | Source of Standard | Column #

Date of Adm/1st Contact | 580 | 8 | NAACCR | 416-423

Description

Date of first patient contact, as inpatient or outpatient, with the respective facility for the diagnosis and/or treatment of the tumor. The date may represent the date of an outpatient visit for a biopsy, x-ray, scan, or laboratory test.

When Class of Case 7 (pathology-specimen-only) cases are collected, the patho-Date of Specimen Collection [7320] recording pathologist report should be used for the Date of 1st Contact. If a pathology specimen collection is followed by a patient contact with the facility for the diagnosis and/or treatment of the respective tumor, the Date of 1st Contact is not changed. The date of the initial pathology laboratory specimen collection remains the Date of 1st Contact.

Rationale

This item is used to assess and monitor the timeliness of reporting. Timeliness of abstracting (and reporting) is a concern for all standard-setting organizations and to measure the timeliness of these standards have been established. This item can be used in conjunction with the Date Case Report Received [2111] to measure timeliness of reporting by individual facilities to central cancer registries.

■ CoC FORDS entry available

11. The fields with * are critical fields. They CANNOT be left blank. A blank in one of the critical fields will create an error and the software will prohibit the case from being released to the central cancer registry until information is supplied.

12. Some of the fields have a drop down box that allows the User to pick a value from a list.

Web Plus

Enter new abstract

All data items marked with an asterisk (*) are required.

AddrDx-City

AddrDx-State

AddrDx-Zipcode

County at DX

Age at Diagnosis

Sex

Race 1

Race 2

Race 3

Race 4

Race 5

CANCER IDENTIFICATION

Save Click to save the abstract and run data Edits. See the box to the right for Edits results each time the abstract is saved.

Alabama Statewide Cancer Registry
email: xuejin.shen@adph.state.al.us

Edit Errors **Help**

Enter an Abstract and click on Save at the bottom of the page to save it to the database. The abstract is edited each time you save. Edit errors, if there are any, will be shown in this message area. All your changes will be saved to the database even if there are edit errors.

Data entry Help Icons

Special Code Lookup icon to the left of the data links to a searchable listing of terms and coded values for the data item. When a specific code in the list is clicked, it is automatically filled into the abstract for the data item.

Calculate Field Value icon to the left of a data item linked to automatically calculate the value for the data item from information that has been entered for other data items.

13. The fields with a “magnifying glass” icon will allow the User to make a selection from a look-up table.

The image shows two windows side-by-side. The left window is 'Web Plus - Windows Internet Explorer' showing a form with various fields. The 'Birthplace' field is highlighted with a yellow box and a magnifying glass icon. The right window is 'BPCode - Windows Internet Explorer' showing a list of codes and labels for birthplaces, with a search bar and navigation buttons.

Code	Label
585	Abyssinia
629	Aden
583	Afars and Issas
638	Afghanistan
570	Africa, East
510	Africa, North
500	Africa, NOS
540	Africa, South
545	Africa, South West
530	Africa, West
580	African Coastal Islands
037	Alabama
031	Alaska
481	Albania
224	Alberta
513	Algeria
250	America, Central
260	America, North
300	America, South
121	American Samoa
811	Anatolia
641	Andaman Islands
443	Andorra
543	Angola
245	Anguilla
865	Annam
750	Antarctica
245	Antigua
245	Antilles, Netherlands
245	Antilles, NOS
625	Arab Palestine (former)
629	Arabia, Saudi
629	Arabian Peninsula
386	Argentina

14. Once all of the abstract information has been entered **Click the Save button** at the bottom left hand corner of the screen.

15. The message “Abstract has been saved to the database” will appear in the window on the right of the screen. The program will then EDIT the record.

Web Plus - Microsoft Internet Explorer provided by Alabama Dept of Public Health

File Edit View Favorites Tools Help

Yahoo! Mail - shen719@yahoo... Web Plus

Web Plus

New Abstract Find/Open Abstract Release Abstracts Reports Change Password Help Log out

Print Preview

Update abstract

All data items marked with an asterisk (*) are required.

HOSPITAL SPECIFIC	
Reporting Hospital	0000530810
Sequence of Tumor	00
PATIENT ID	
Last Name *	JOHN
First Name *	DOE
Middle Name	
Maiden Name	
Social Security No. *	222997777
Med Rec No.	12345
Addr at Dx-Number *	UNK
Addr at Dx - Additional	
Address at Dx-City *	UNK
Address at Dx-State *	AL
Address at Dx-Zip *	99999

Abstract has been saved to the database.

Save Click to save the abstract and run data Edits. See the box to the right for Edits results each time the abstract is saved.

Waiting for https://dph.state.al.us/webplus/dataentrytype1.aspx?absrefid=0...

Start Xuejun Sh... Vicki Nelso... Diane Hedi... C Intern... Microsoft... AL Urolog... 9:39 AM

- a. If there are errors present, an error message will appear in the window on the right. Click on the EDIT error field in question to make appropriate corrections in the data.

Web Plus - Microsoft Internet Explorer provided by Alabama Dept of Public Health

File Edit View Favorites Tools Help

Yahoo! Mail - shen719@yahoo... Web Plus

Web Plus

New Abstract Find/Open Abstract Release Abstracts Reports Change Password Help Log out

Print Preview

Alabama Statewide Cancer Registry email: xiahen@dph.state.al.us

Update abstract

All data items marked with an asterisk (*) are required.

HOSPITAL SPECIFIC	
Reporting Hospital	0000530810
Sequence of Tumor	00
PATIENT ID	
Last Name *	JOHN
First Name *	DOE
Middle Name	
Maiden Name	
Social Security No. *	222997777
Med Rec No.	12345
Addr at Dx-Number *	UNK
Addr at Dx - Additional	
Address at Dx-City *	UNK
Address at Dx-State *	AL
Address at Dx-Zip *	99999

-----EDIT RESULT-----

Ediset Name: ASCR: 11C w/NPCR Hosp

There are edit errors in the abstract. Error messages along with the error fields are listed below. You can click on an error field to move to it in the data entry area. Click on the Save button to save the changes and rerun Edits.

Total edit errors: 15

1. Date of 1st Contact is required.
 2. Date of Diagnosis is required.
 3. History and Physical Information is required.
 4. Managing Physician is required.
 5. Primary Site is required.
 6. Tumor Size is required.
 7. Method of Diagnosis is required.
 8. X-rays/Scans is required.
 9. Scopes is required.
 10. Lab Tests is required.
 11. Surgical Procedures is required.

Save Click to save the abstract and run data Edits. See the box to the right for Edits results each time the abstract is saved.

Done, but with errors on page.

Start Xuejun Sh... Vicki Nelso... Diane Hedi... C Intern... Microsoft... AL Urolog... 9:40 AM

- b. If there are NO errors, you will see the message “This abstract passed all edits and can be released to the central cancer registry. Do you want to release it?” Yes or No?

Web Plus - Microsoft Internet Explorer provided by Alabama Dept of Public Health

File Edit View Favorites Tools Help

Yahoo! Mail - shen719@yahoo... Web Plus

Alabama Statewide Cancer Registry
email: xishen@dph.state.al.us
205-855-4173

New Abstract Find/Open Abstract Release Abstracts Reports Change Password Help Log out

Print Preview

Web Plus

Update abstract

All data items marked with an asterisk (*) are required.

HOSPITAL SPECIFIC

Reporting Hospital: 0000530810

Sequence of Tumor: 00

PATIENT ID

Last Name *: JOHN

First Name *: DOE

Middle Name:

Maiden Name:

Social Security No. *: 222997777

Med Rec No.: 12345

Addr at Dx-Number *: UNK

Addr at Dx - Additional:

Address at Dx-City *: UNK

Address at Dx-State *: AL

Address at Dx -Zip *: 99999

Save Click to save the abstract and run data Edits. See the box to the right for Edits results each time the abstract is saved.

Done

start Xuejun Sh... Vicki Nelso... Diane Hadl... Internet Microsoft... AL Urolog... 9:45 AM

- If you click ‘Yes’, you will get a message “**The abstract has been released to the central cancer registry.**” Please use next option if you enter several cases together
- If you click “No”, the case may be released later by clicking on the “Release Abstracts” tab. The option to select which abstracts to release is available from this window.

Web Plus - Microsoft Internet Explorer provided by Alabama Dept of Public Health

File Edit View Favorites Tools Help

Yahoo! Mail - shen719@yahoo... Web Plus

Alabama Statewide Cancer Registry
email: xishen@dph.state.al.us
205-855-4173

New Abstract Find/Open Abstract Release Abstracts Reports Change Password Help Log out

Web Plus

Release Abstracts

Please select the abstracts that you would like to release to your central registry by checking the box in the Release column. Then click the Release Selected Abstracts button at the bottom of the page. Please note that only completed abstracts are available for release.

AbsRefID	Last Name	First Name	Abstractor	Date Case Completed	Release
5529			JD	03/20/2007	<input type="checkbox"/>
5531			JD	03/20/2007	<input checked="" type="checkbox"/>
5534	KRAFT	DOUGLAS	JD	03/20/2007	<input type="checkbox"/>

Select All Unselect All Release Selected Abstracts

start Xuejun Sh... Vicki Nelso... Diane Hadl... Internet Microsoft... AL Urolog... 9:56 AM

16. To find or open previously entered abstracts, click on the “Find/Open Abstract” tab. You can search by name or SSN. Leave both search fields blank in order to see a list of all abstracts.



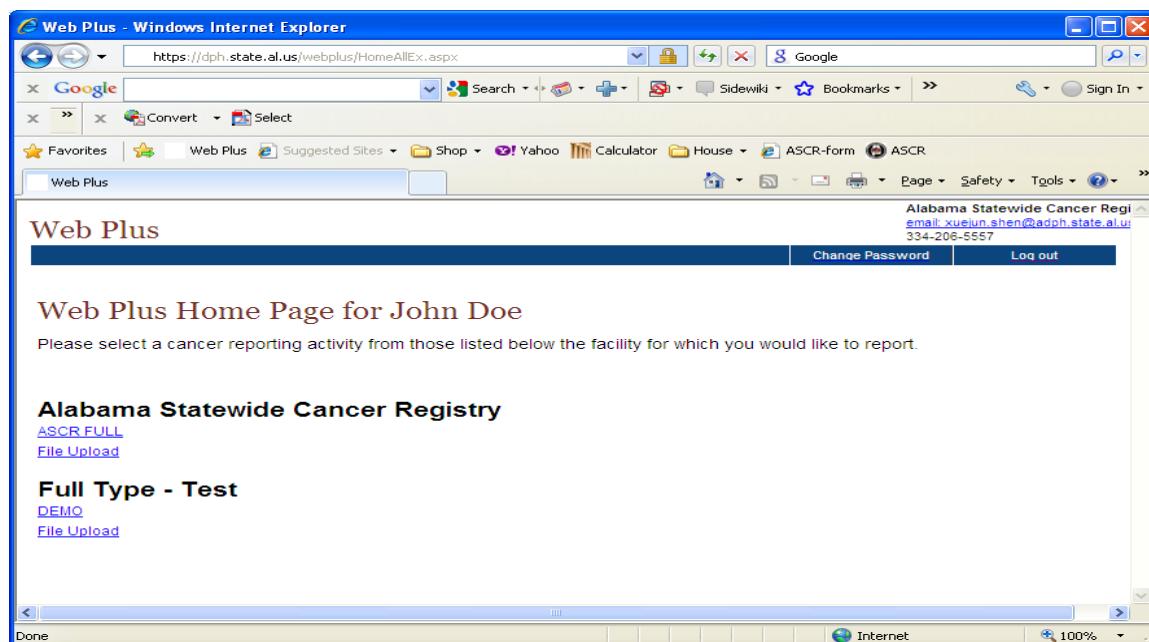
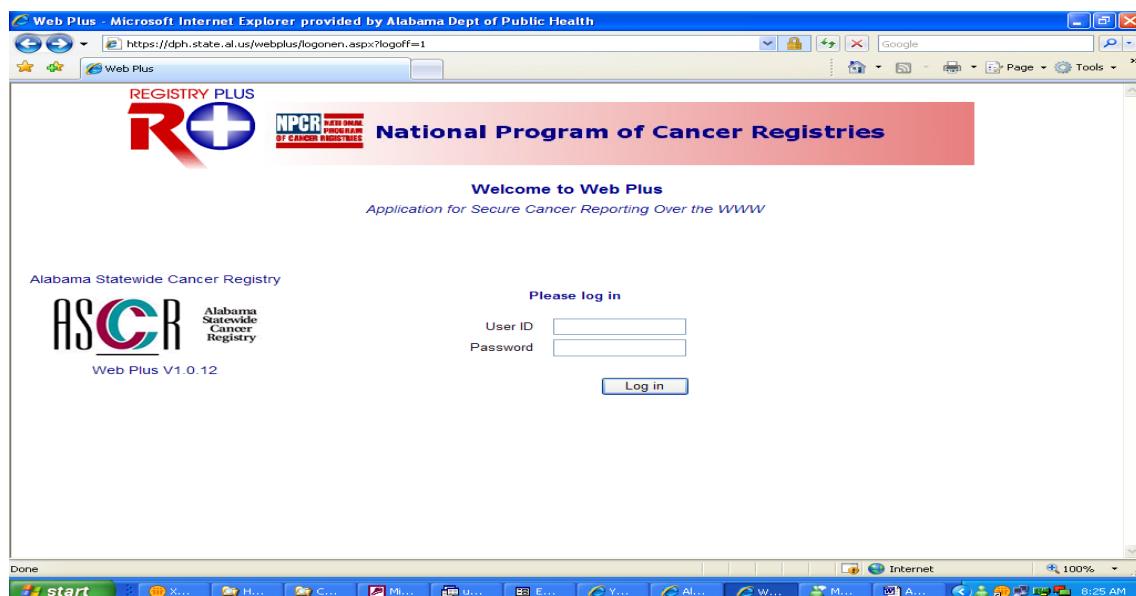
17. Web Plus can generate several reports which can be viewed by clicking the “Reports” tab.

Upload/Download

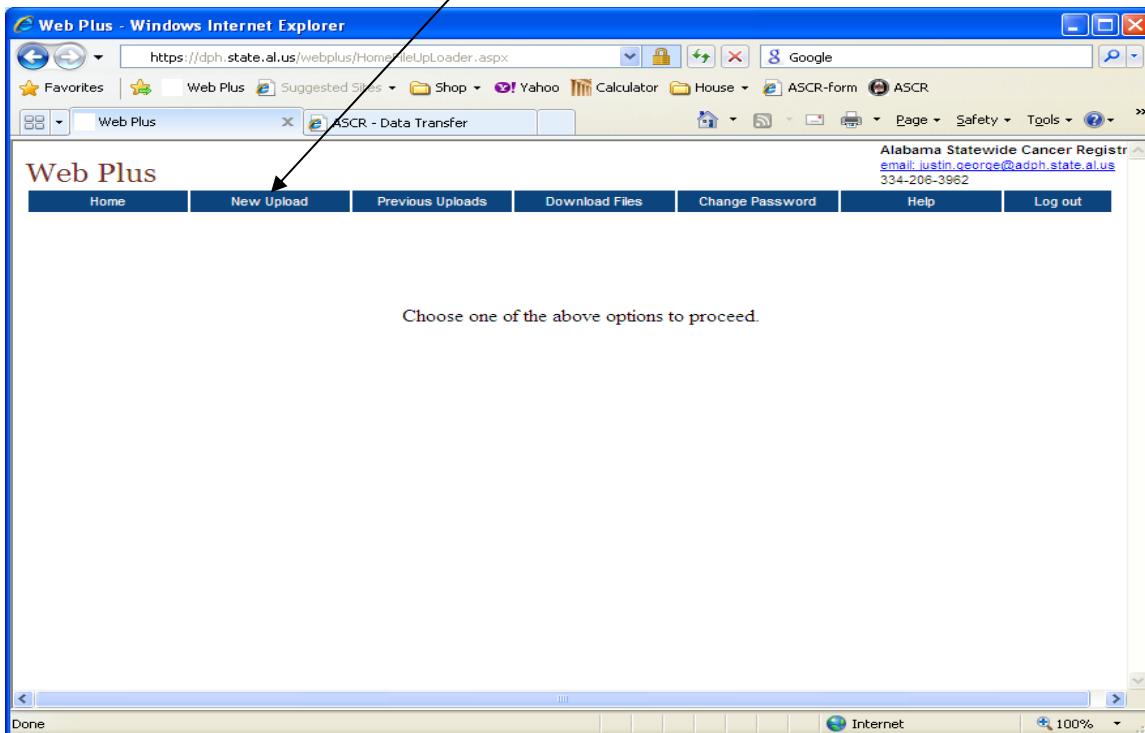
Web Plus can also be used to upload files (NAACCR format or non-NAACCR format) to ASCR – like the ASCR secure online data transfer system. You can also receive information containing confidential information from ASCR. To use this function, your role has to be set as “File Uploader”.

Users will access to webplus the same way as using webplus as abstraction tool

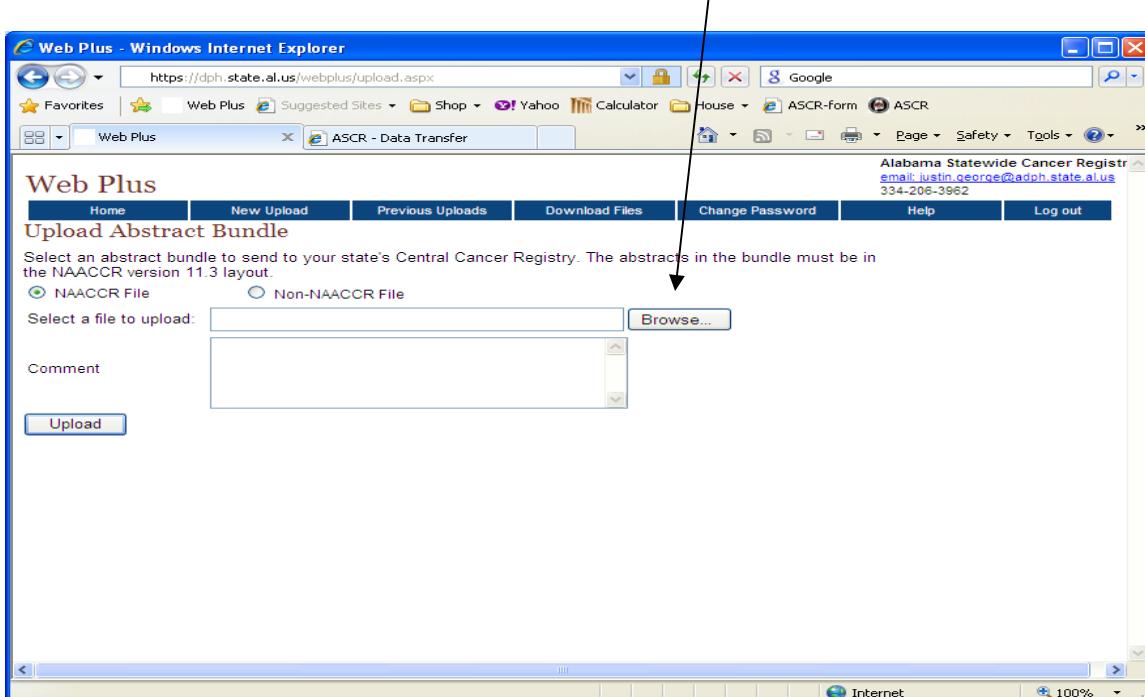
1. Open by typing the following web address http://www.adph.org/cancer_registry/ into your Internet Browser and choose the “Data Transfer” link to [Access to Web Plus](#).
2. The direct web address to Web Plus is <https://dph.state.al.us/webplus/logonen.aspx>.



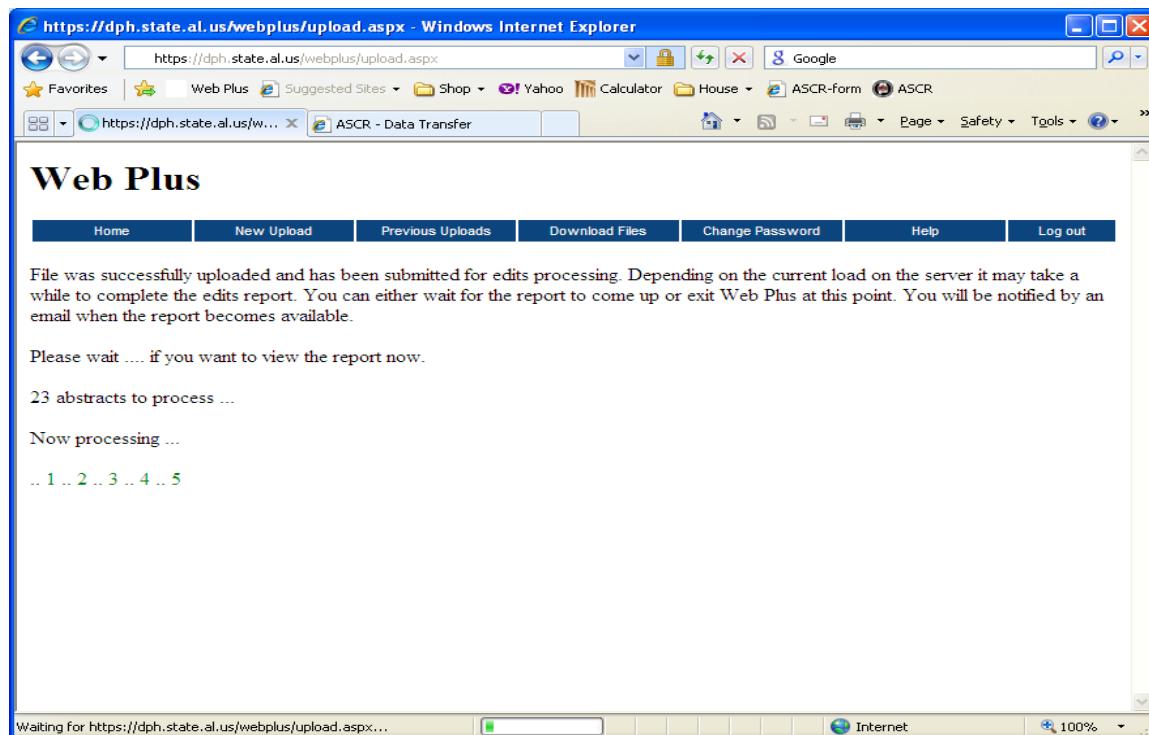
After user logs in web plus, to upload a file, click on File Upload under the facility name. In File Upload page, click “New Upload”.



Choose NAACCR File if it's a NAACCR format data file. Otherwise, choose Non-NAACCR File. Then select the file by clicking on “Browse”.

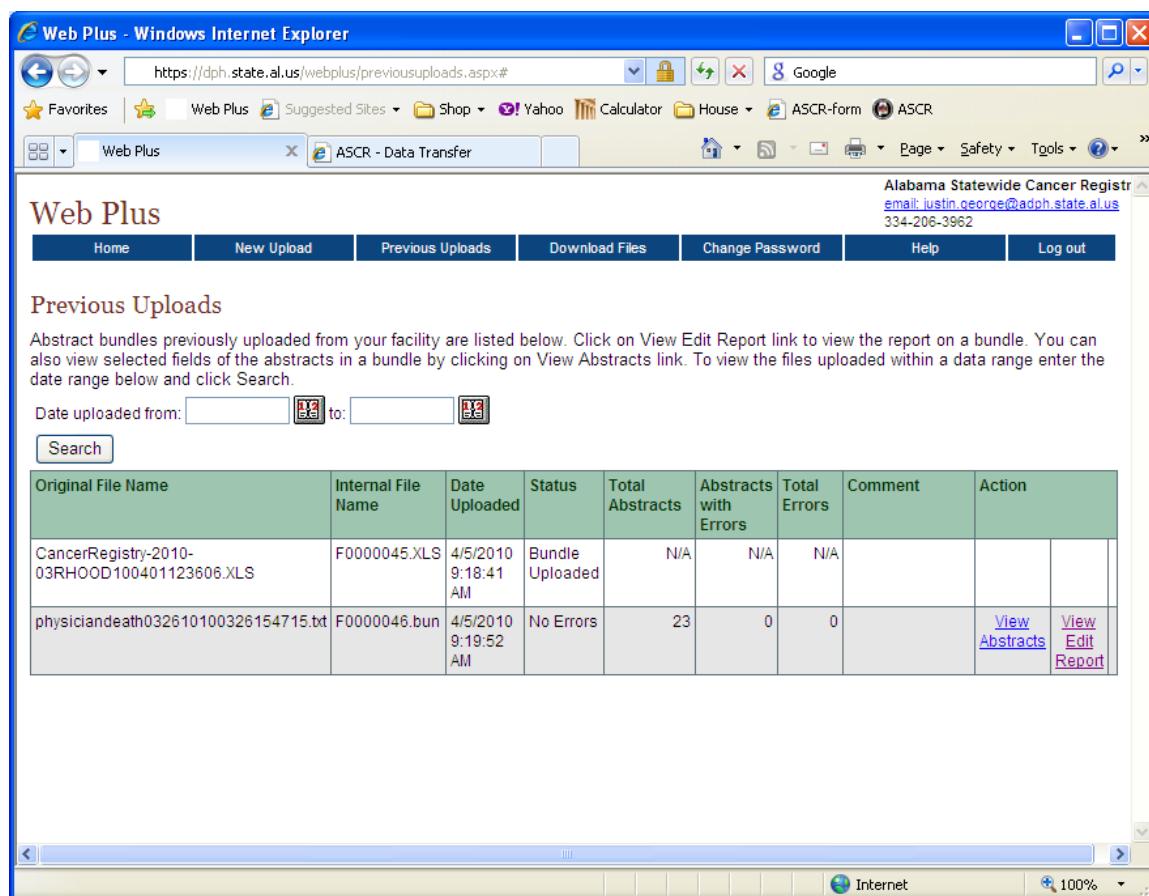


You will see processing report in next page.



The screenshot shows a Windows Internet Explorer window with the URL <https://dph.state.al.us/webplus/upload.aspx>. The page title is "Web Plus". The main content area displays a message: "File was successfully uploaded and has been submitted for edits processing. Depending on the current load on the server it may take a while to complete the edits report. You can either wait for the report to come up or exit Web Plus at this point. You will be notified by an email when the report becomes available." Below this message, there is a link "Please wait if you want to view the report now." and a status message "23 abstracts to process ...". Underneath, it says "Now processing ..." followed by a sequence of numbers: "... 1 .. 2 .. 3 .. 4 .. 5". At the bottom of the page, there is a status bar with the text "Waiting for https://dph.state.al.us/webplus/upload.aspx..." and a progress bar indicating 100% completion.

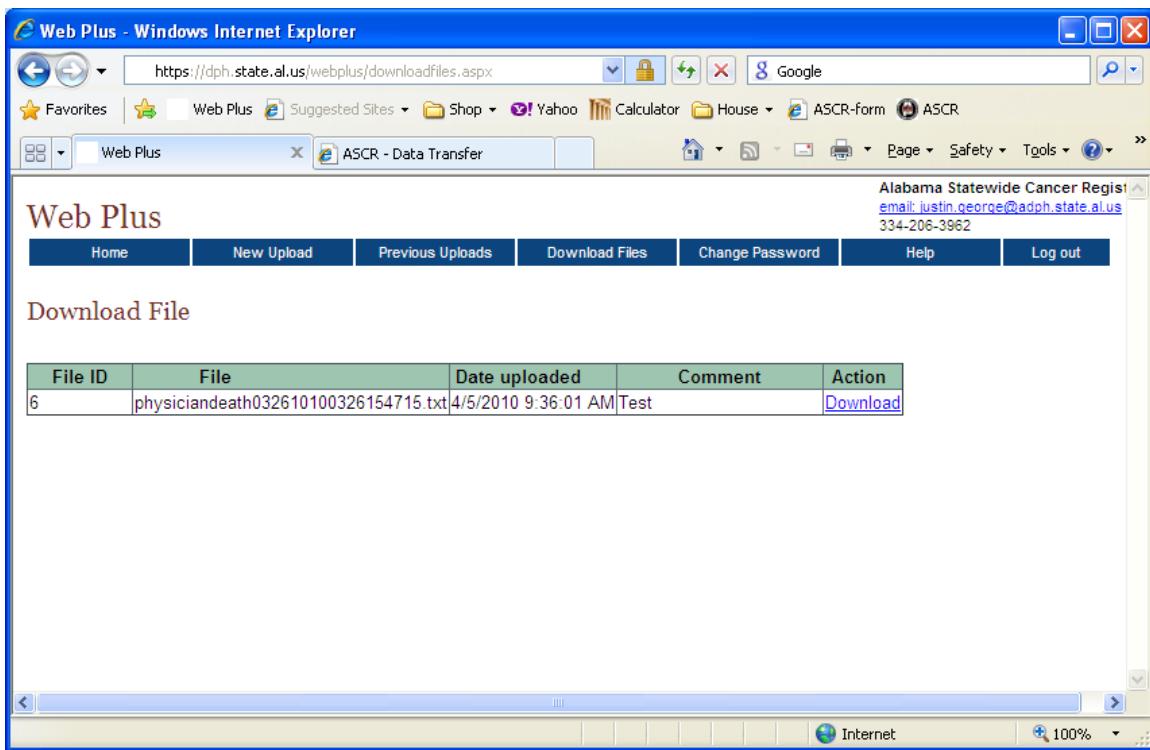
You can click on **Previous Uploads** to view the files you just sent or sent in the past.



The screenshot shows a Windows Internet Explorer window with the URL <https://dph.state.al.us/webplus/previousuploads.aspx#>. The page title is "Web Plus". The main content area displays a heading "Previous Uploads" and a sub-instruction: "Abstract bundles previously uploaded from your facility are listed below. Click on View Edit Report link to view the report on a bundle. You can also view selected fields of the abstracts in a bundle by clicking on View Abstracts link. To view the files uploaded within a date range enter the date range below and click Search." Below this, there is a search form with fields for "Date uploaded from:" and "to:", and a "Search" button. A table follows, showing a list of uploaded files with columns: Original File Name, Internal File Name, Date Uploaded, Status, Total Abstracts, Abstracts with Errors, Total Errors, Comment, and Action. The table contains two rows of data:

Original File Name	Internal File Name	Date Uploaded	Status	Total Abstracts	Abstracts with Errors	Total Errors	Comment	Action
CancerRegistry-2010-03RHOOD100401123606.xls	F0000045.xls	4/5/2010 9:18:41 AM	Bundle Uploaded	N/A	N/A	N/A		
physiciandeath032610100326154715.txt	F0000046.bun	4/5/2010 9:19:52 AM	No Errors	23	0	0	View Abstracts	View Edit Report

To view or download the file sent from ASCR, click on “Download File”.



When you click on “Download”, you will see the prompt to open or save the file.



CONFIDENTIALITY AND HIPAA

The ASCR has policies and procedures that address patient confidentiality. It is also stated in the state law Section 22-13-33. Confidentiality in the “Rules and Regulations”, states that the clinical records of individual patients submitted to the ASCR shall be confidential and shall not be public records open to inspection. Only state personnel authorized by the State Health Officer and other individuals authorized by the State Health Officer or designee shall have access to the records.

Based on HIPAA privacy regulations, the ASCR is a “public health authority authorized by law to collect and receive such information for the purpose of preventing and controlling disease, injury and disability, including ... reporting of disease ... and the conduct of public health surveillance...” [C.F.R. 164.512 (b)(1)(i)(2001)] This makes it possible for any facility that is eligible to report cancer to the central registry (i.e. hospital, hospice, etc) without obtaining an individual informed consent.

For more information, see “Frequently Asked Questions and Answers about the HIPAA Regarding Cancer Reporting.”

RESOURCES/ADDITIONAL FORMS

ASCR Staff Resources

For more information regarding scheduling an in-service:

CONTACT:

Program Director		
<u>Xuejun Shen</u> , Ph. D, MS	334-206-5557	334-206-3823
North Region/Completeness Coordinator		
<u>Diane Hadley</u> , BS, CTR	256-775-8970	256-734-1840
South Region/QA Coordinator		
<u>Mark Jackson</u> , CTR	251-433-7809	251-432-3238
Central Region Coordinator		
<u>Shri Walker</u> , , BS, CTR	334-206-7035	334-206-3823
Death Clearance/Research Coordinator		
<u>Tara Freeman</u> , MSM, RHIA, CHDA	334-206-7072	334-206-7073
Non-hospital Reporting Coordinator		
<u>Teisha Robertson</u>	334-206-7068	334-206-3823
Case Finding Auditor (North Region)		
<u>Bobbie Bailey</u>	205-554-4516	205-556-2701
Case Finding Auditor (South Region)		
<u>Shirley Williams</u>	334-206-7072	334-206-3823

For more information regarding:

- ◆ Studies or reports
- ◆ Special data requests
- ◆ General administrative issues

CONTACT:

Xuejun Shen, Ph. D. MS
ASCR Program Director
334-206-5557
334-206-3823 fax
Xuejun.shen@adph.state.al.us

To access the cancer registry's website, go to:

http://www.adph.org/cancer_registry/

FREQUENTLY ASKED QUESTIONS AND ANSWERS REGARDING CANCER REPORTING

1. When does Heath Insurance Portability and Accountability Act (HIPAA) become effective?

President Bush approved the regulations on April 12, 2001.

The official effective date of the regulations was April 14, 2001. Covered entities, including hospital and physicians, have two (2) years to comply (by April 14, 2003), except for small health plans which have until April 14, 2004 to comply.

2. What is a ‘Public Health Authority’ under HIPAA?

Under HIPAA, a ‘Public Health Authority’ refers to “an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors of persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate.” “...Such agencies are authorized by law to collect or receive such information for the purposes of preventing or controlling disease injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions.” ***Central cancer registries and hospital cancer registries if required to report cancer cases are considered public health authorities because state laws mandate their duties.***

3. What is a ‘Covered Entity’ under HIPAA?

A ‘Covered Entity’ is a health care plan, a healthcare clearinghouse, or a health care provider who transmits any health information in electronic form for financial and administrative transactions. A ‘heath care provider’ is “a provider of medical or health services, and any other person who furnishes, bills or is paid for health care in the normal course of business.”

4. What if a patient does not want follow-up information to be collected?

State-mandated cancer reporting typically does not require patient informed consent nor can individuals elect to be removed from reporting. In a state, which allows the collection of follow-up cancer data for public health purposes, it can be collected regardless of consent from a patient.

5. Will private practice physicians be permitted to continue to provide follow-up information to hospital cancer registries without patient consent

Yes. Although private practice physicians are health providers, and thus covered under the provisions of the HIPAA privacy regulations, there are several reasons why they can continue to provide follow-up information to hospital cancer registries without patient consent. First, the hospital cancer registry is likely to be viewed as public health authority because it is an entity acting under a grant of authority from or contract with a State, tribal, or local public health agency to provide for public health surveillance.

The HIPAA regulations specify that covered entities may use or disclose protected health information without the written consent or authorization of the

individual...under specific circumstances. These include disclosures for public health activities and purposes to public health authorities authorized by law to collect or receive such information for the purpose of preventing or controlling disease or conduct public health surveillance.

As public health authorities, hospital cancer registries are exempt from the HIPAA regulations and may continue to seek public health data from providers the same as before the HIPAA regulations were finalized. DHHS did not attempt to interfere with state and local public health matters such as cancer surveillance through the implementation of these regulations.

Second, even if some hospital cancer registries are not public health authorities (because they are not associated with a state or local public health agency to work on public health matters), physicians may still have to provide follow-up information. HIPAA regulation Sec. 164-512(a) specifically states that: a covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.

Thus, where a hospital cancer registry is required by state or local law to collect cancer data, physicians must follow the follow-up requirements of the registry to the exclusions of HIPAA privacy protections.

Finally, the consent requirement for disclosures under the HIPAA regulations does not limit the types of disclosures allowed. Provided a patient consents to the use or disclosure of his or her health data to a hospital cancer registry as part of the broader consent language, regularly sharing data between physicians and hospital cancer registries is permissible. In future cases, patient consents may specifically reference the sharing of data with all hospital cancer registries. For existing cases, written patient consent may also suffice for the purpose of authorizing these exchanges.

6. How does HIPAA impact the data collection of non-reportable/benign diseases (i.e. benign brain, CIN III, Co-morbid conditions)?

HIPAA does not obstruct any state law that supports or mandates the reporting of such cases.

7. Are private practice physicians still required to report new cancer cases?

Yes, in compliance with state reporting regulations. The central cancer registry has a reportable list that identifies which cancers are reportable, and all reportable cancers should be reported, as required by state law.

8. Is there specific legal documentation that supports the requirement to release cancer patient information to any agency?

Individual state laws and regulations document cancer reporting requirements. Central registries should be able to provide copies of their state's law(s) and regulations(s) upon request.

9. What, if any, are the consequences of not cooperating with state cancer registry requests for new cancer case information?

HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes. Penalties for failing to comply with state reporting are specified in the state law and often consist of significant fines.

10. Doesn't HIPAA nullify the state law for reporting cancer cases to Central Cancer Registry?

No. Public health reporting under the authority of state law is specifically exempted from HIPAA rules.

11. Once HIPAA is in place, will pathology labs be able to continue to send new cancer case information to the state cancer registry?

Yes. Public health reporting under the authority of state law is specifically exempted from HIPAA rules.

12. Since HIPAA is federal, will it override the state laws?

No. HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes.

13. If the government-authorized public health entity is not located in the same state as the covered entity, is it still ok under HIPAA to provide the data?

Yes. In fact, the definition of a 'public health entity' was broadened in the section "Uses and Disclosures for Public Health Activities", which states specifically "...We broaden the scope of allowable disclosures ...by allowing covered entities to disclose protected health information not only to U.S. public health authorities but also, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority."