

# Privacy and Health Information Technology: The American Cancer Society Experience

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Washington, DC  
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## Topics:

- Internet-based information strategy
- National Cancer Database
- Opportunities for the future of electronic healthcare IT

## Background:

- 1996: Volunteer-led design group begins discussions
- 1/1997: National call center opens
- Mid 1997: Work begins on strengthening Cancer.org

Current statistics:

**[www.cancer.org](http://www.cancer.org)**

1.5 million visitors hosted each month

**1-800-ACS-2345**

100,000 callers each month

# Health Information Confidentiality Principles:

The American Cancer Society:

- 1) Recognizes that individuals entrust the Society with their health information, and acknowledges individuals' rights to confidentiality and access to their health information;
- 2) Accepts its obligation to protect these rights and to institute an organization-wide system for adherence;
- 3) Acknowledges that full disclosure and informed consent shall guide the use or transfer of individual health information. The Society will use such information only for the provision of services and for internally approved purposes. Any other use of such information will be based on informed consent.

## Health Information Confidentiality Principles (cont'd):

The American Cancer Society:

- 4) Recognizes that certain activities involving research participants will require adherence to standards that exceed these principles; and
- 5) Is committed to educate and hold accountable all individuals who work on its behalf regarding the Society's obligation to protect the confidentiality of individual health information.

www.cancer.org

American Cancer Society Homepage - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Search Favorites Media

Address http://www.cancer.org/docroot/home/index.asp

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Search powered by Google

**No matter who you are, We can help.**

It's one cancer you can avoid. **Colon testing saves lives.**

Select a group to find the information that most closely matches your needs. [Información en español](#)  
[Asian language materials](#)

- Patients, Family, & Friends**  
[Learn about cancer, treatment options, treatment decision tools, clinical trials, coping.](#)  
Choose a cancer topic for specific information.
- Survivors**  
Connect through [Cancer Survivors Network](#) and support programs
- Health Information Seekers**  
[Statistics, prevention & early detection, quitting smoking, Bookstore.](#)
- ACS Supporters**  
Help in the fight against cancer. [Donate or volunteer.](#)
- Professionals**  
Find [Facts and Figures, publications, media information, research programs, jobs.](#)

**Interactive Help**

- [Make Treatment Decisions](#)
- [Explore Treatment Options](#)
- [Find a Clinical Trial](#)
- [Try More Tools](#)

**ACS News Center**

**News and Features**

- [Medical Updates](#)
- [News You Can Use](#)
- [Stories of Hope](#)

**Get Involved**

**Relay For Life**

Walk or jog to celebrate life at your local [Relay For Life](#) event.

**This Month**

**Colon Testing Saves Lives**  
Learn which test is right for you.

- [Love Stories by People Living with Cancer](#)
- [Sex and Cancer](#)
- [The Black/White Cancer Gap](#)
- [Send Daffodils, Fight Cancer](#)

start

Taskbar: Testa..., Window..., Clinical..., Contacts..., C:\peos..., 002205..., C:\Decu..., acrupdat..., 002205..., Presenta..., American...

11:10 AM Tuesday 2/22/2006

# www.acscsn.org

The screenshot shows a Microsoft Internet Explorer browser window displaying the website for the Cancer Survivors Network (www.acscsn.org). The browser's address bar shows the URL <http://www.acscsn.org/index.html?popup=1>. The website features the American Cancer Society logo and a navigation menu with links for [ACS Home](#), [Cancer Information](#), [ACS Support Programs](#), [Contact ACS](#), and [Contact CSN Webmaster](#). A prominent green banner reads "Cancer Survivors Network" with a small photo of a woman. Below the banner is a search bar and the date "Tuesday, February 22, 2005".

The main content area is divided into several sections:

- Language Selection:** Buttons for "中文" and "En Español".
- Welcome:** A message stating, "Hello and welcome! You've entered a vibrant community established by people just like you whose lives have been touched by cancer. We hope you'll find strength and inspiration from our personal stories, discussions and expressions of caring."
- Celebrating Love and Relationships:** A section titled "Celebrating Love and Relationships" with the text: "Love is in the air! Celebrate love and relationships of all kinds this month -- everything from romantic partners to cherished friends, family members, caregivers, and even our pets! Their love and support makes a big difference in our daily lives. We invite you to look at some stories, poems, and pictures from your fellow CSN members!" Below this, it says: "If you're considering treatment for cancer, register for your [free cancer treatment decision tools](#), brought to you by the American Cancer Society and NexCura."
- CSN Sign In:** A green box containing a sign-in form with fields for "username" and "password", a "Go" button, and a link to "or login via our secure server". It also includes a link for "Forgot your password?" and a link for "Not a CSN Member Yet? Register here."
- Free CSN Newsletters:** A green box stating: "Registered CSN members receive a free monthly CSN eNewsletter!"

The browser's taskbar at the bottom shows the Windows Start button, several open applications (including "Testin...", "Windows...", "Classical...", "Contacts...", "C:\Docu...", "022105...", "C:\Docu...", "acsupdat...", "022205...", "Presenta...", and "The Can..."), and the system tray with the date and time "11:20 AM Tuesday 2/22/2005".



ACS :: Treatment Decision Tools - Microsoft Internet Explorer


File Edit View Favorites Tools Help

Back - Home - Search - Favorites - Media - Print - Stop - Refresh - Go


Address [http://www.cancer.org/docroot/ETO/eto\\_1\\_1a.asp](http://www.cancer.org/docroot/ETO/eto_1_1a.asp) Go

Google - Search Web - PageRank - Site popups allowed - Options

Home | Community | Get Involved | Donate | Contact Us | Site Index | Search



## Making Treatment Decisions



My Planner Register | Sign In

### Making Treatment Decisions

[Types of Treatment](#)  
[Clinical Trials](#)  
[NCCN Treatment Guidelines for Patients](#)  
[Treatment Decision Tools](#)  
[Choosing Treatment Facilities and Health Professionals](#)  
[Find Treatment](#)

## Treatment Decision Tools

Treatment decision tools, like these NexProfiler Treatment Option Tools, can help you make an informed decision about your treatment. Using these tools, you can access the detailed analysis of your specific condition, uncover a statistical breakdown of treatment types, and pinpoint the exact topics you should discuss with your doctor.

Choose one of the NexProfiler Tools for Cancer to begin:

- [Bladder Cancer](#)
- [Breast Cancer](#)
- [Cervical Cancer](#)
- [Colorectal Cancer](#)
- [Hodgkin Disease](#)
- [Kidney Cancer](#)
- [Leukemia - Acute Lymphocytic \(ALL\)](#)
- [Leukemia - Acute Myeloid \(AML\)](#)
- [Leukemia - Chronic Myeloid \(CML\)](#)

### Related Tools & Topics

- [Learn About Cancer](#)
- [Treatment Topics and Resources](#)
- [Building a Support Network](#)

**Sign In**

Not registered yet?  
[Register now](#) or see [reasons to register](#).

start

> Testa... Windows... Clinical... Contacts... C:\Docu... 002105 ... 11:32 AM Tuesday 2/22/2005

C:\Docu... acrupdat... 022205... Presenta... ACS :: Tr...

ACS :: Clinical Trials - Microsoft Internet Explorer


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Back Forward Stop Home Search Favorites Media Print Mail News RSS Feeds

Address http://www.cancer.org/docroot/ETO/ETO\_6.asp?sitearea=ETO Go

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**Making Treatment Decisions**

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**Making Treatment Decisions**

**Clinical Trials**

Find out how you can use our free, confidential matching service for cancer clinical trials nationwide as well as why a cancer clinical trial is important, how you can benefit, and what you should ask your doctor.

**Clinical Trials: What You Need to Know**

Learn why clinical trials are important, how they're used, and what to expect.

**Clinical Trials: Related Topics**

- [Clinical Trials Patient Worksheet](#)  
Questions to ask your doctor if you are thinking about taking part in a clinical trial.
- [State Laws Regarding Clinical Trials Coverage](#)  
Does your state have laws about insurance coverage of clinical trials? Find out here.

**Find a Cancer Clinical Trial**

This free and confidential service can help you locate a cancer clinical trial, based on your situation and personal preferences. Begin by entering information about your cancer and with a few clicks you can see a list of clinical trials that may be appropriate for you. Brought to you by the American Cancer Society and EmergingMed.

- [Use our matching service](#)

**Clinical Trials Web Sites**

The following Web sites offer information and

start > Testa... Windows... Clinical... Contacts... C:\Docu... 002105... 11:32 AM Tuesday 2/20/2008


American College of Surgeons: Cancer Programs: National Cancer Data Base (NCDB) - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Media Print Options

Address http://www.facs.org/cancer/ncdb/index.html Go


Commission on Cancer Search Web PageRank 215 blocked Options Commission on Cancer



# NATIONAL CANCER DATA BASE (NCDB)

Home Page Members Only Table of Contents Search This Site Contact Us Site Index

American College of Surgeons



## National Cancer Data Base

- What is the NCDB?
  - Quality Information Committee (QIC) and Disease Site Teams
- Statistics
  - Public Access NCDB Benchmark Reports - Tip Sheet
  - Public Access NCDB Survival Reports
  - Hospital Commission Benchmark Reports (Login Required) - Tip Sheet
  - NCDB Analytic Cases: Diagnosis Year 2001: Disease Site by AJCC Stage Table

start

Taskbar: > Testa... Windows... Clinical... Contacts... C:\poo... 002205... C:\Deu... acrupdat... 002205... Presenta... American...

System Tray: 11:04 AM Tuesday 2/22/2006

# What do we need?

- Nationwide commitment to make systems operational and effective
- Strike a balance to protect privacy and allow access to information to improve quality of care
- Advance science based programs that improve health without compromising respect for the individual
- Rules that are clearly understood
- Guidance that permits us to share information across state borders





The American Cancer Society hopes that policies will be developed which:

- Support our mission to educate the public
- Permit collection of data to improve the quality of cancer care
- Allow conduct of research using the internet

## Thank you...

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### **EmergingMed:**

Courtney Hudson



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