Privacy and Health Information Technology:

The American Cancer Society Experience

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National Committee on Vital Health Statistics
Washington, DC
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American Cancer Society®

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

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

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American Cancer Society

Search Go

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No matter who you are,

We can help.

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

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

Internet

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www.acscsn.org

The Cancer Survivors Network, supplying information, resources, chat, stories, discussion forum - Microsoft Internet Explorer

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Cancer Survivors Network®

CSN Home

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Tuesday, February 22, 2005

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- CSN Home
- About CSN
- Announcements
- Talk Shows & Stories
- Expressions Gallery
- Personal Web Pages
- Discussions and Chat
- Resource Library

- Sign In / Register
- Your CSN Start Page
- Give Us Your Comments

- Help

Welcome

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

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!

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

IMPORTANT NOTE: Login information is case sensitive.

username

password Go

or, login via our secure server.

forget your password?

Not a CSN Member Yet? Register here.

Free CSN Newsletters

Registered CSN members receive a free monthly CSN eNewsletter!

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ACS :: Treatment Decision Tools - Microsoft Internet Explorer

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Address http://www.cancer.org/docroot/ETO/eto_1_1a.asp

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American Cancer Society

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.

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ACS :: Clinical Trials - Microsoft Internet Explorer

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American Cancer Society

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

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

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

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NATIONAL CANCER DATA BASE (NCDB)

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American College of Surgeons

ACS

- Public Resources
- About Commission on Cancer
- CoC News and Events
- CoC Meetings
- Approvals Program
- Cancer Liaison Program
- Education Activities
- National Cancer Data Base (NCDB)
- Submit NCDB Data
- HIPAA
- FIPS
- Standards
- Approvals
- Data

NCDB

National Cancer Data Base

- What is the NCDB?
  - Quality Integration Committee (QIC) and Disease Site Teams

Statistics

- Public Access NCDB Benchmark Reports–Tip Sheet
- Public Access NCDB Survival Reports
- Hospital Comparison Benchmark Reports (Login Required)–Tip Sheet
- NCDB Analytic Cases: Diagnosis Year 2001: Disease Site by AJCC Stage Table

Internet

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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…

American Cancer Society:

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