## Privacy and Health Information Technology:

The American Cancer Society Experience

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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

1.5 million visitors hosted each month

## 1-800-ACS-2345

100,000 callers each month

#### **Health Information Confidentiality Principles:**

The American Cancer Society:

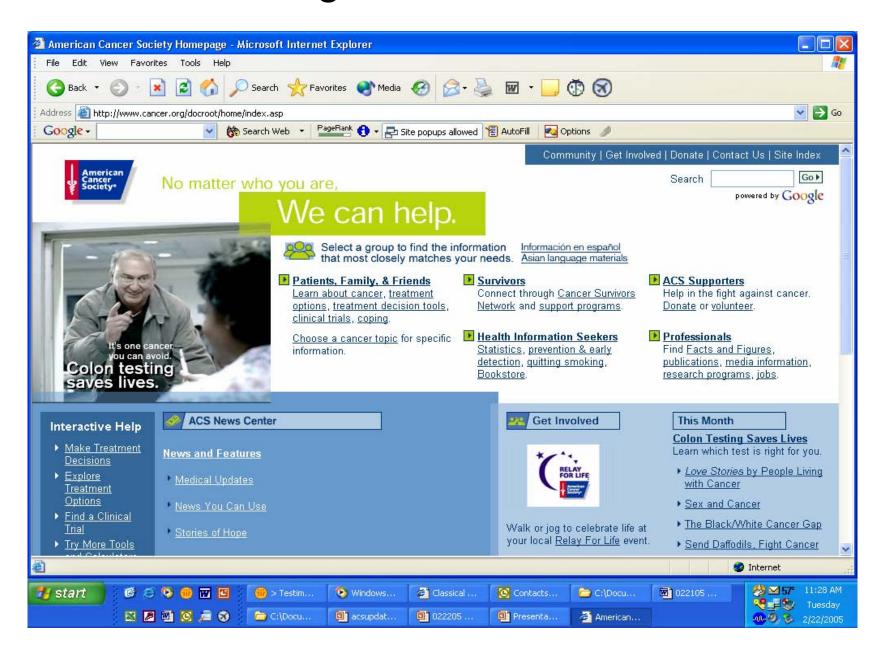
- Recognizes that individuals entrust the Society with their health information, and acknowledges individuals' rights to confidentiality and access to their health information;
- Accepts its obligation to protect these rights and to institute an organization-wide system for adherence;
- 3) Acknowledges 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):

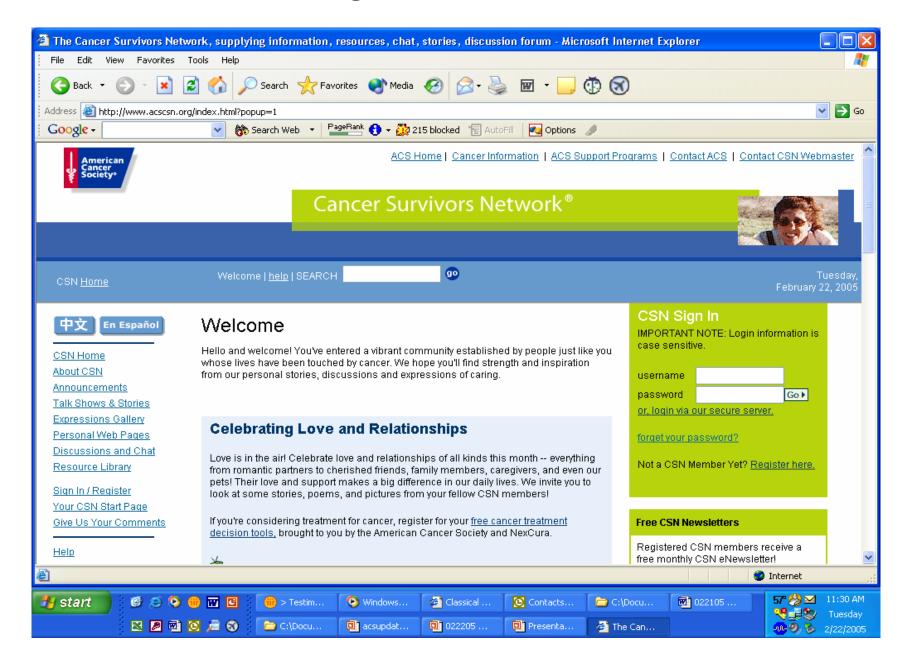
The American Cancer Society:

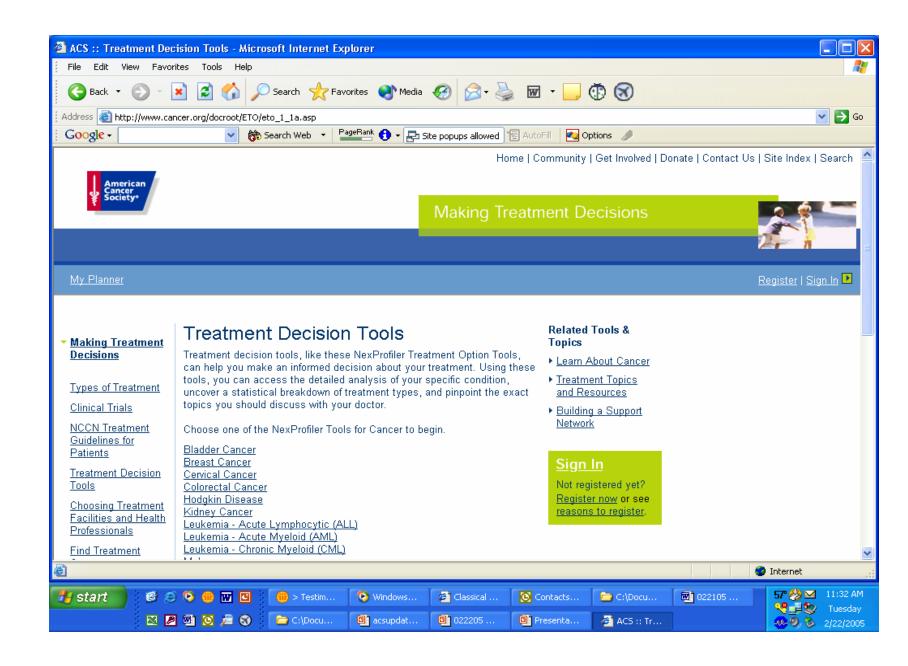
- Recognizes that certain activities involving research participants will require adherence to standards that exceed these principles; and
- 5) Is committed to educate and hold accountable all individuals who work on its behalf regarding the Society's obligation to protect the confidentiality of individual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

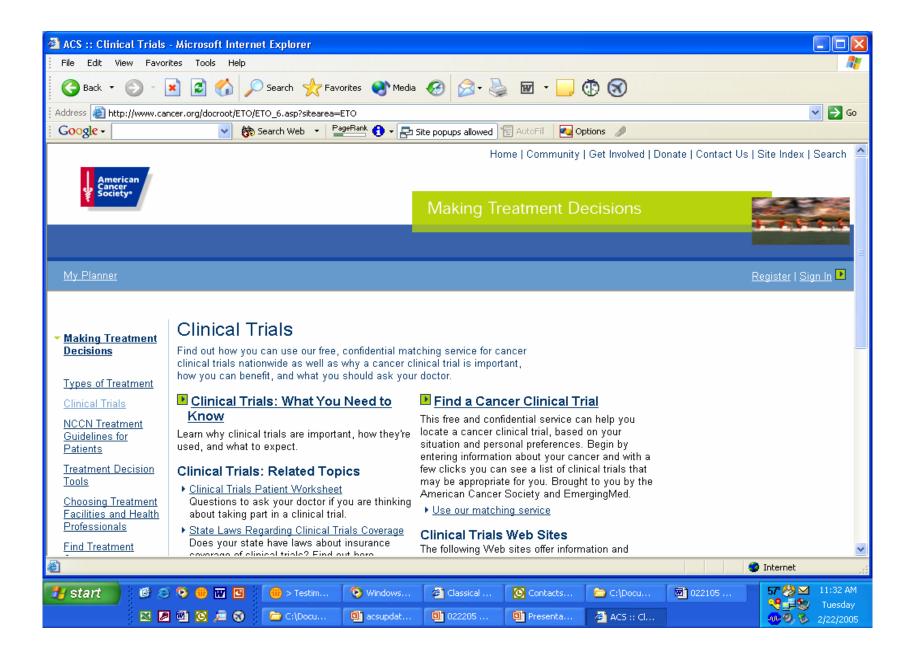
#### www.cancer.org

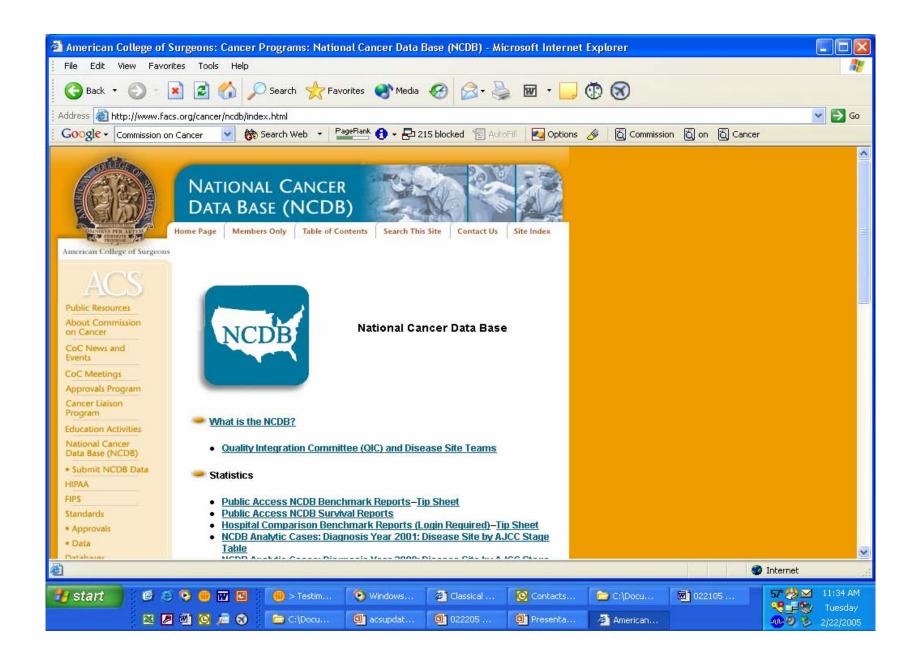


#### www.acscsn.org









#### 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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