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Coordinating Systems to Accelerate Successes
Against Cancer

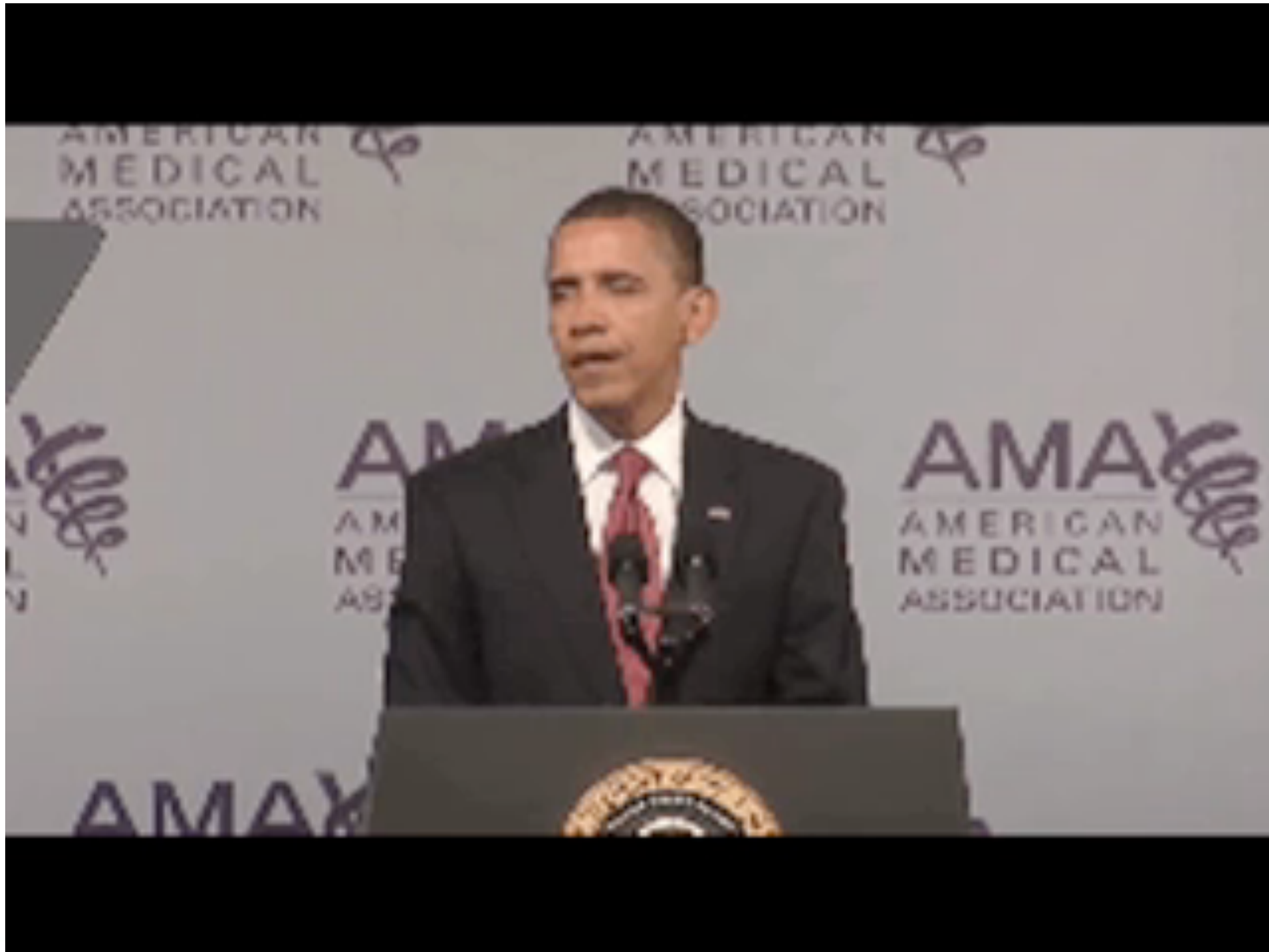
Bradford Hesse

National Cancer Institute



NATIONAL
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President Obama to the American Medical Association



June 15, 2009

Why Are Electronic Records So Important?

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ANNUAL CONFERENCE
MAY 20 – MAY 21

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From Biomedical Research to People's Health**

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Electronic Health Records and Economic Recovery

David M. Cutler
Department of Economics
Harvard University

Why Are Electronic Records So Important?



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The Challenges Facing the United States

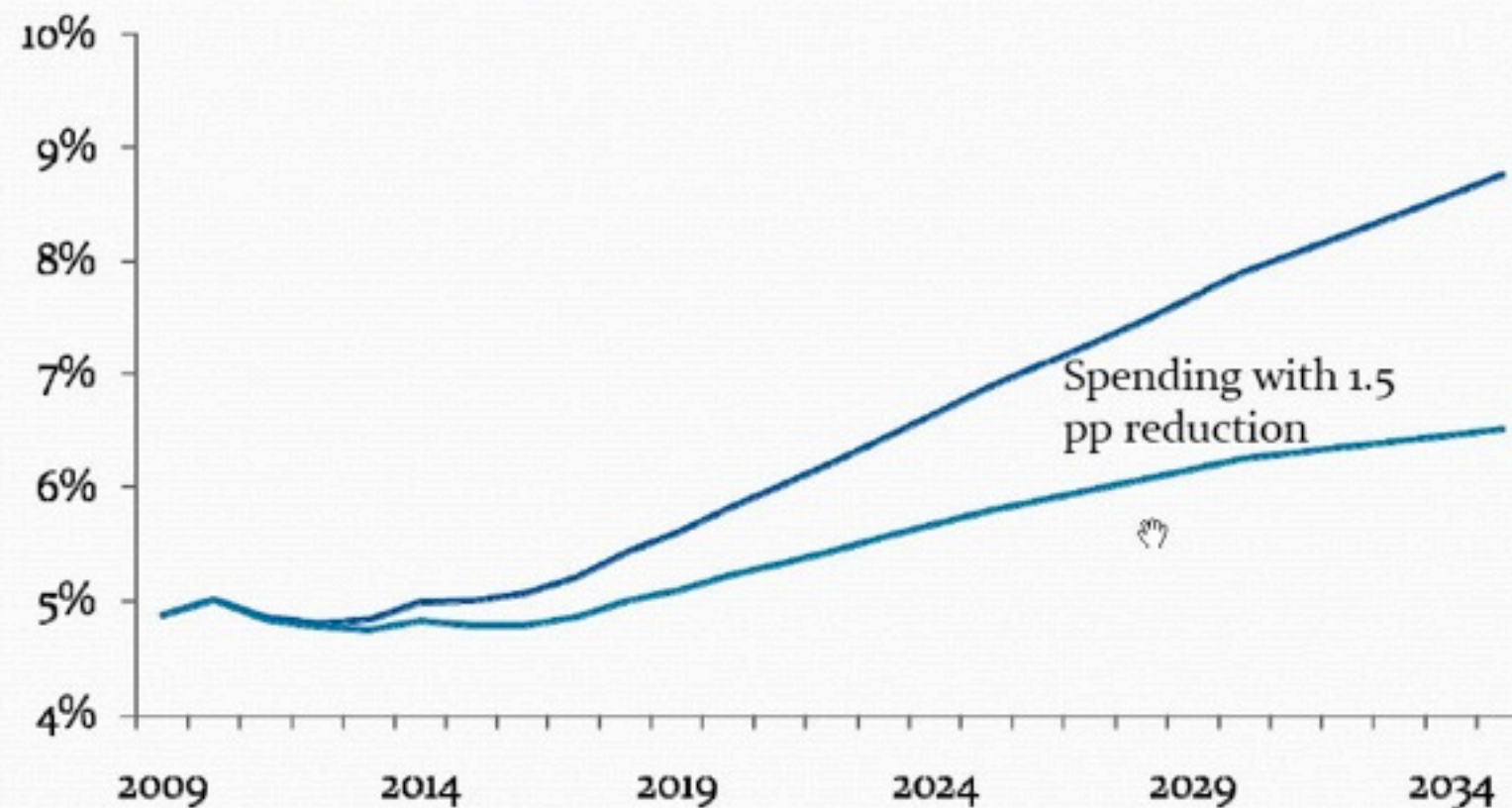
- Spend more now – any spending is good in a recession
- Put us on a path towards long-term economic growth
 - Investment in key infrastructure
 - Solving the Federal budget
- Both of these lead to health care IT
 - ARRA: \$19 billion in health IT with goal of 90% uptake by 2014

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A modest increase in productivity
would significantly 'bend the curve'

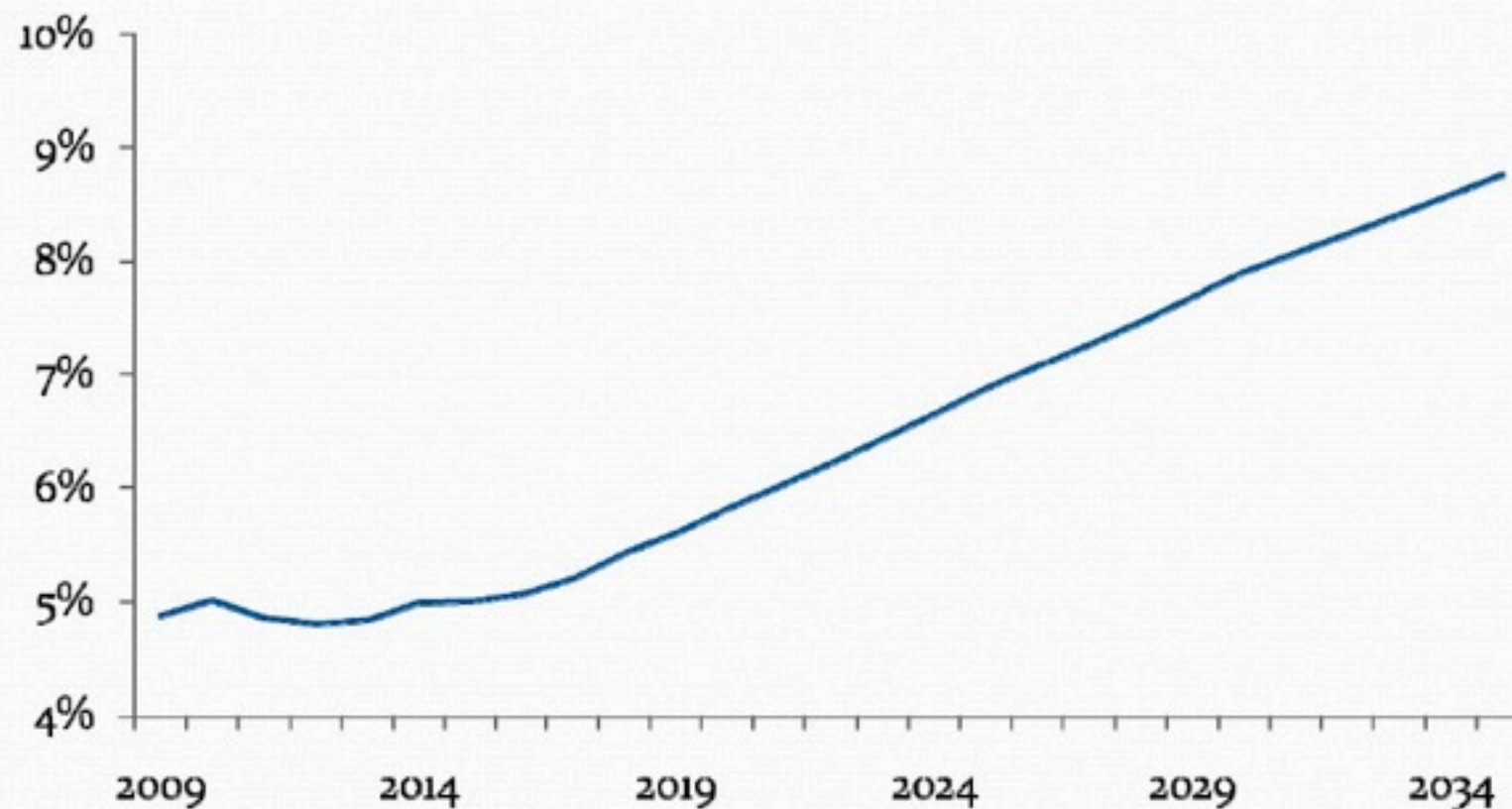


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Health care is projected to blow up
the Federal budget



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Three lessons about productivity come from industry studies

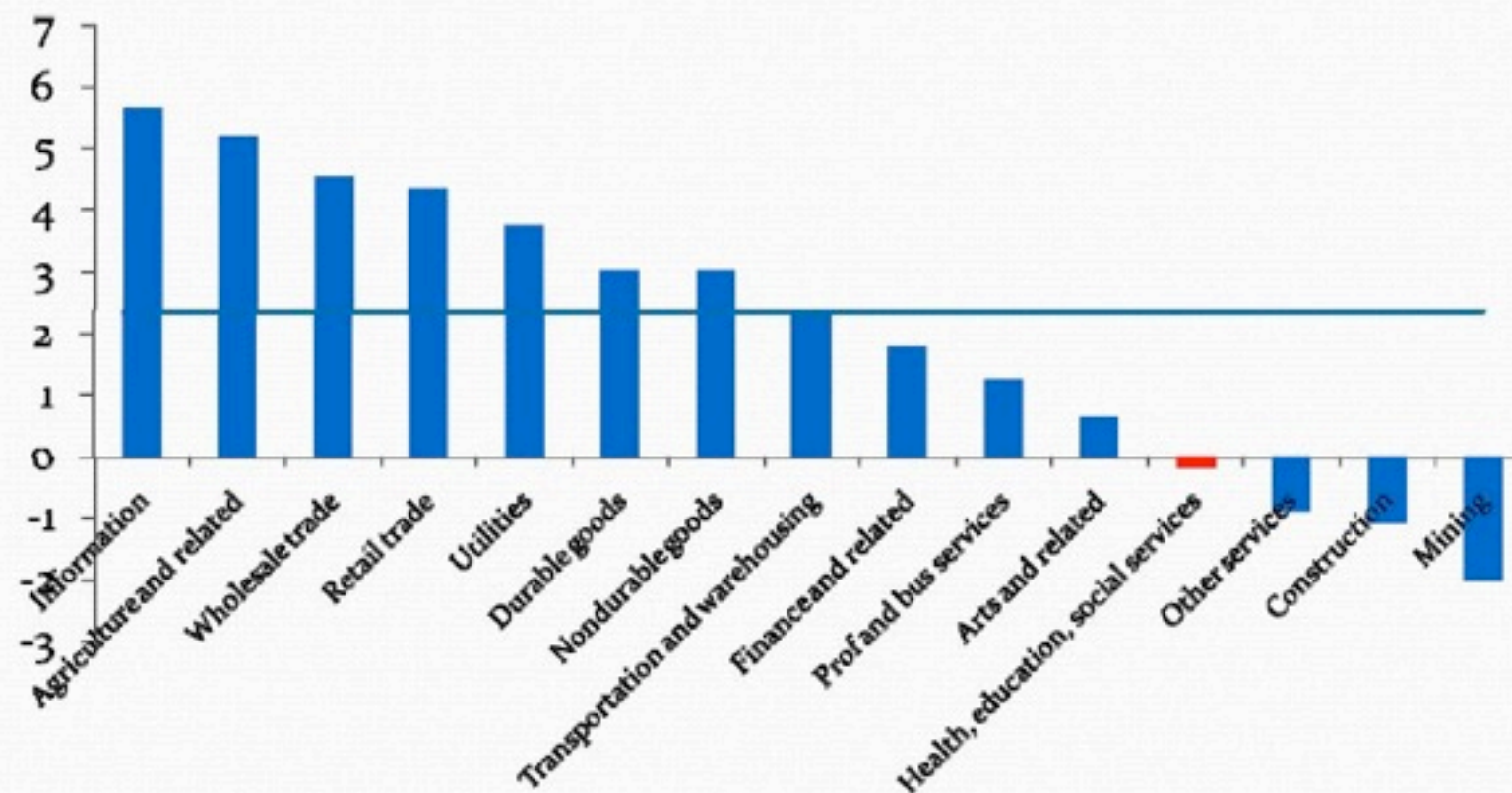
- **Information** – knowing what is done
- **Compensation arrangements** – supporting productivity
- **Worker empowerment** – allowing workers to make changes to production

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Productivity Growth by Industry, 1995-2005



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Conclusion

- Electronic medical records are the beginning, not the end.

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Am J Prev Med. 2007 May ; 32(5 Suppl): S97-103.

eHealth Research from the User's Perspective

Bradford W. Hesse, PhD¹ and Ben Shneiderman, PhD²

¹National Cancer Institute, Bethesda, Maryland ²University of Maryland, College Park, Maryland

Abstract

The application of Information Technology (IT) to issues of healthcare delivery has had a long and tortuous history in the U.S. Within the field of eHealth, vanguard applications of advanced computing techniques, such as applications in artificial intelligence or expert systems, have languished in spite of a track record of scholarly publication and decisional accuracy. The problem is one of purpose, of asking the right questions for the science to solve. Historically, many computer science pioneers have been tempted to ask “what can the *computer* do?” New advances in eHealth are prompting developers to ask “what can *people* do?” How can eHealth take part in national goals for healthcare reform to empower relationships between healthcare professionals and patients, healthcare teams and families, and hospitals and communities to improve health equitably throughout the population? To do this, eHealth researchers must combine best evidence from the user sciences (human factors engineering, human-computer interaction, psychology, and usability) with best evidence in medicine to create transformational improvements in the quality of care that medicine offers. These improvements should follow recommendations from the Institute of Medicine to create a health care system that is (a) safe, (b) effective (evidence-based), (c) patient-centered, and (d) timely. Relying on the eHealth researcher’s intuitive grasp of systems issues, improvements should be made with considerations of users and beneficiaries at the individual (patient/physician), group (family/staff), community, and broad environmental levels.

BACKGROUND

The application of information technology (IT) to issues of personal health and healthcare has had a long and surprisingly complex history within the United States. It was not long after the first mainframe computer systems began automating record keeping that hospitals began applying IT to the tasks of billing and financial record keeping.¹ Yet, in spite of an early application of IT to administrative and actuarial tasks, the challenge of developing a consistent, interoperable system for transporting patients' medical records across health care systems has been an elusive and seemingly intractable goal.² Reasons given for delays in this and other areas of health IT include grappling with competing incentive structures, dealing with issues

Informaticians have generally asked: “What can the computer do?”

Expert systems » MYCIN

Work on MYCIN, an expert system for treating blood infections, began at Stanford University in 1972. MYCIN would attempt to diagnose patients based on reported symptoms and medical test results. The program could request further information concerning the patient, as well as suggest additional laboratory tests, to arrive at a probable diagnosis, after which it would recommend a course of treatment. If requested, MYCIN would explain the reasoning that led to its diagnosis and recommendation. Using about 500 production rules, MYCIN operated at roughly the same level of competence as human specialists in blood infections and rather better than general practitioners.

Nevertheless, expert systems have no common sense or understanding of the limits of their expertise. For instance, if MYCIN were told that a patient who had received a **gunshot wound** was bleeding to death, the program would attempt to diagnose a bacterial cause for the patient's symptoms. Expert systems can also act on absurd clerical errors, such as prescribing an obviously incorrect dosage of a drug for a patient whose weight and age data were accidentally transposed.

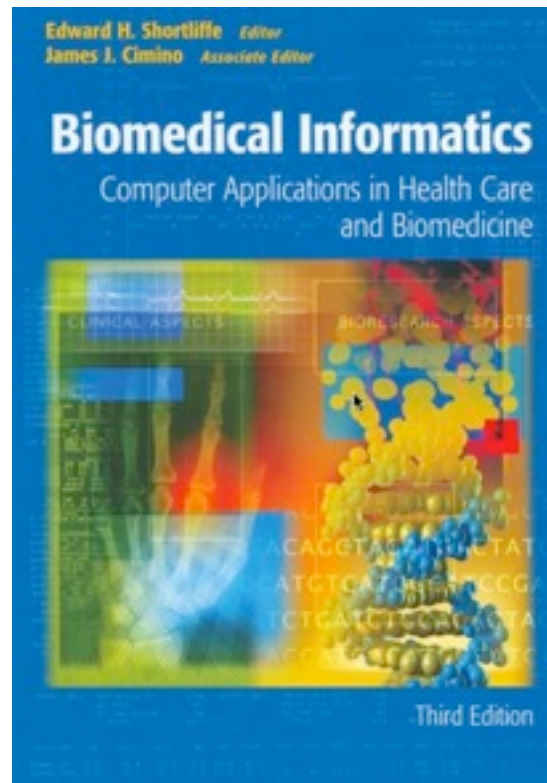
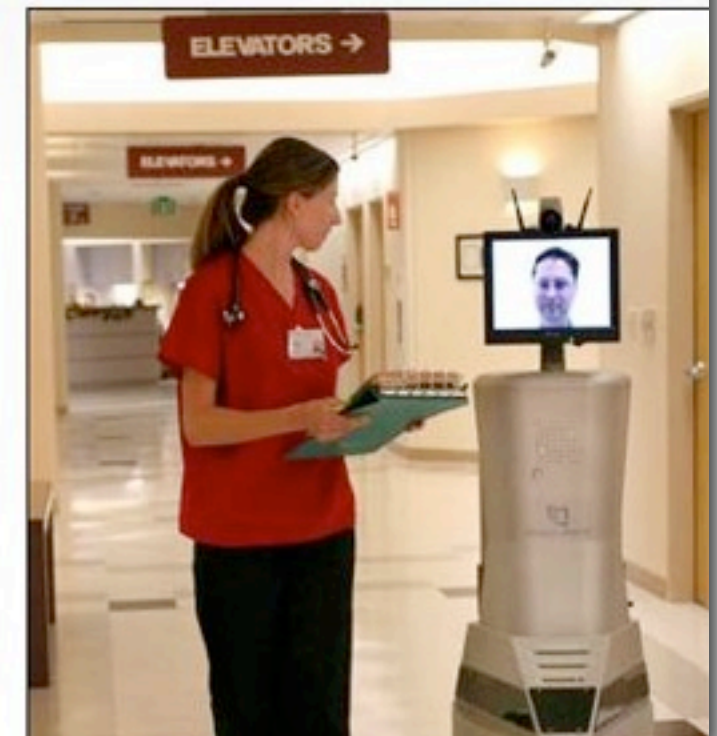
Robot doctor gets thumbs-up from patients

Half of those surveyed prefer virtual visit by their own physician to real visit by unfamiliar doctor

msnbc.com staff and news service reports
updated 1:43 p.m. ET, Tues., May 11, 2004

Which would you rather have come to your hospital room: a doctor you've never met before, or a robot that lets you interact with your personal physician? A new study indicates that many patients would prefer the robot they know to the human they don't know.

The study, conducted by researchers at [Johns Hopkins](#) University and presented Saturday at the **American Urological Association's annual meeting** in San Francisco, focused on how patients reacted to a "rounding robot." Fifteen of the mobile robo-docs, manufactured by California-based **InTouch Health**, have been placed in hospitals and [nursing homes](#).



With Stagnation and Problems in Results

EDITORIALS

Editorials represent the opinions of the authors and JAMA and not those of the American Medical Association.

Computer Technology and Clinical Work Still Waiting for Godot

Robert L. Wears, MD, MS

Marc Berg, MA, MD, PhD

PROCESS-SUPPORTING INFORMATION TECHNOLOGY (IT) has been heralded as an important building block in attempts to improve the quality and safety of health care. Two areas in particular have drawn both attention and funding. The first is clinical decision support; that is, information systems designed to improve clinicians' decision making. The second is computerized physician order entry (CPOE) as a means for reducing medication errors. The literature in these fields has been characterized by frequent reports of success, often accompanied by predictions of a bright new (and near) future; however, the future seems never to arrive. Behind the cheers and high hopes that dominate conference proceedings, vendor information, and large parts of the scientific literature, the reality is that systems that are in use in multiple locations, that have satisfied users, and that effectively and efficiently contribute to the quality and safety of care are few and far between.¹

In this issue of JAMA, 2 articles report results in these areas. Garg et al² provide an updated systematic review evaluating the impact of computerized clinical decision support systems, and Koppel et al³ examine the specific failures introduced by a CPOE system intended (at least in part) to reduce such failures.

The summary by Garg et al of 100 trials of clinical decision support systems over a 6-year span is critical. About two thirds of the studies claimed improved clinician performance, but these assessments were often biased; when the authors were not also the system developers, less than half of the systems showed an improvement. In fact, "grading oneself" was the only factor that was consistently associated with good evaluations.

Clinical decision support systems come in many different forms, have myriad aims, and can be implemented in many ways, so it is fair to ask if these systems can really be approached as a single intervention, as Garg et al do. In addition, lack of improved performance could be due to poorly designed decision technology or to poor use of the technology by clinicians. This, in turn, could be due to a poor human-computer interface or to much simpler factors such as goal

conflicts or lack of time or support among colleagues.⁴ So, it is not clear exactly what is being measured.

In a different design, the study by Koppel et al of users of a single CPOE system in a large academic medical center identified 24 different types of failures of which users were aware; roughly half the participants said these faults occurred from several times per week to daily. While this study examined only the problems, not the successes of CPOE, it serves as a cautionary balance to reports of success, particularly because it studied a mature, widely used, commercially available system, as opposed to a "one-off," single-site system assessed by its own developers.

These results are disappointing but should not be surprising. There is a long-standing, rich, and abundant literature on the problems associated with the introduction of computer technology into complex work in other domains,^{5,6} as well as occasional notes in health care.¹³⁻¹⁵ Clearly, there is no reason to expect health care, which is from an organizational standpoint probably the most complex enterprise in modern society, to be immune to them. Taken together, these 2 studies^{2,3} suggest that important lessons about introducing new technologies into complex work seem to have been missed. For a small but important example, it has long been established in software engineering that systems cannot be adequately evaluated by their developers,¹⁶ a principle that seems to be commonly overlooked in health care. Since roughly 75% of all large IT projects in health care fail,¹⁷ inattention to these lessons is, at best, wasteful of time and resources and, at worst, harmful to patients and clinicians.

To begin to move forward, it is necessary to dispense with the commonly held notion that these problems are simply bits of bad programming or poor implementation that can easily be excised or avoided the next time around. The reality is that many of the difficulties do not result from bad parts of the systems but are inherent in the perspectives and theories of medical work (and the role of IT in this work) that are prevalent among health informaticians and those who make decisions on acquisition and implementation. In

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Corresponding Author: Robert L. Wears, MD, MS, Clinical Safety Research Unit, 10th Floor, Queen Elizabeth the Queen Mother Building, St Mary's Hospital, South Wharf Road, Paddington, London W2 1NY, England (wears@ufl.edu).

See also pp 1197 and 1223.

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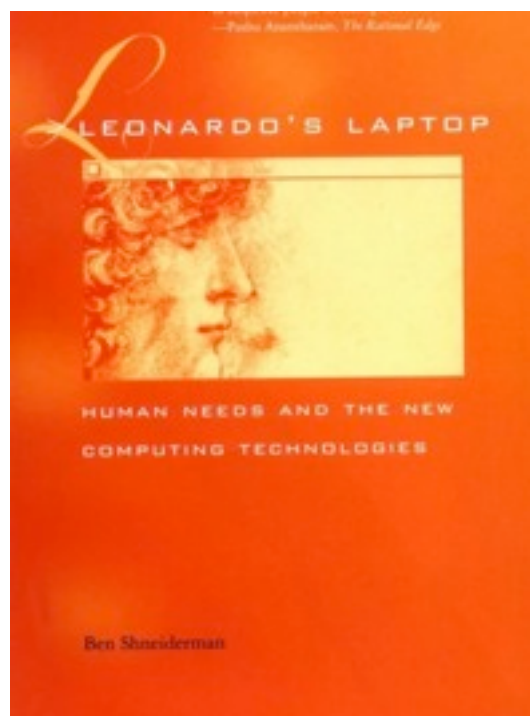
(Reprinted) JAMA, March 9, 2005—Vol 293, No. 10 1261

Two-thirds of studies on clinical decision support systems revealed improvement, but ...

- Reports are biased, improvements only noted by internal (not external) reviewers.
- Some technologies (e.g., computerized ordering) introduce more errors than they resolve.
- Applications rarely scaled up

“What can people do?”

Ben Shneiderman



A transformation from “old computing” to “new computing:”

- A shift in what users value
- A shift from machine-centered automation to user-centered services and tools

Health I.T. is About Patient Outcomes



David Brailer, M.D.

First National Coordinator for Health Information
Technology (2004-2006) and Chairman, Health
Evolution Partners

“Everyone thought Health I.T. was about computers, but we’ve refined that to say that IT is about healthcare — it’s about the experience we really have.”

-David Brailer, 2005

National Research Council Report

January 2009



Computational Technology for Effective Health Care advocates re-balancing the portfolio of investments in health care IT

- Greater cognitive support for physicians, patients, and caregivers
- Observing user-centered design principles
- Accelerating research related to health care in the computer and social sciences and in health/biomedical informatics

American Recovery and Reinvestment Act of 2009

\$19 Billion

TITLE XIII—HEALTH INFORMATION TECHNOLOGY

SEC. 13001. SHORT TITLE; TABLE OF CONTENTS OF TITLE.

(a) **SHORT TITLE.**—This title (and title IV of division B) may be cited as the “Health Information Technology for Economic and Clinical Health Act” or the “HITECH Act”.

(b) **TABLE OF CONTENTS OF TITLE.**—The table of contents of this title is as follows:

Sec. 13001. Short title; table of contents of title.

Subtitle A—Promotion of Health Information Technology

PART 1—IMPROVING HEALTH CARE QUALITY, SAFETY, AND EFFICIENCY

Sec. 13101. ONCHIT; standards development and adoption.

“TITLE XXX—HEALTH INFORMATION TECHNOLOGY AND QUALITY

“Sec. 3000. Definitions.

American Recovery and Reinvestment Act of 2009

\$19 Billion

TITLE XIII—HEALTH INFORMATION TECHNOLOGY

SEC. 13001. SHORT TITLE; TABLE OF CONTENTS OF TITLE.

(a) **SHORT TITLE.**—This title (and title IV of division B) may

- **Key goals*:**
 - Improve quality, safety, & efficiency
 - Engage patients & their families
 - Improve care coordination
 - Improve population and public health; reduce disparities
 - Ensure privacy and security protections

*Adapted from National Priorities Partnership. National Priorities and Goals: Aligning Our Efforts to Transform America's Healthcare. Washington, DC: National Quality Forum; 2008.

Accelerating Success Against Cancer

Clifton Leaf on the Charlie Rose Show: April 29, 2004



Clifton Leaf on the Charlie Rose Show: April 29, 2004



565,650 deaths

Cancer Facts & Figures 2008



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BETWEEN THE LINES | **Jonathan Alter**

What the Next President Can Do

If a war were killing 565,000 Americans a year, you'd hear more than one or two references to it at the party conventions.

Published Sep 6, 2008

From the magazine issue dated Sep 15, 2008

From the Editors (2)

- [Rethinking the War on Cancer](#)
- [Alter: Why Sarah Palin Is Likely to Belly-](#)

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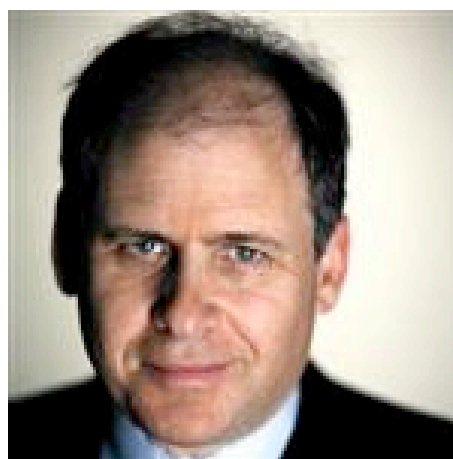
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I'm a four-year [cancer](#) survivor, and when people inquire how I'm feeling nowadays I say "good" and sincerely thank them for asking. But some well-wishers respond awkwardly. One politician I know has me in his mental file under "cancer" and accompanies his hearty hello with "Glad you beat it!" As anyone who has had advanced cancer can tell you, this is understandable but unhelpful. It also reflects why politicians are still so out of touch about the disease.

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THE OBAMA-BIDEN PLAN TO COMBAT CANCER

Nearly 1.5 million Americans are expected to be diagnosed with cancer this year, joining over 10 million Americans who have experienced cancer in their lifetime.¹ Fighting cancer cost families and businesses \$78 billion in medical costs last year, and the overall cost of cancer to our economy was estimated to be over \$200 billion.² Barack Obama understands firsthand the toll cancer takes on families – his mother died from ovarian cancer in her early 50s and his grandfather battled prostate cancer. Barack Obama has spent his career fighting to improve prevention and treatment of cancer. As an Illinois State Senator, Obama passed laws to mandate insurance coverage of colorectal cancer examinations, ensure Medicaid coverage for treatment of breast and cervical cancers, promote early detection of prostate and testicular cancers, and helped create the Illinois Task Force on Cervical Cancer Elimination. As United States Senator, he has fought for increased funding for cancer research, and championed genomics and personalized medicine to identify new and better treatments for cancer and other diseases. As president, Barack Obama will build upon his career-long efforts and launch a new campaign to combat cancer and provide greater lifetime support to cancer survivors and their families.

Double Funding for Cancer Research: The National Institutes of Health (NIH), National Cancer Institute (NCI) and Centers for Disease Control and Prevention (CDC) have made significant advances in understanding cancer biology, and translating that knowledge into effective prevention programs, diagnostics, treatments and cures. Notably, this knowledge has also benefited individuals with other diseases, such as autoimmune disorders. Despite these advances, cancer funding has stagnated in recent federal budgets.³ Barack Obama and Joe Biden are committed to reversing this trend, and providing our nation's scientists with the resources they need to expand and accelerate bench-to-bedside research that will lead to enhanced prevention and diagnostic tools and innovative treatments. The Obama-Biden plan will double federal funding for cancer research within 5 years, focusing on NIH and NCI. Obama and Biden will also work with Congress to increase funding for the



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Ensure All Americans Have Affordable, Accessible and Quality Health Care: Individuals who lack health insurance or are underinsured receive fewer preventive cancer screenings, have a greater likelihood of being diagnosed with late stages of cancer, and experience poorer health outcomes than cancer patients who have adequate insurance.⁴ The Obama-Biden administration will ensure affordable health coverage for all Americans. His plan maintains patient choice, and establishes a National Health Insurance Exchange with a range of private insurance options as well as a new public health plan to allow individuals and small businesses to buy affordable and accessible health coverage similar to that available to federal employees. The Obama-Biden health plan will provide tax credits to people so they can afford health care and will reduce the typical family's medical expenditures by \$2,500 per year while providing them with more health care options and greater security.

Ensure All Americans Have Access to Preventive Health Care: The Obama-Biden health plan will ensure that all Americans have access to preventive health care services. Their proposal creates a voluntary national pool, the National Health Insurance Exchange, comprised of a range of private plans and a new public plan.

- Access to preventive care
- Evidence-based quality improvement
- Support advances in personalized medicine
- Improve federal coordination of research, treatment, and awareness
- Provide new supports for cancer survivors and their families

National Cancer Institute

*Recommendations from the
NCI-designated Cancer Center Directors*

ACCELERATING SUCCESSES AGAINST CANCER

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health

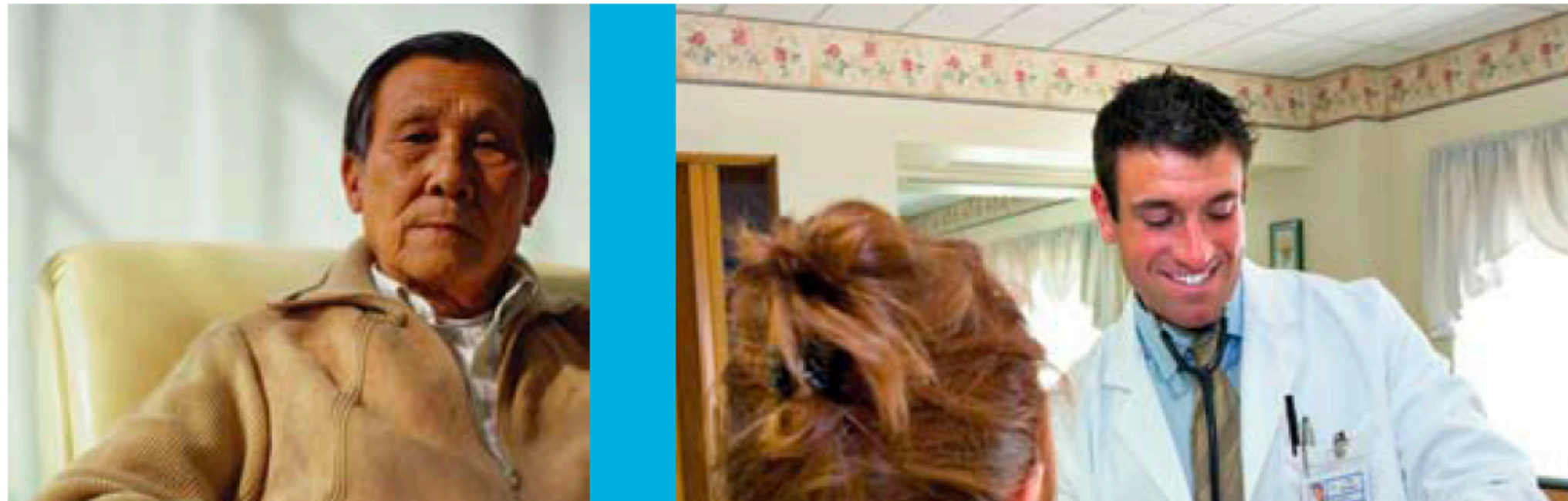
NCI Cancer Center Directors' Report, 2006

Economists at UIC: 1% reduction in cancer deaths = \$400 billion savings

and 3) re-engineering the clinical research enterprise and incorporating community-based physicians, in order to place more patients in innovative clinical trials. The Nation's Cancer Centers and academic cancer research programs are leading the way in all three of these areas, and have been doing so for decades. By their very nature, research programs in NCI-designated Cancer Centers bring together basic, clinical, and population scientists to focus on cancer. Since their inception, the Cancer Centers have been peer-reviewed and scored by NCI based upon the strength of their

and cancer is a disease whose risk increases with aging. We can substantially reduce deaths from cancer just by broadening the application of knowledge we have today. By expanding our knowledge through further research, even greater gains are well within our reach.

The total impact of cancer on health is high. It was recently reported that for Americans under the age of 85, cancer is the leading cause of death. The American Cancer Society reported that last year there were 1,399,790 new cases of cancer and 564,830 deaths. Economists at the University of



“We can substantially reduce deaths from cancer just by broadening the application of knowledge we have today...”

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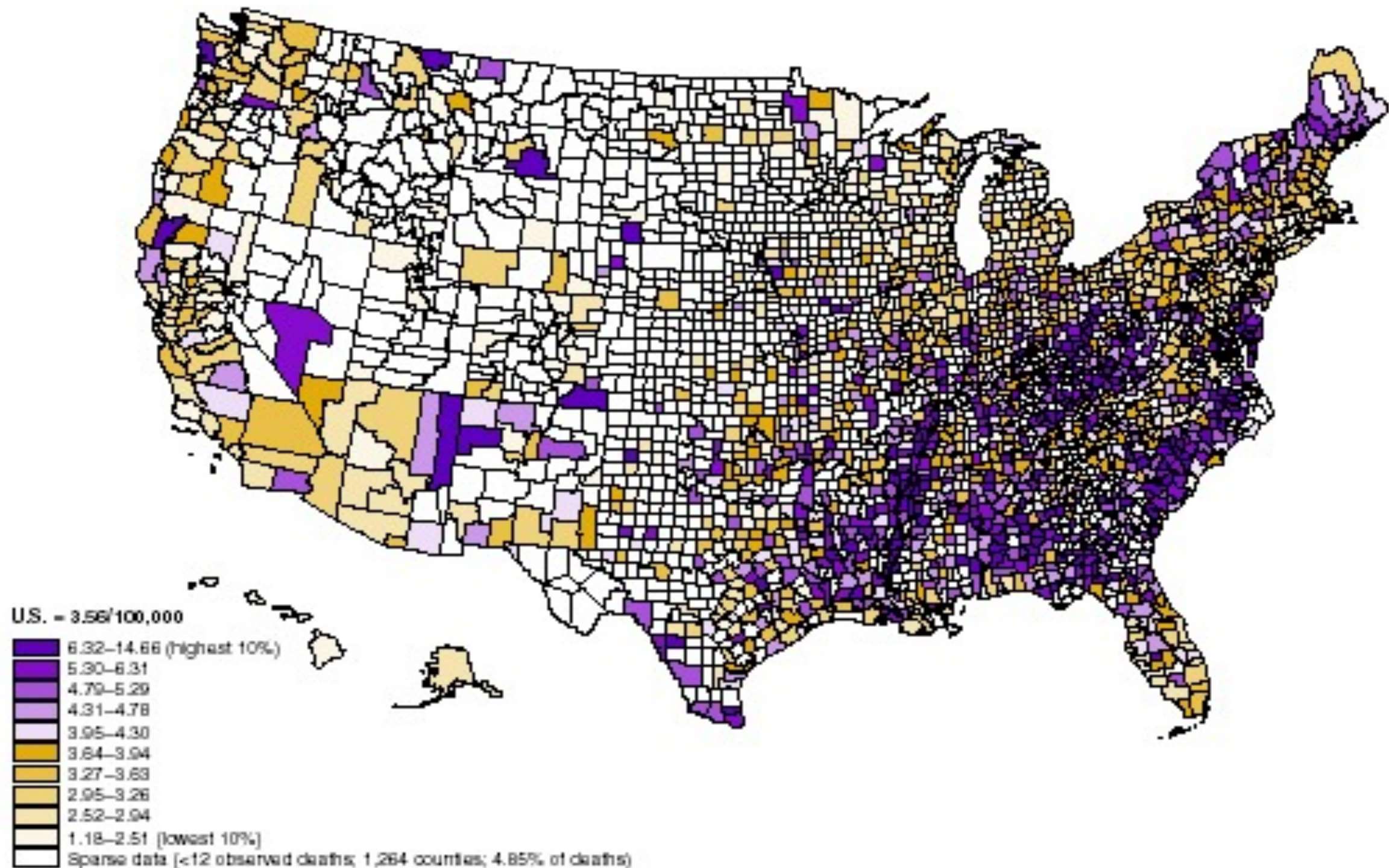
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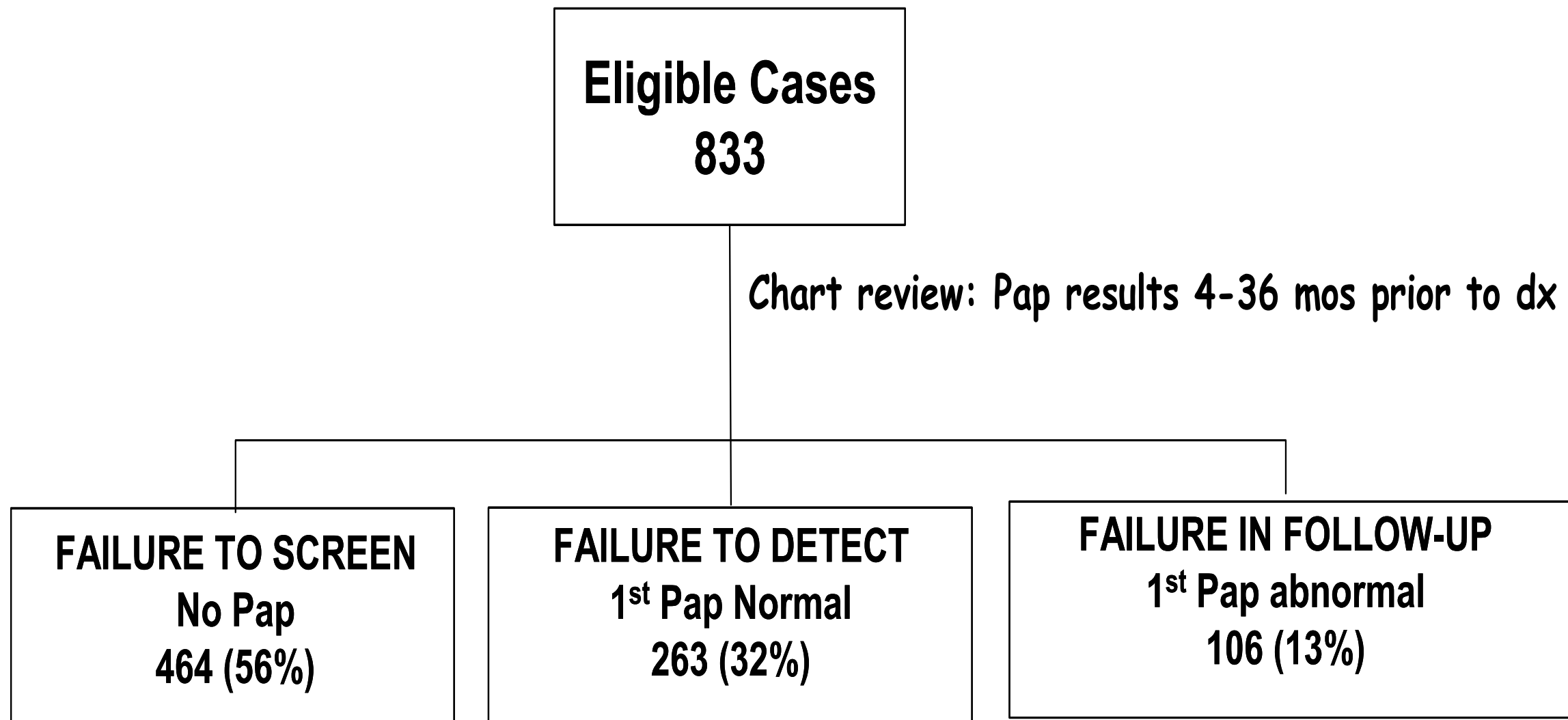


“E.g., No One Should Die from Cervical Cancer in 21st Century”

Map 1. Cancer Mortality Rates by County (Age-adjusted 1970 U.S. Population)
Cervix Uteri: All Races, Females, 1970–1998

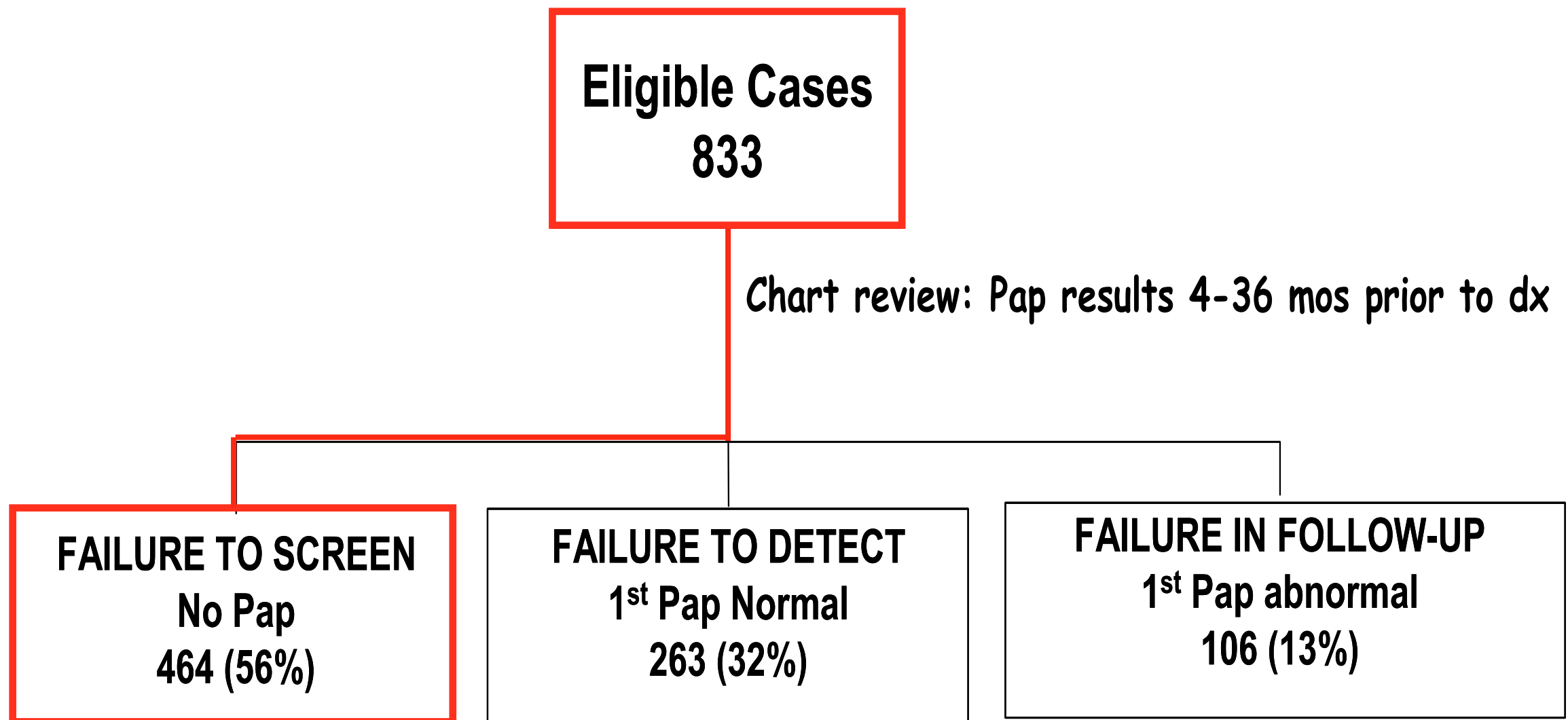


Case Report: Late Stage Cervical Cancer



Source: Leyden WA, Manos MM, Geiger AM, Weinmann S, Mouchawar J, Bischoff K, Yood JG, Taplin SH (2005). Cervical cancer in women with comprehensive health care access: Attributable factors in the screening process. JNCI, 97(9), 675-683.

Case Report: Late Stage Cervical Cancer



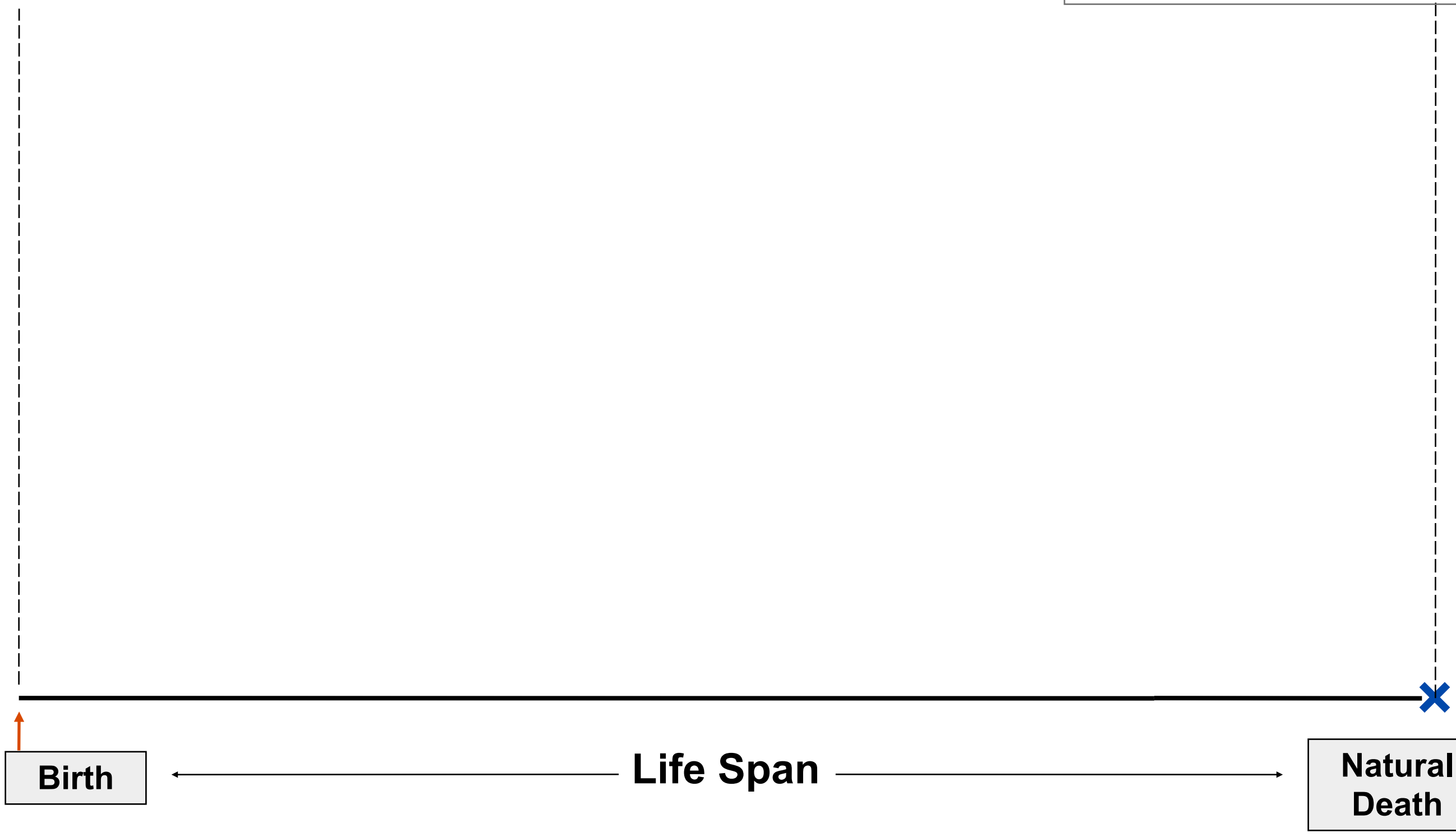
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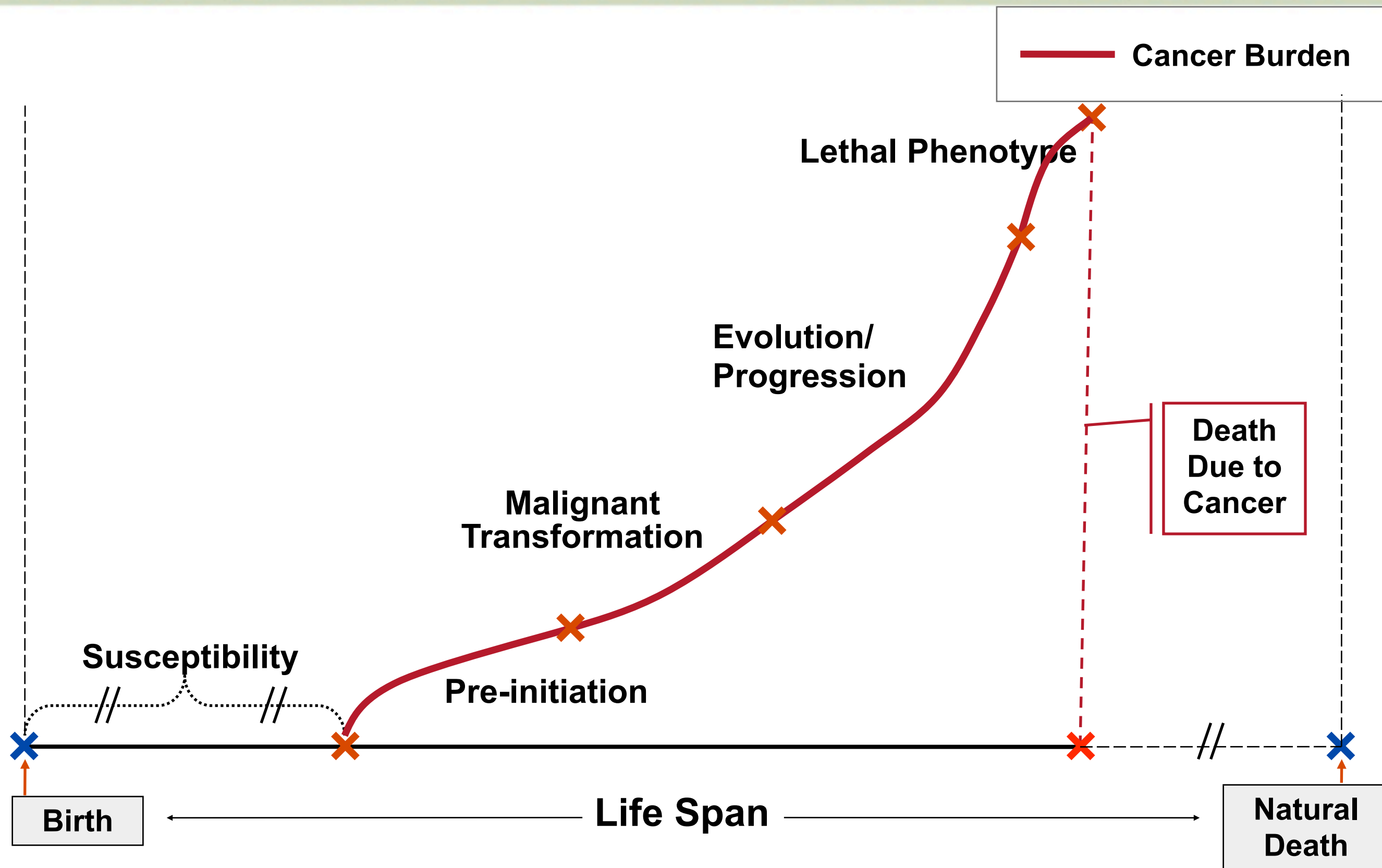
Etiology & Progression of Cancer

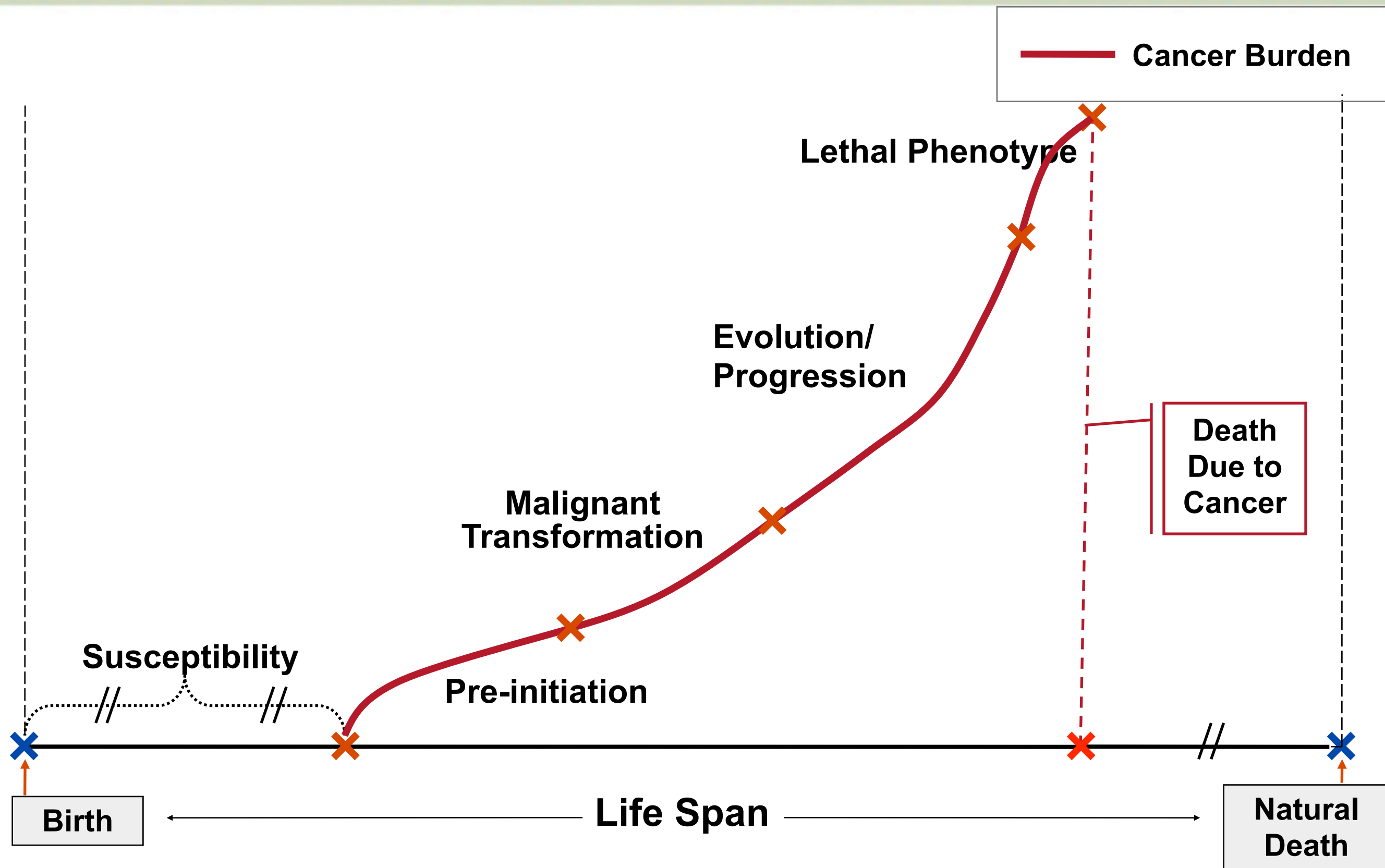
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Public Health Focus

- FDA Letter to Iovate Health Sciences, April 30, 2009
- FDA Warns Consumers Not to Use Dietary Supplements Labeled Hydroxycut because of the Potential Risk of Severe Liver Injury
- Letter to Healthcare Professionals on the Potential Risk of Severe Liver Injury from the Use of Hydroxycut Dietary Supplements
- Peanut Product Recall Widget
- Photos: FDA Warns Consumers Not to Use Skin Products Made by Clarcon Due to Bacterial Contamination Risk
- Questions and Answers: Hydroxycut

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- Comment on FDA's Regulation of Tobacco Products

FDA & Tobacco Regulation

On June 22, 2009, President Barack Obama signed the Family Smoking Prevention and Tobacco Control Act (PDF, 350 K). This historic legislation grants authority to regulate tobacco products to the U.S. Food and Drug Administration. FDA looks forward to taking on this challenge and in doing so will partner with public health leaders at our sister agencies, at the state level, and in localities all around the country. FDA will perform its duties by using the best available science to guide the development and implementation of effective public health strategies to reduce the burden of illness and death caused by tobacco products. FDA will seek input from the public as we begin working to implement the Act. Read and comment on the Federal Register Notice and Request for Comments on the Regulation of Tobacco Products.

Smoking & Tobacco

- Health Issues
- Quitting Smoking
- Regulating Tobacco
- Surgeon General
- Dependency

Get & Share

Avert or Delay its Onset

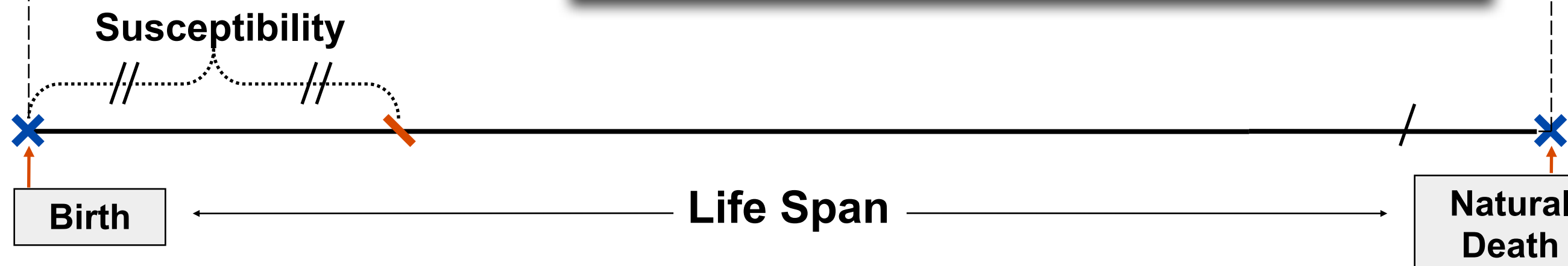


Figure E2. U.S. death rates for common cancers: 1975-2003

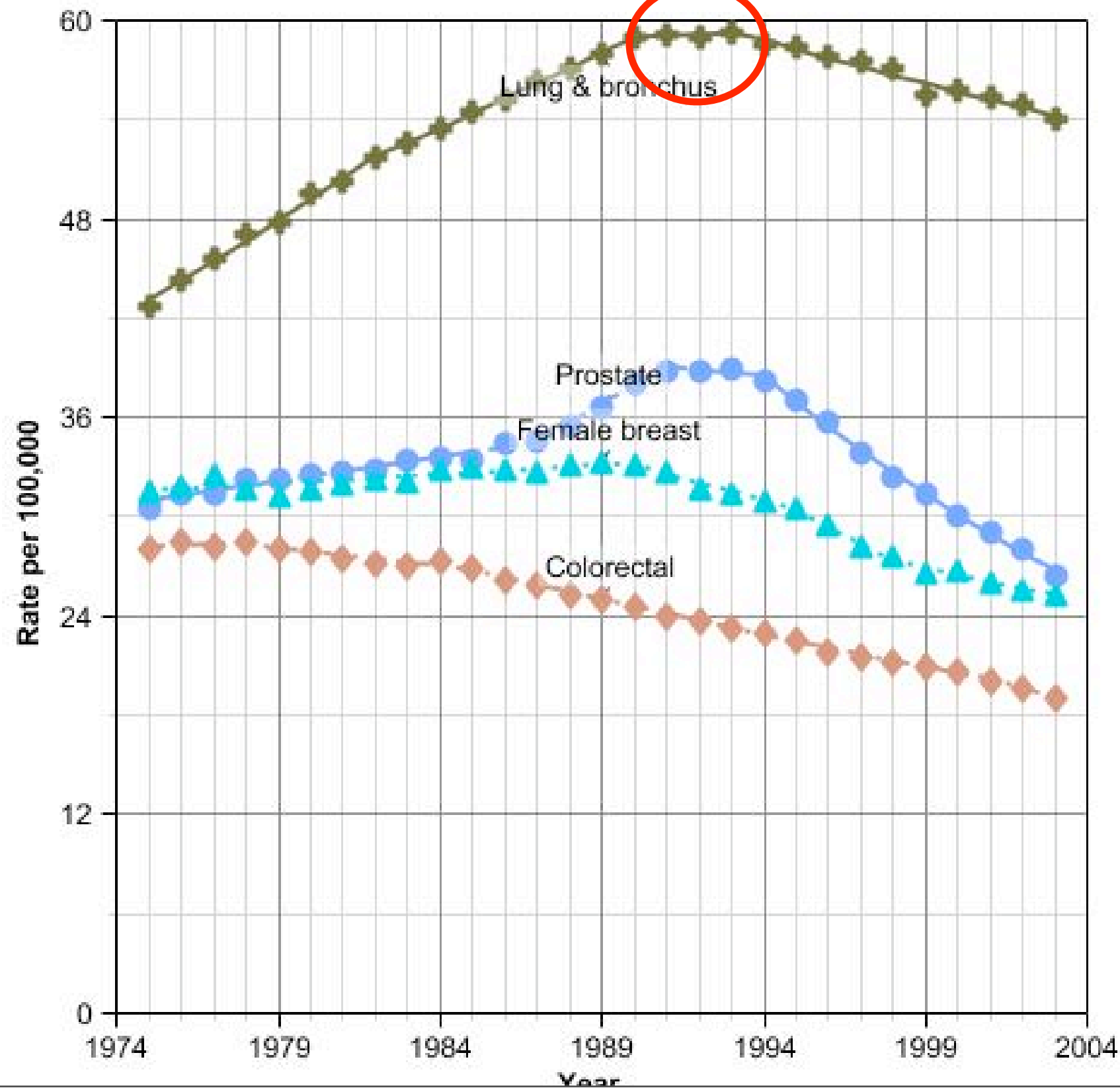
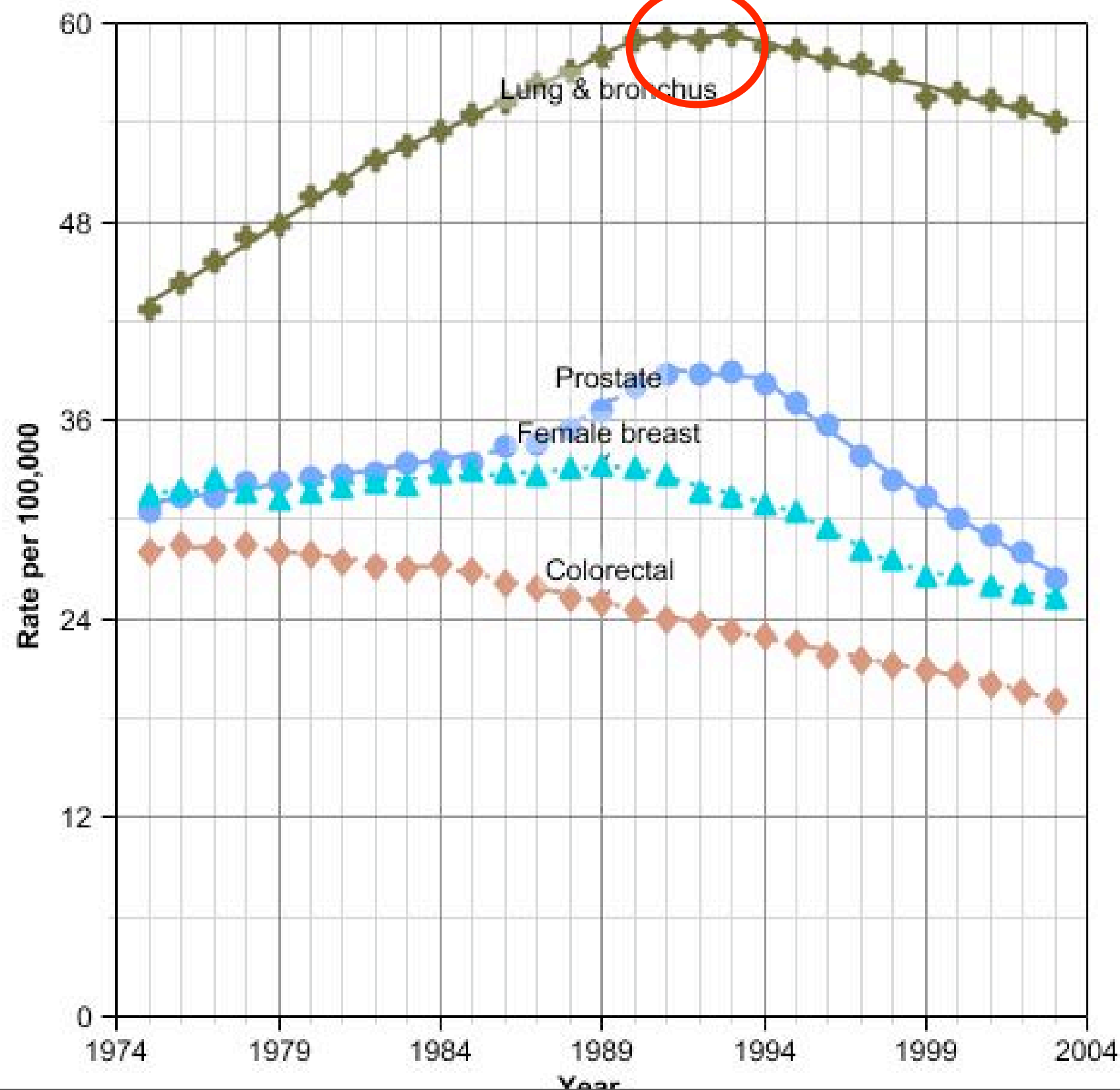
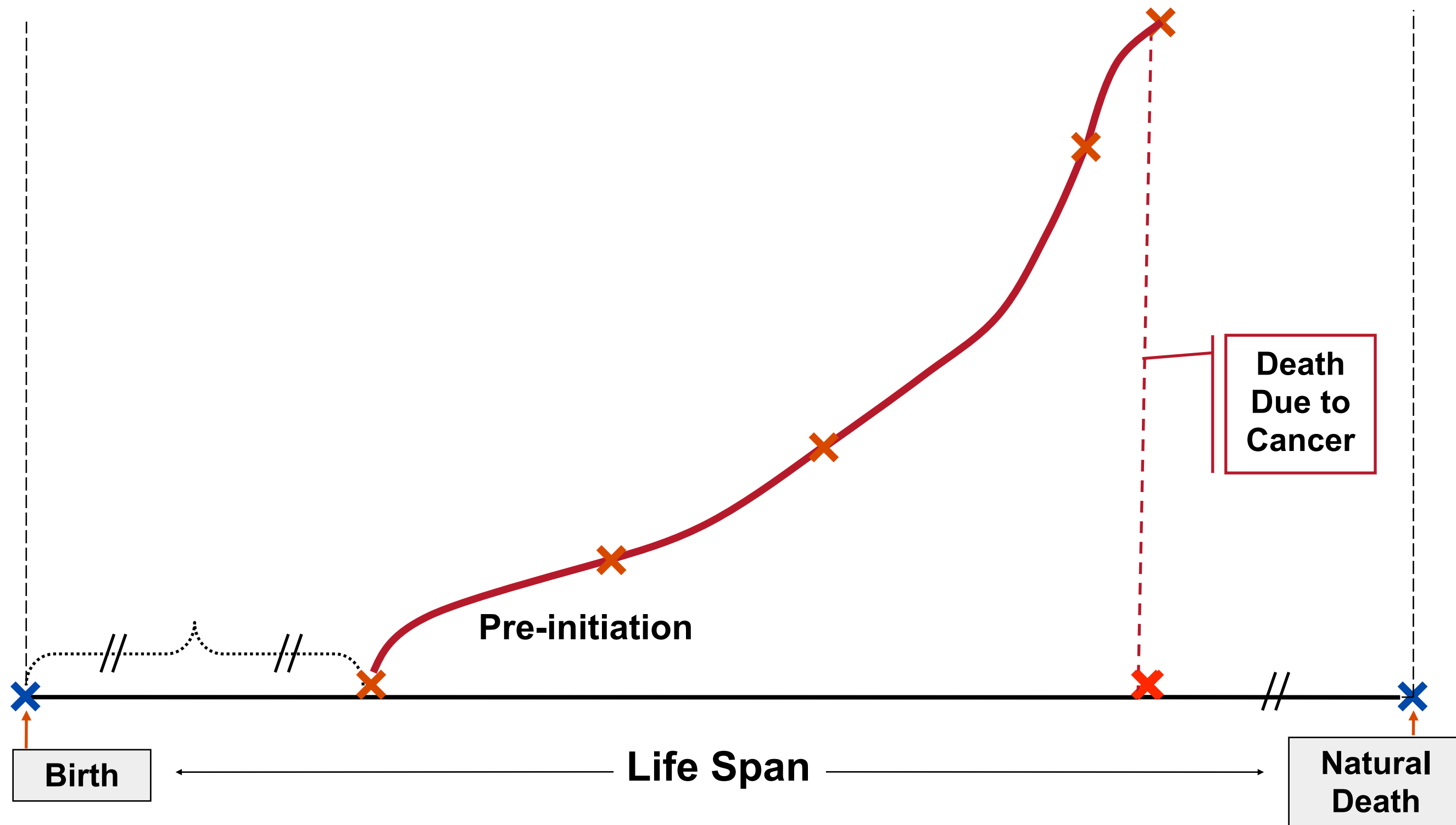


Figure E2. U.S. death rates for common cancers: 1975-2003





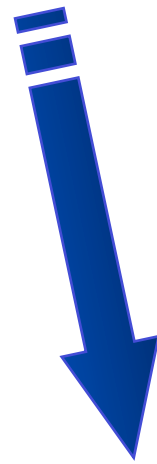


National Cancer Institute

colonoscopy (KOH-luh-NOS-koh-pee)

Examination of the inside of the colon using a colonoscope, inserted into the rectum. A colonoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease.

[Enlarge](#)



*Detect and
Eradicate its
Presence*

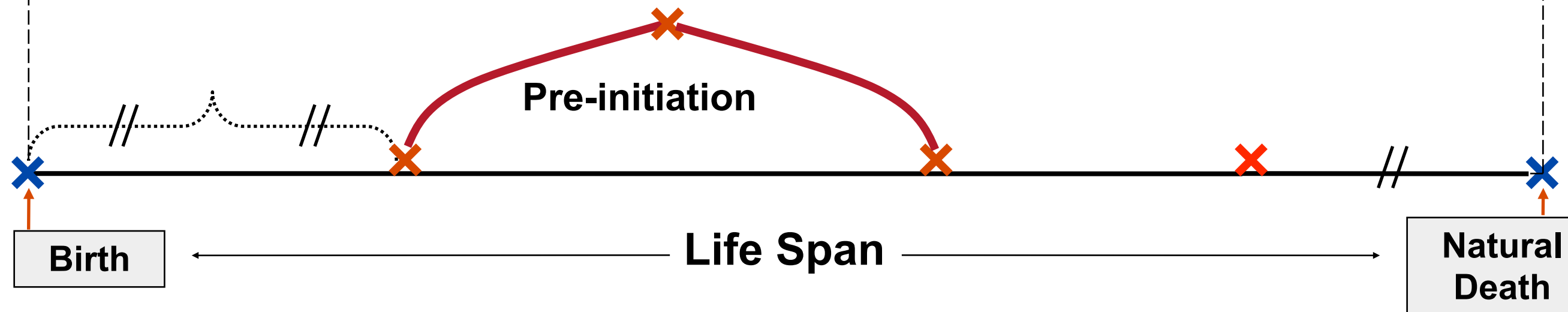


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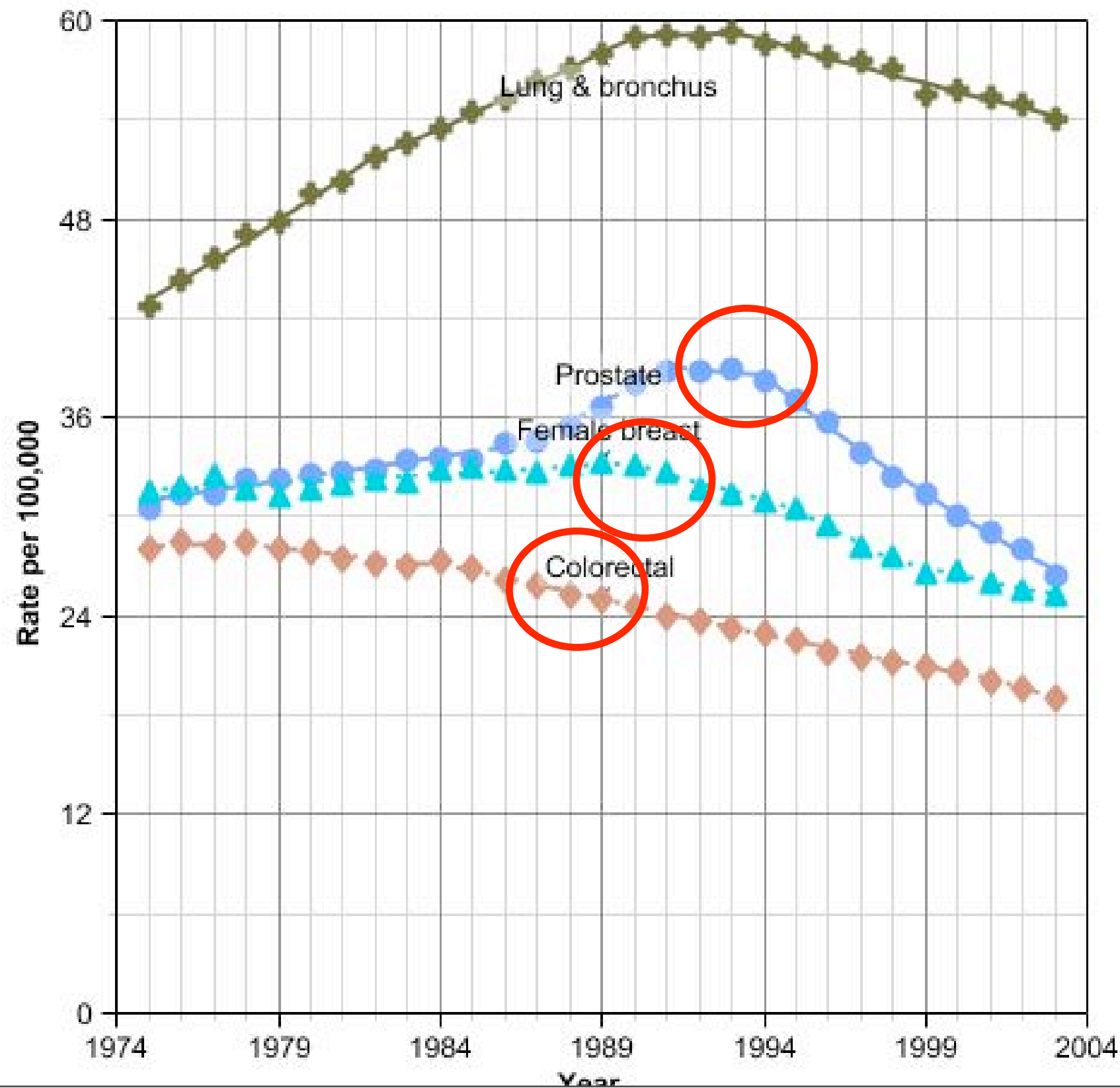
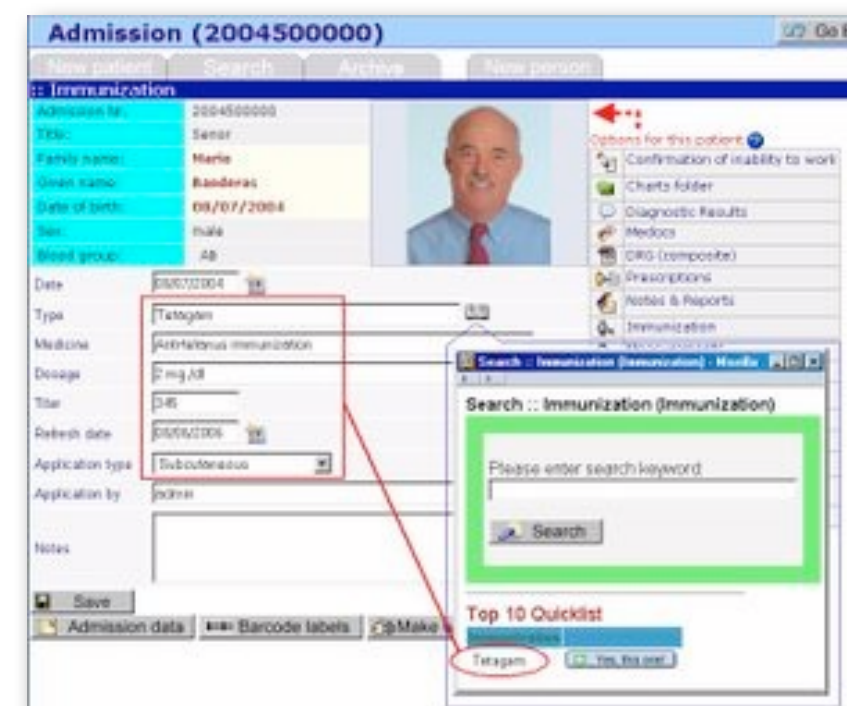
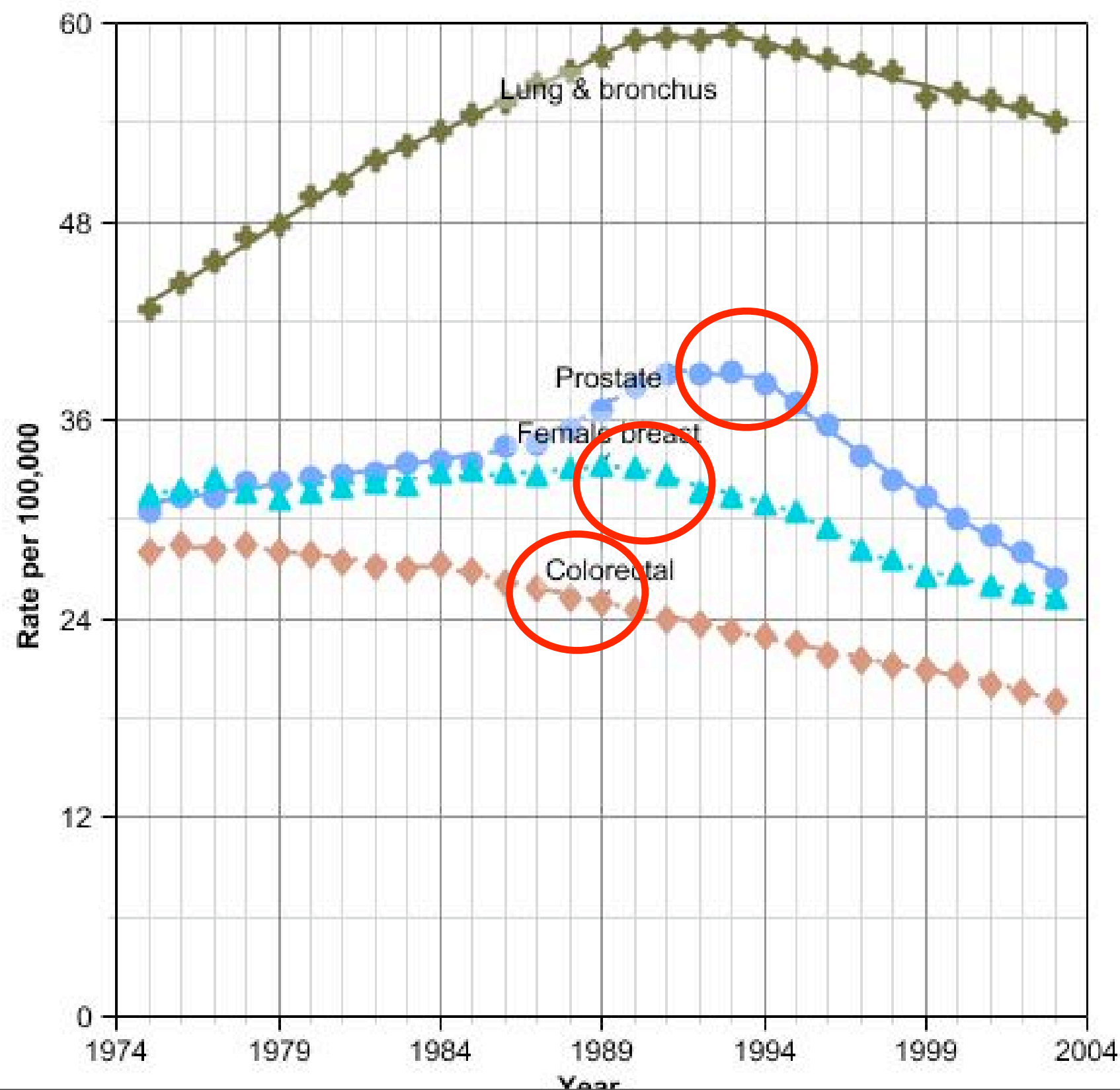
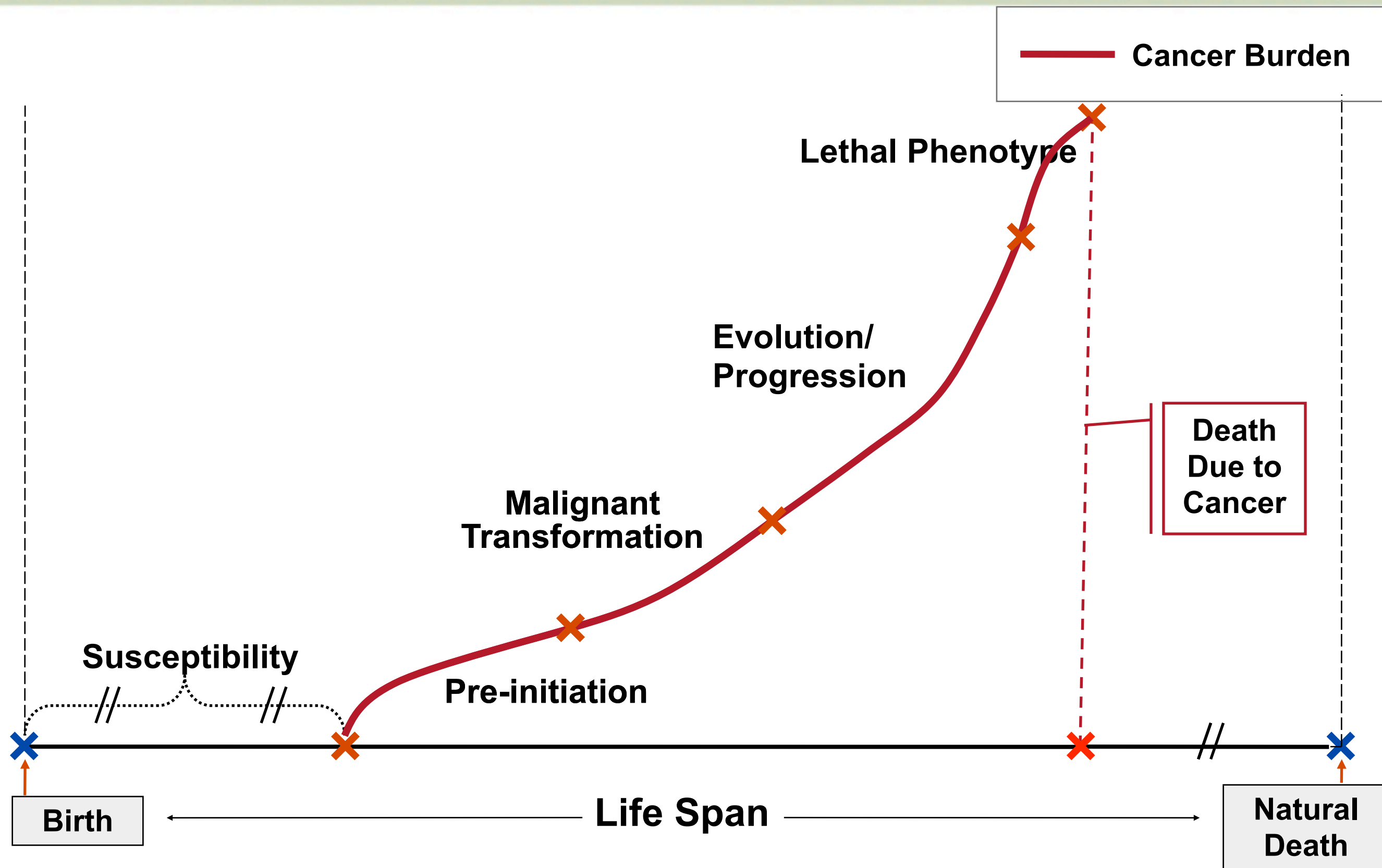


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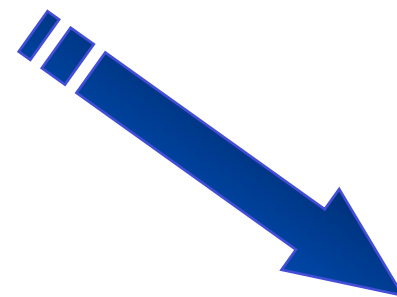
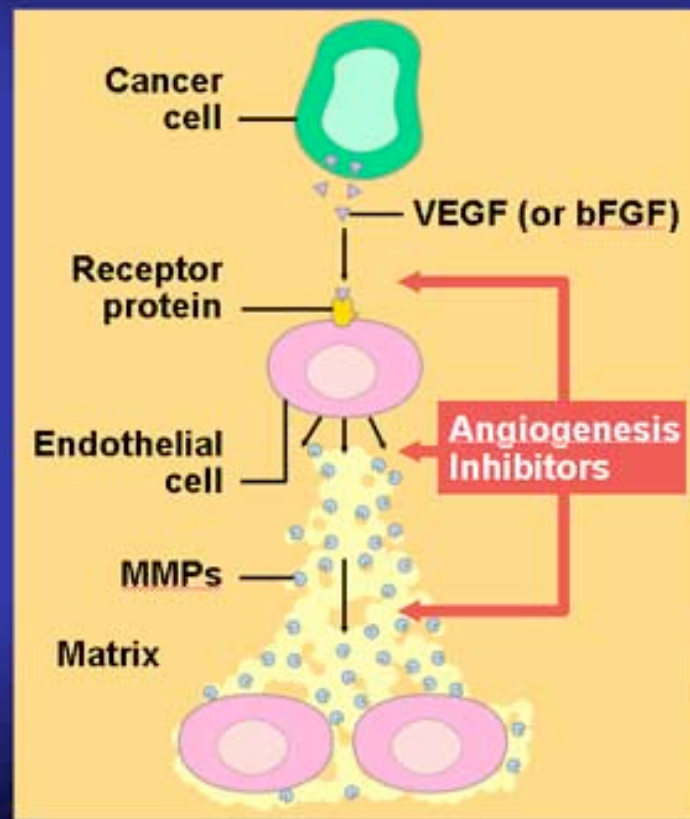


“Moving toward a streaming, life-sensitive medical record – where data are collected continuously over a life time.”

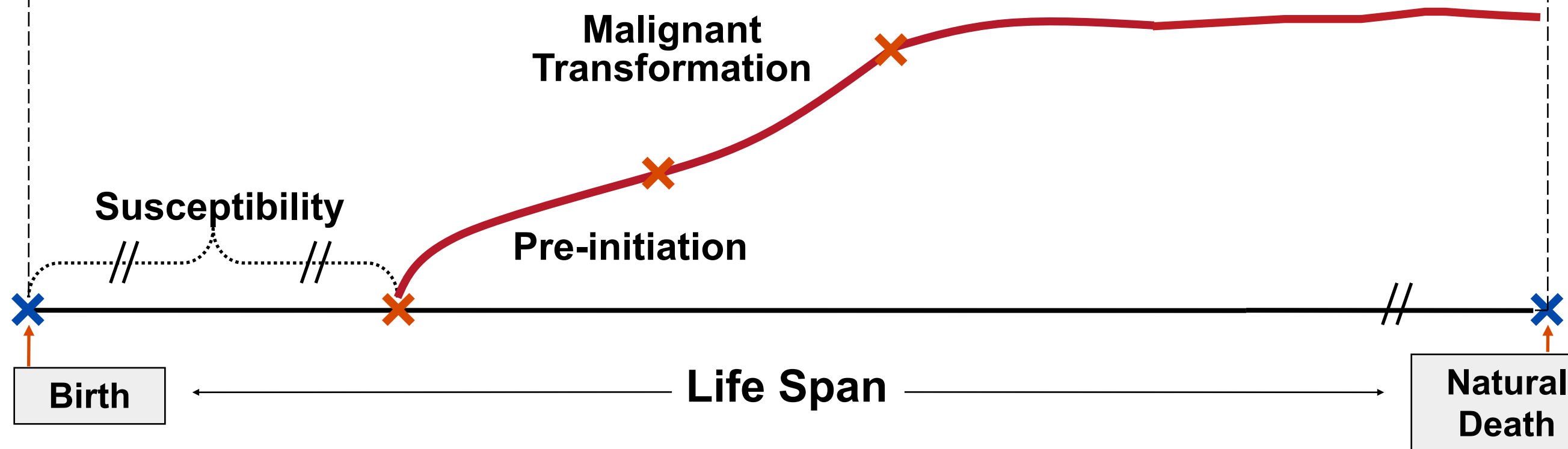
-Dr. David Brailer



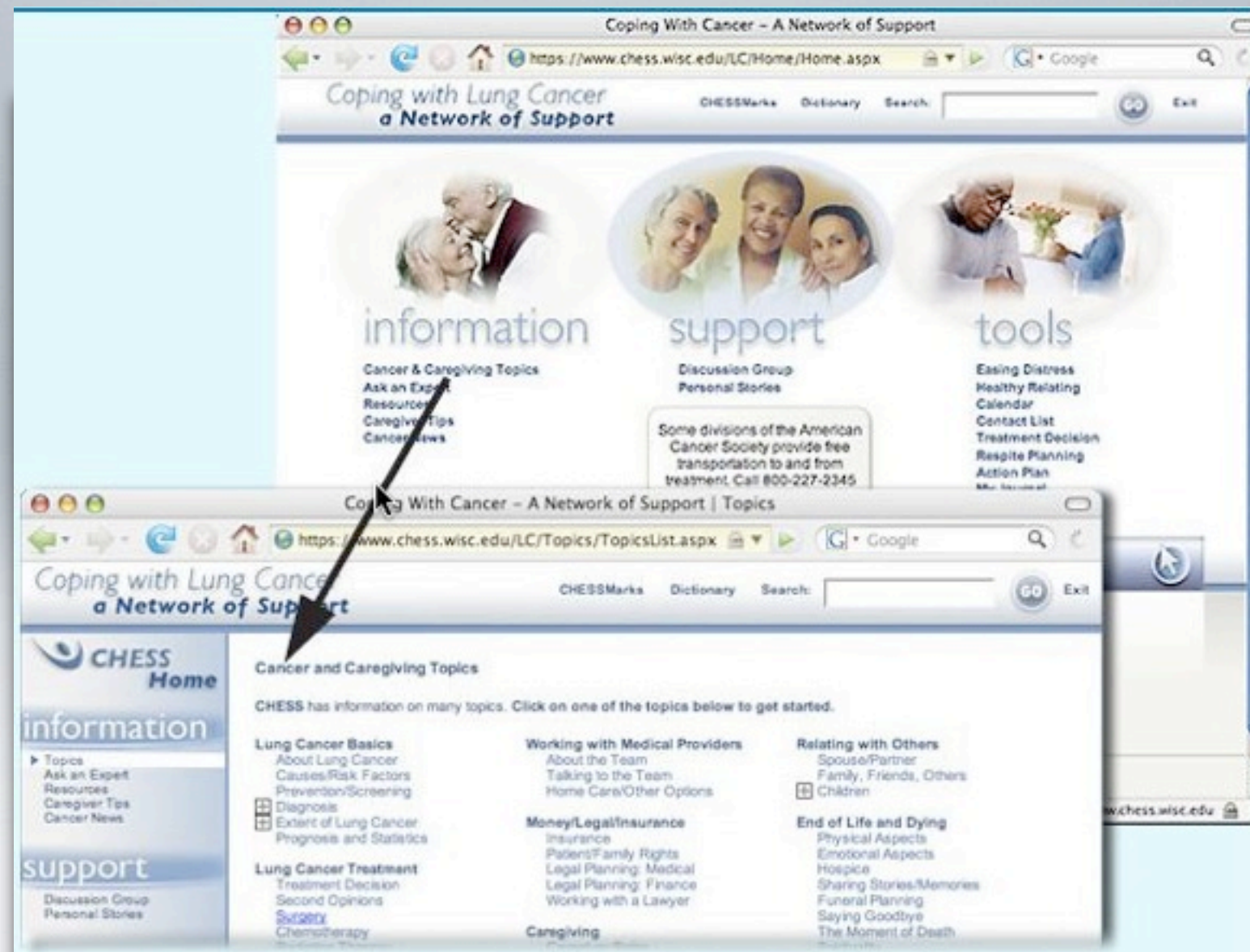
Angiogenesis Inhibitors in the Treatment of Human Cancer



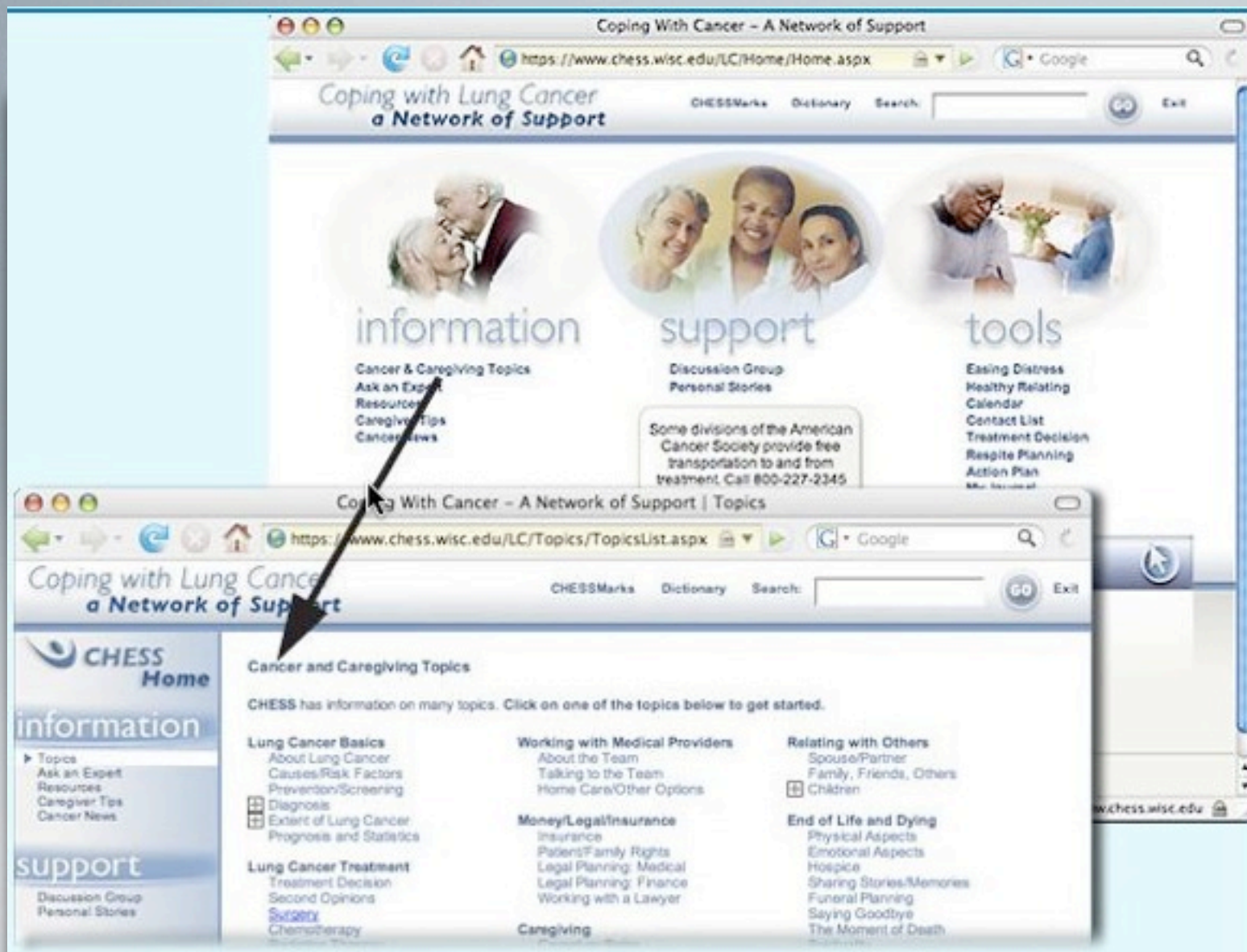
Control its Behavior



Comprehensive Health Enhancement Support System (CHESS): Lung Cancer Support Module

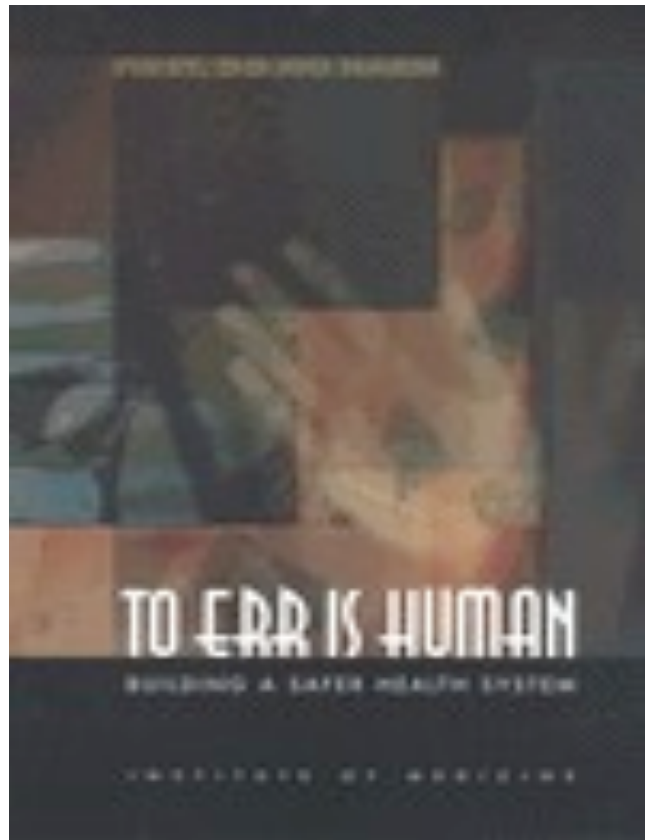


Comprehensive Health Enhancement Support System (CHESS): Lung Cancer Support Module



What is the Role of Human Systems Integration Research?

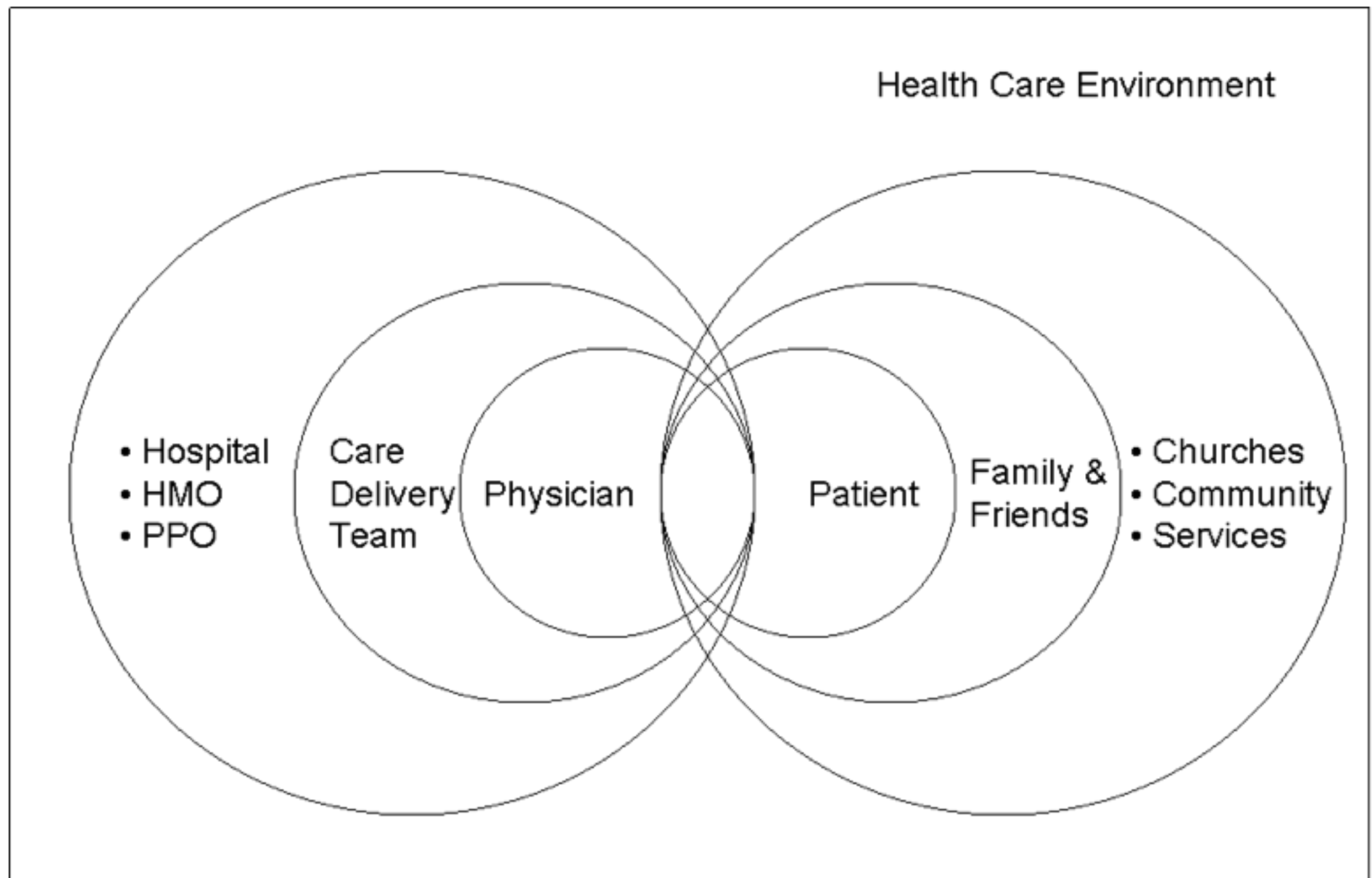
Improving Quality in Health Care



Deliver Care that is:

- Safe
- Effective (Evidence-based)
- Patient-centered
- Equitable
- Timely
- Efficient

Users within Healthcare



Goal: Safety

Patient/Family

- Usable design on all patient interfaces
- Patient as participant in safety management
- Systems accessible 24 X 7



Physician/Team

- Human factors engineering to prevent error
- Coordinated system of safeguards
- Culture of safety



← E.g. Redesigned Pill Bottle (Target)

Error Prevention in Electronic Systems →



Goal: Effectiveness (Evidence-based)

Patient/Family



Physician/Team

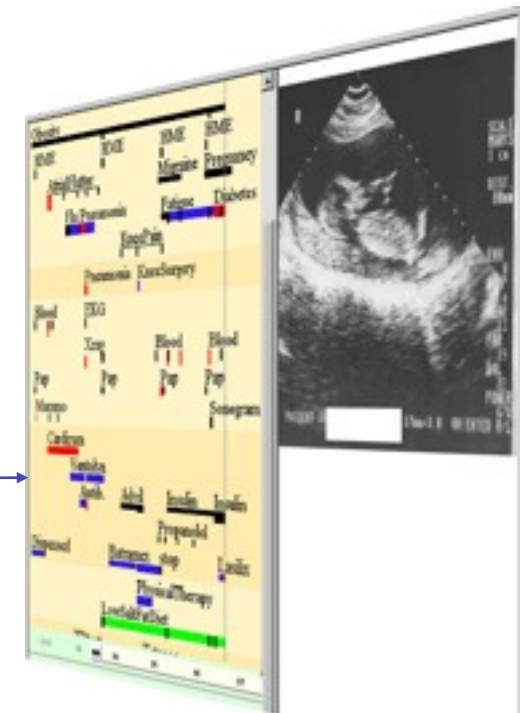
- Informed, healthy public
- “Vital Information” available as needed to guide decision making

- Practice anchored on medical evidence
- Displays ensure effective use of data
- Health I.T. puts the right information into hands of medical team at the right time



Trusted,
Reliable
Sources

Research needed on
effective displays



Goal: Patient-Centered

Patient/Family

- Activated, empowered patient
- Patient has access to, and control over, personal health information
- Care is equitable throughout population



Physician/Team

- Coordinated systems of care
- Personalized health care oriented to needs of patient
- Communication centered on improving outcomes, quality of life



Personal Health Record guides decision making

Personalized delivery of health care



Goal: Timely

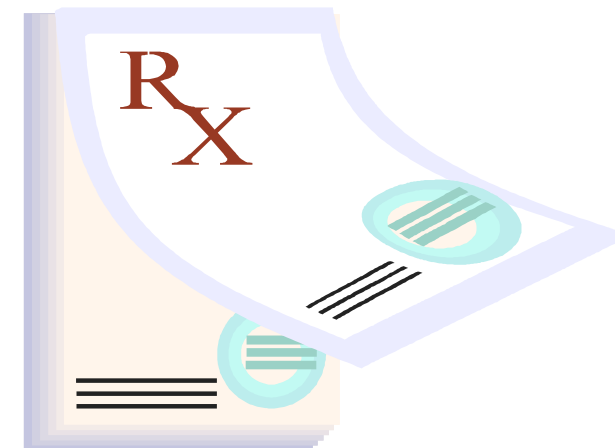
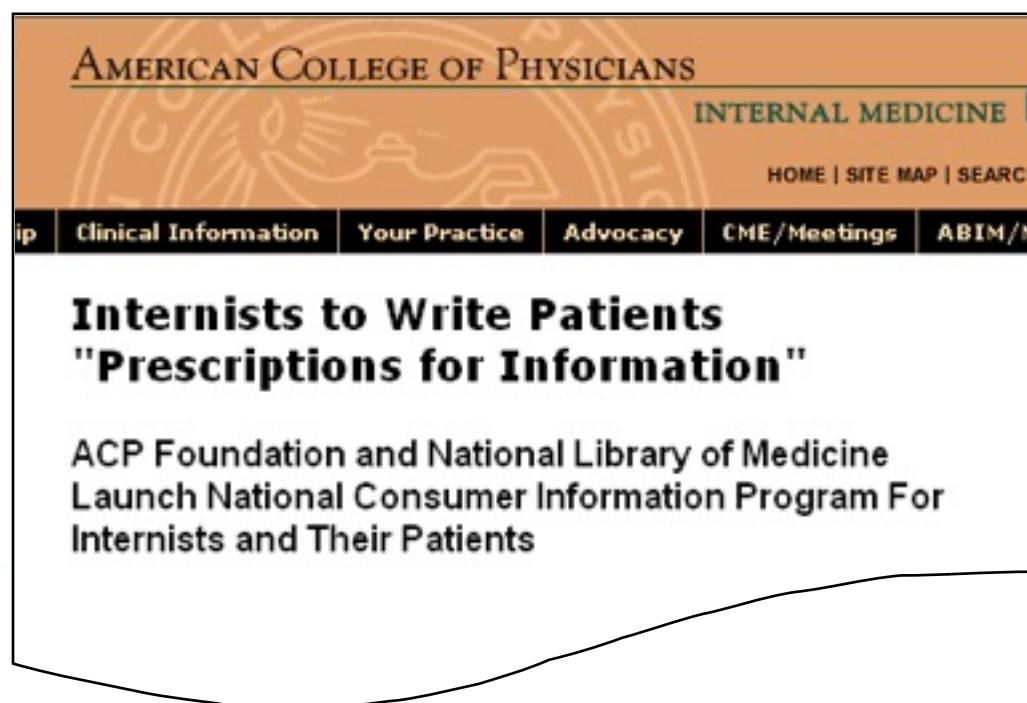
Patient/Family



Physician/Team

- Time as “currency of 21st Century”
- “Healing Relationships” over time
- Efficient balance of in-office, out-of-office resources

- Clinical systems support work flow
- Reminder systems ensure that all steps are followed in sequence of care



Goal: Equity

Patient/Family



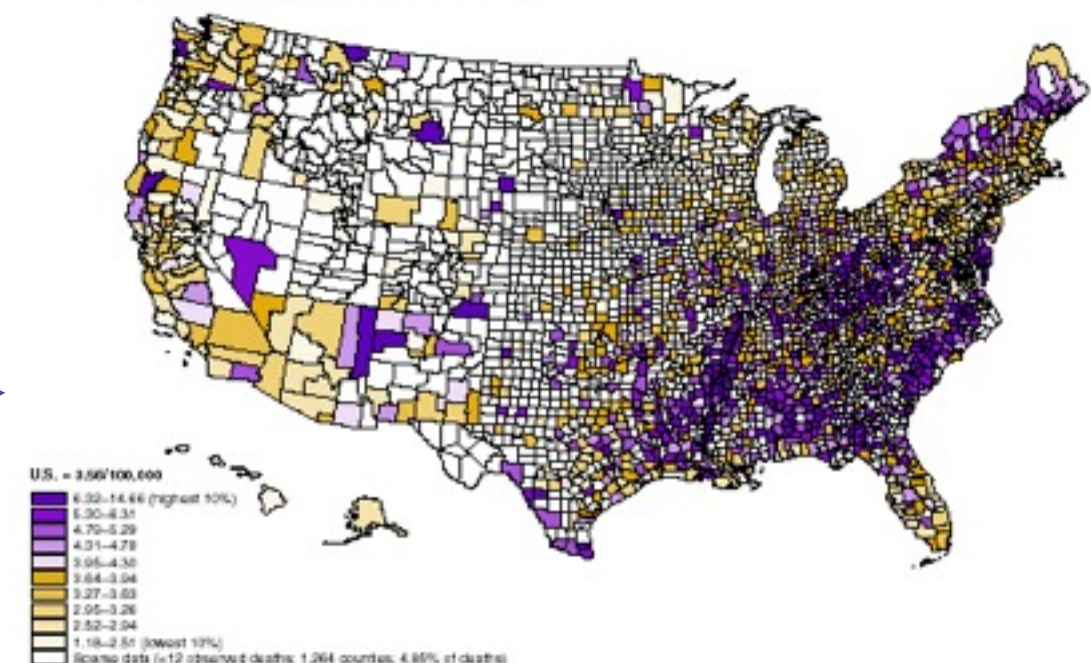
Physician/Team

- “Universal Design” addresses health literacy issues
- Communication reach extended to bridge “knowledge gaps”
- Trust is high in equitable systems of care

- Clinical information systems enforce uniform standards of care
- Support systems offer culturally sensitive linkages

How can information systems be used to ensure high quality delivery to all segments of population?

Map 1. Cancer Mortality Rates by County (Age-adjusted 1970 U.S. Population)
Cervix Uteri: All Races, Females, 1970–1998



Goal: Efficiency

Patient/Family



Physician/Team

- Focus on relationship minimizes unproductive interactions
- Information is available as needed
- Connective technologies improve support among caregivers

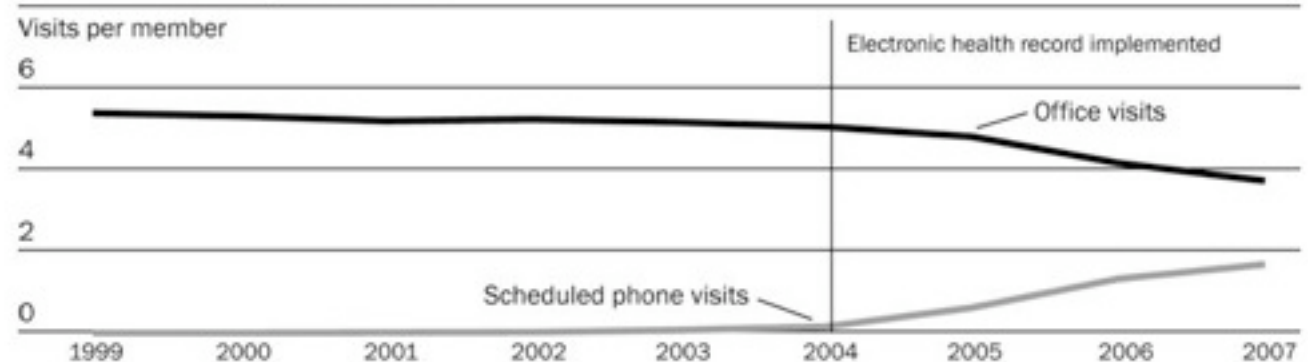
- Coordination between systems is reliable and seamless
- Efficiencies in delivery improve cost-effectiveness

How can information systems be used to deliver interventions in cost-effective ways?



EXHIBIT 2

Changes In Office Visit Versus Telephone Visit Rates Among Kaiser Permanente (KP) Hawaii Members, 1999–2007

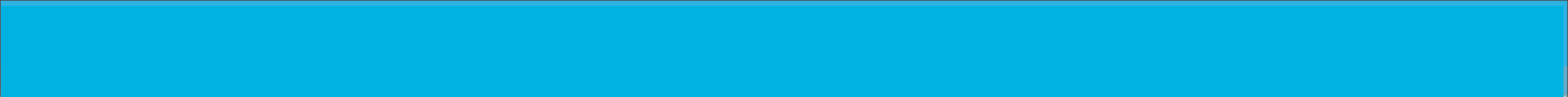


SOURCE: Authors' analysis using data from the Kaiser Permanente Hawaii Data Warehouse and secure messaging database.

HEALTH
AFFAIRS

Catherine Chen, Terhilda Garrido, Don Chock, Grant Okawa, and Louise Liang.
The Kaiser Permanente Electronic Health Record: Transforming And Streamlining Modalities Of Care,
Health Affairs, Vol 28, Issue 2, 323-333

Closing Thoughts

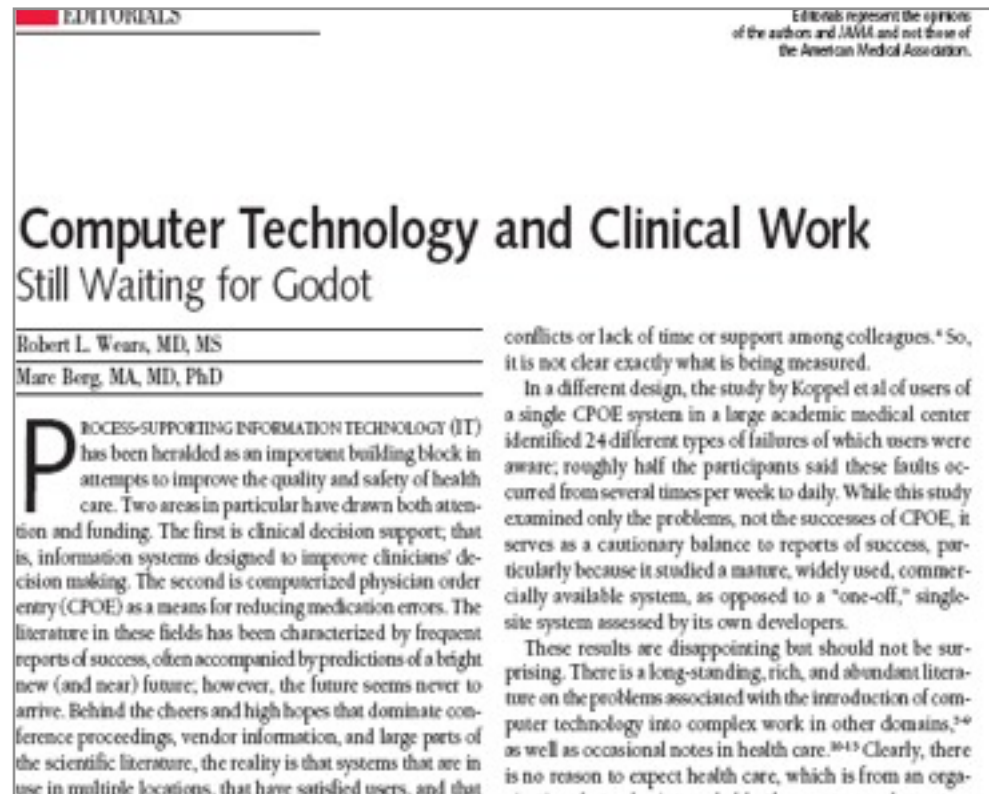


“Medicine used to be *simple*,
ineffective, and relatively *safe*.

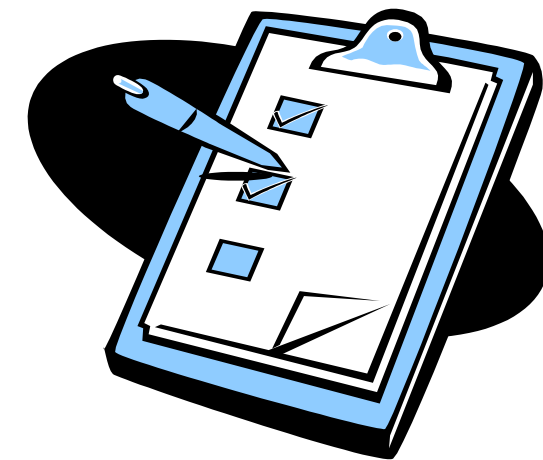
Now it is *complex*, *effective*, and
potentially *dangerous*.”

§ Chantler, Cyril. The role and education of doctors in the delivery of health care. Lancet 1999; 353:1178-81.

People & Technology: Sociotechnical Design

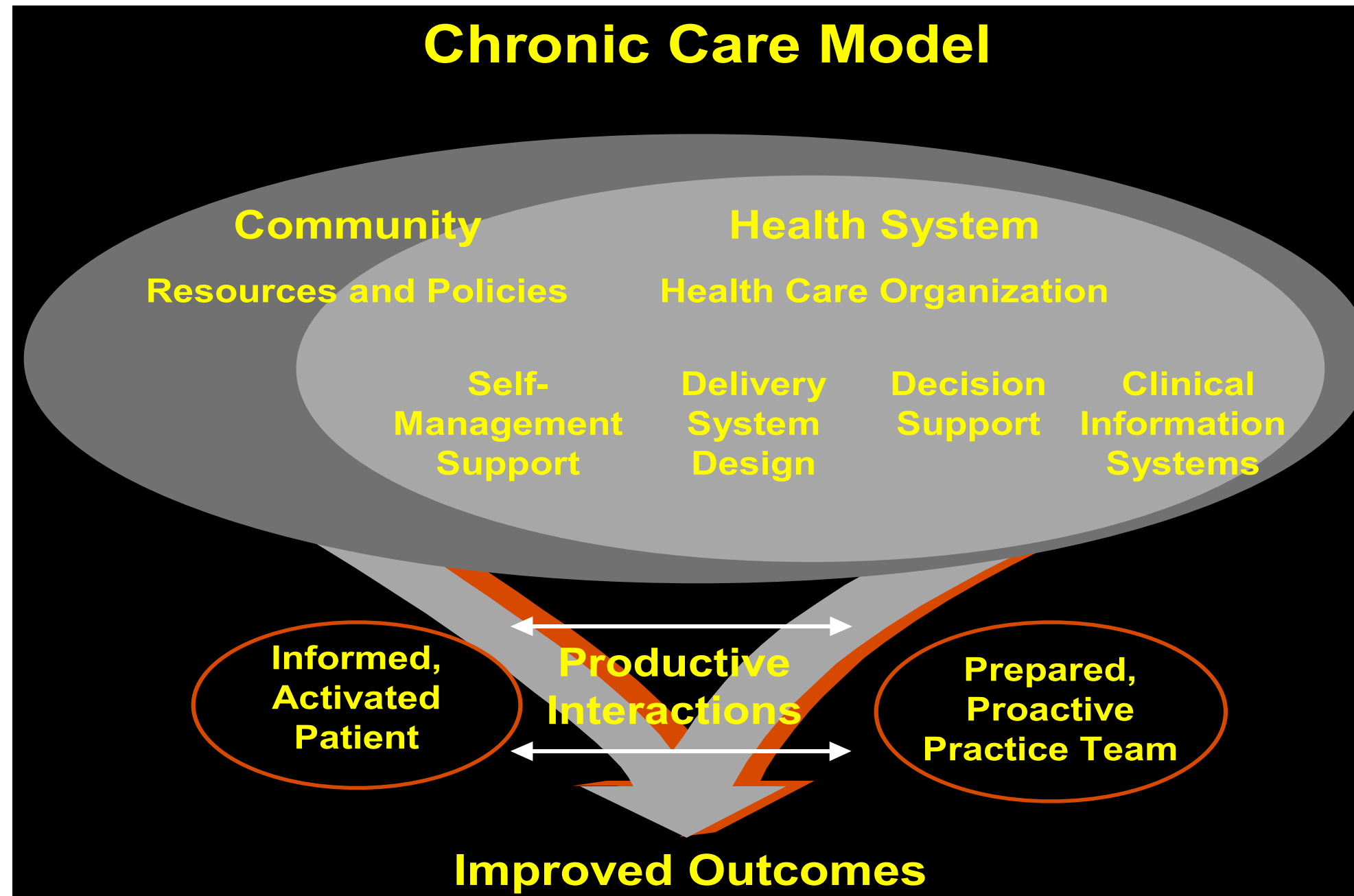


Early evidence is riddled with failure in delivering on quality objectives through Information Technology solutions alone



- ✓ Technical systems have social consequences
- ✓ Social systems have technical consequences
- ✓ We don't design technology, we design sociotechnical systems
- ✓ Understand how people and technologies interact






Engineering Support for the “Activated Patient”



The “Activated Patient” from the *Chronic Care Model*
(Wagner, 2004)*

*Source: Wagner EH. Chronic disease care. Bmj 2004; 328(7433):177-8.

Questions for Committee

-  How can the methodologies of HSI be marshaled to improve system design?
-  Can we elevate all “software maturity” processes in HIT to include HSI?
-  Is medicine different from other sectors; will models for elevating HSI in other sectors work in medicine?
-  How do we fund HSI work in medicine and informatics?
-  Can we influence design before norms crystallize?