CONCORD Programme: Worldwide Surveillance of Cancer Survival

The US Perspective

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Centers for Disease Control and Prevention
Overview

- Cancer Surveillance in the US
- EUROCare
- CONCORD Programme
- CONCORD-2 Study
History of Population-based Cancer Registration in the United States

- 1941 - Connecticut Cancer Registry
- 1971 - National Cancer Act
  - 1973 - first diagnosis year for the Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute
- 1987 – North American Association of Central Cancer Registries (NAACCR)
- 1992 - Public Law 102-515
  - 1995 - first diagnosis year for the National Program of Cancer Registries (NPCR), CDC
Population-based Cancer Registries

- Hospitals
- Outpatient facilities
- Laboratories
- Radiation therapy
- Medical oncology facilities
- Physicians offices
- Death Certificates

Electronic Hard copy → Statewide Cancer Registry → Final data
Nationwide Data

- ~ 1.5 M cancers diagnosed each year
  - Annual cancers expected to double between 2000 and 2050
- ~ 0.5 M cancer deaths
  - Cancer is 2\textsuperscript{nd} leading cause of death in US
  - Leading cause of death in half the states
- Prevalence (living with a diagnosis of cancer)
  - 13.7 M 2012
  - 18 M 2020
Annual Report to the Nation

- Collaboration between CDC, NCI, NAACCR, and the American Cancer Society
- Update of cancer death and incidence rates
- Special topics:
  - 2013 – Prevalence of Comorbidity and Impact on Survival Among Persons With Lung, Colorectal, Breast, or Prostate Cancer
  - 2012 - Burden and Trends in HPV-Associated Cancers and HPV Vaccination Coverage Level
  - 2011 - Cancers Associated with Excess Weight and Lack of Sufficient Physical Activity
  - 2010 – benign and malignant brain cancers
  - others
Vital Signs

- 2013 – Colorectal Cancer Tests Save Lives
- 2012 – Breast Cancer
- 2011 – Colorectal Cancer

http://www.cdc.gov/vitalsigns/
MMWR Surveillance Summary

- 2013 - Invasive Cancer Incidence — United States, 2009
- 2013 - Colorectal Cancer Incidence and Screening — United States, 2008 and 2010
- 2008 - Surveillance for Cancers Associated with Tobacco Use - United States, 1999-2004

http://www.cdc.gov/mmwr/
State Cancer Profiles

- Comprehensive Cancer Control Plans
- Dynamic views of cancer statistics for prioritizing cancer control efforts
  - Nation
  - State
  - County

http://statecancerprofiles.cancer.gov/
United States Cancer Statistics (USCS)

- State, regional, and national data
- Rates for whites, blacks, Asians/Pacific Islanders (A/PI), American Indians/Alaska Natives (AI/AN), Hispanics, and children

http://www.cdc.gov/uscs
USCS: Cancers Ranked by State
Colorectal cancer, males, 2010
USCS: State Maps
– Female Breast Cancer In situ 2010
# USCS: Rates by Census Regions/Division

## Female Breast Cancer In Situ 2010

<table>
<thead>
<tr>
<th>Geographic Area</th>
<th>All Races</th>
<th>White</th>
<th>Black</th>
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<td>36.6</td>
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<tr>
<td>Nebraska</td>
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<tr>
<td><strong>Mountain</strong></td>
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<td>19.2</td>
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<td><strong>Pacific</strong></td>
<td>29</td>
<td>28.8</td>
<td>26.3</td>
<td>18.8</td>
</tr>
</tbody>
</table>
USCS: Leading Cancers by Sex, Race and Ethnicity

Top 10 Cancer Sites: 2010, Male, Michigan—All Races

- Prostate: 149.8
- Lung and Bronchus: 81.8
- Colon and Rectum: 46.8
- Urinary Bladder: 40.1
- Non-Hodgkin Lymphoma: 25.8
- Kidney and Renal Pelvis: 21.9
- Melanomas of the Skin: 21.9
- Leukemia: 18.5
- Oral Cavity and Pharynx: 17.3
- Pancreas: 14.5

Top 10 Cancer Sites: 2010, Male, Michigan—White

- Prostate: 134.0
- Lung and Bronchus: 79.4
- Colon and Rectum: 44.5
- Urinary Bladder: 41.2
- Non-Hodgkin Lymphoma: 25.8
- Melanomas of the Skin: 23.1
- Kidney and Renal Pelvis: 19.8
- Leukemia: 15.0
- Oral Cavity and Pharynx: 17.2
- Pancreas: 13.9

Top 10 Cancer Sites: 2010, Male, Michigan—Black

- Prostate: 229.6
- Lung and Bronchus: 90.9
- Colon and Rectum: 62.9
- Kidney and Renal Pelvis: 35.6
- Non-Hodgkin Lymphoma: 22.1
- Pancreas: 19.0
- Urinary Bladder: 19.8
- Liver and Intrahepatic Bile Duct: 18.1
- Myeloma: 17.1
- Oral Cavity and Pharynx: 14.0

Top 10 Cancer Sites: 2010, Male, Michigan—Asian/Pacific Islander

- Prostate: 85.9
- Lung and Bronchus: 46.0
- Colon and Rectum: 32.7
- Liver and Intrahepatic Bile Duct: 16.2

Top 10 Cancer Sites: 2010, Male, Michigan—Hispanic

- Prostate: 104.0
- Lung and Bronchus: 35.8
- Colon and Rectum: 35.5
- Urinary Bladder: 16.5
- Liver and Intrahepatic Bile Duct: 16.6
- Non-Hodgkin Lymphoma: 15.4
- Kidney and Renal Pelvis: 15.1
Cancer Survival

Clinical trials *highest* achievable survival

Population-based *average* survival *achieved*

Coleman 1999
Population-based Cancer Registries

- Hospitals
- Outpatient facilities
- Laboratories
- Radiation therapy
- Medical oncology facilities
- Physicians offices
- Death Certificates

Statewide Cancer Registry

Electronic
Hard copy

State Death Certificates
National Death Index

Final data

Electronic
Hard copy

CDC
SEER
NAACCR

North American Association of Central Cancer Registries
Types of Population-based Survival

Crude survival:
... how many individuals diagnosed with cancer are alive after xx (e.g., five) years?
... endpoint is death from any cause

Cause-specific survival:
... how many individuals diagnosed with cancer have not died specifically of cancer after xx years?
... endpoint is death from cancer

Relative survival:
... compares the survival experience of individuals with cancer to individuals without cancer (of the same age, race, gender, etc.) *
... measure excess mortality among cancer patients
... endpoint is death from any cause

* Uses life tables
Advantages and Disadvantages of Relative vs. Cause-specific Survival

<table>
<thead>
<tr>
<th></th>
<th>Advantage</th>
<th>Disadvantages</th>
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<tbody>
<tr>
<td>Relative</td>
<td>Relies on fact of death not cause of death</td>
<td>Life tables may not be available for all populations</td>
</tr>
<tr>
<td>Cause-specific</td>
<td>Not limited to populations with life tables</td>
<td>Death Certificates are not reliable (e.g., may be coded to site of mets or recurrence)</td>
</tr>
</tbody>
</table>
Overview

- Cancer Surveillance in the US
- EUROCare
- CONCORD Programme
- CONCORD-2 Study
## History of EUROCARE

<table>
<thead>
<tr>
<th></th>
<th>Diagnosis Years</th>
<th>Countries</th>
<th>Registries</th>
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<tr>
<td>EUROCARE 1</td>
<td>1978 - 84</td>
<td>11</td>
<td>30</td>
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<tr>
<td>EUROCARE 2</td>
<td>1985 - 89</td>
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<tr>
<td>EUROCARE 3</td>
<td>1990 - 94</td>
<td>21</td>
<td>70</td>
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<tr>
<td>EUROCARE 4</td>
<td>1995 - 99</td>
<td>23</td>
<td>93</td>
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<tr>
<td>EUROCARE 5</td>
<td>2000 - 07</td>
<td>29</td>
<td>116</td>
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</tbody>
</table>
National Cancer Strategies: response to poor UK cancer survival (EUROCARE 4)

Five-year relative survival (%) Europe 1995-99
All Cancers
Survival gap for UK cancer patients

The UK is worse than most of its European neighbours when it comes to cancer survival rates, a study has found.

Only eastern European countries fare worse in the league tables published on Thursday.

The Eurocare study revealed that France and Austria have the best five-year survival rates - and that Poland has the worst.

Cancer survival is heavily influenced by factors such as the speed the cancer is diagnosed, and the treatments available to patients, say experts.

*Click here to see European cancer figures*

Early findings from the study, which looked at countries from Scandinavia to eastern Europe, were presented to the European Cancer Conference in Copenhagen.

The researchers analysed data from 22 countries, covering 42 kinds of cancer.

It looked at five-year survival in 1.8m adult cancer sufferers and 24,000 children diagnosed between 1990 and 1994 and followed until 1999.

In overall survival rates for men, England, Scotland and Wales were ranked 11th to 13th.

"There are fewer cancer specialists in Britain than in many of the other comparative countries in western Europe."
Professor Michel Colaman, London School of Hygiene and Tropical Medicine
Five-year relative survival (%)  
Europe, 1995-99  
All Cancers
Avoidable Premature Deaths

Deaths within five years of diagnosis

Avoidable Premature Deaths

- Total: 18,000
  - Excess: 10,000
  - Expected: 8,000
- Avoidable: 6,000
Avoidable Premature Deaths per year in Britain vs. Highest European Survival

Abdel-Rahman et al. 2009
Funnel plot

Cancer survival (%) vs. Precision of the survival estimate

- Control limits
- More reliable
- Less reliable
- Indicator
- Target
- ??? Truly different ???
All-cancers survival index: 1-year survival, PCT

Data points: 151 Primary Care Trusts

PCT outliers for 1996 are tracked (red dots)

National average
2006

All cancers

One-year survival index (%) vs. Precision of the survival index.
The Main Messages from Funnel Plots

• Increasing national average survival during 1996-2009

• Increasing survival for individual PCT

• Fewer divergent PCTs in more recent years
Meanwhile......

*Toward a comparison of survival in American and European cancer patients.* Gatta et al. 2000
Cancer survival (5-years) in Europe and USA: patients diagnosed 1985-89

Gatta et al., 2000
Why are US (SEER) survival rates so high?

- Artefact of method
  - SEER populations not fully representative
  - Incomplete adjustment for expected mortality in US
  - Higher DCO rates in Europe
  - Differences in loss to follow-up
- Delay in presentation and stage distribution at diagnosis
  - Access to treatment (breast, colon)
- Adherence to protocol
- Older patients treated more aggressively in USA
- Availability of health care resources
Overview

- Cancer Surveillance in the US
- EUROCare
- CONCORD Programme
- CONCORD-2 Study

Michel P Coleman, BM BCh MSc FFPH
Professor of Epidemiology and Vital Statistics
Population-based Cancer Survival in High Income Countries

<table>
<thead>
<tr>
<th>EUROCARE</th>
<th>Patients diagnosed</th>
<th>Countries</th>
<th>Cancer registries</th>
<th>Year</th>
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</table>
CONCORD Study

Objectives: to obtain directly comparable, quantitative estimates of differences in population survival for approximately 1.7 million patients diagnosed (1990-94) and followed through 1999 with female breast, colon and rectum, or prostate

Common protocol, data evaluation, standardized data analysis, including construction of life tables
NPCR Eligibility Criteria

- High quality population-based incidence data 1990-1994
  - Met NAACCR data standards for inclusion in CINA
- Performed death linkage with state death certificates (1990-1999)
- Linked with the National Death Index (1990-99)
North American Coverage
What we learned from the first CONCORD study.....

Coleman et al., 2008
Five-year relative survival (%) - prostate cancer (15-99 years)
Five-year relative survival (%) - breast cancer, women (15-99 years)
Five-year relative survival (%) - colorectum cancer, women (15-99 years)
Five-year relative survival (%) - colorectum cancer, men (15-99 years)
Five-year relative survival (%) - breast cancer women (15-99 years): USA, by race
Five-year relative survival (%) - colorectum cancer, men (15-99 years): USA, by race
Five-year relative survival (%), colon (F)
USA, 1990-99, by race and program area
What we learned from the first CONCORD study

- Canada and US survival was among highest worldwide
- In the US, 5-year survival in black men and women was systematically and substantially lower than in white men and women.
  - Breast Cancer - survival was 85% for white women and 71% for black women (difference of 15%)
  - Colorectal Cancers - survival was 60% for white men and women and 50% for black men and women (difference of 10%)
  - Prostate Cancer - survival was 92% for white men and 86% for black men (difference of 7%)
- Differences represent a large number of avoidable deaths
Economics Determine Cancer Survival Worldwide but Race Matters in U.S.

By Crystal Phend, Staff Writer, MedPage Today
Published: Jul 18, 2008
Reviewed by Zafman S. Agus, MD, Emeritus Professor University of Pennsylvania School of Medicine.

LONDON, July 16 -- Cancer survival rates differ widely around the world, primarily along economic lines but racially in the U.S., according to the first direct global comparison.

Five-year survival rates for breast, colorectal, and prostate cancer were generally higher in North America, Australia...
Overview

- Cancer Surveillance in the US
- EUROCARE
- CONCORD Programme
- CONCORD-2 Study
Background to the CONCORD-2 Study

- Cancer registration in the US has expanded to nationwide coverage.
- Changes in clinical practice (including screening, diagnosis and treatment) have continued to improve in the 15+ years since the first CONCORD study, at least in wealthier countries.
**CONCORD-2 Study**

**Objectives**: to obtain directly comparable, quantitative estimates of differences in population survival for approximately 30 million patients diagnosed (1995-2009) and followed through 2009 with stomach, colon, rectum, liver, lung, breast (women), cervix, ovary, prostate, leukaemia (adults and children)

Common protocol, data evaluation, standardized data analysis, including construction of life tables
# Population-based Cancer Survival in High Income Countries

<table>
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<th>EUROCARE</th>
<th>Patients diagnosed</th>
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<th>Cancer registries</th>
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<tr>
<td>5</td>
<td>2003 – 2007</td>
<td>-</td>
<td>-</td>
<td>2013</td>
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## Cancer registries, data sets, quality control

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<th>Signed up</th>
<th>Submitted</th>
<th>Data sets</th>
<th>Checked</th>
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<td>Africa</td>
<td>12</td>
<td>12</td>
<td>79</td>
<td>79</td>
</tr>
<tr>
<td>America C+S</td>
<td>27</td>
<td>26</td>
<td>171</td>
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<tr>
<td>Asia</td>
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<tr>
<td>Europe</td>
<td>127</td>
<td>127</td>
<td>1,136</td>
<td>1,056</td>
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<td>Oceania</td>
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<tr>
<td><strong>Total</strong></td>
<td>283</td>
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# Number of cancer patients

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</table>

*Note: provisional figures, February 2014*
What we expect to learn from the CONCORD-2 study

- Period Analysis and “prediction” of survival
- Trends over 15+ years
  - Do racial disparities within the US persist?
- Avoidable deaths: How many cancer-related deaths within five years of diagnosis would be expected *not* to occur, if racial inequalities were eliminated?
- Prevalence
Relative survival: cohort and period approaches

- The basic cohort method
  - Uses everyone diagnosed with cancer in the past, who has had sufficient follow up time
  - Traditional approach to survival statistics; reflect the survival expectations of patients diagnosed many years ago (i.e., everyone in the cohort must have had five years of follow up)
Relative survival: cohort and period approaches

- The Period approach\(^1\)
  - Provides more ‘up-to-date’ estimates of long-term survival rates, incorporates the survival experience of recently diagnosed cases into the analysis.
  - e.g., 5-year survival for people diagnosed 2003-2007, with follow-up to the end of 2008
    - 1-year estimate will include the 1-year survival experience of people diagnosed in 2003-2007
    - 2-year estimate will include the survival experience for people diagnosed in 2003-2006
    - 3-year estimate will include 2003-2005 follow-up,
    - …. And so on

Brenner and Gefeller 1996
WCD 2008 – 11 goals for 2020

- Achieve major improvements in cancer survival in all countries (#11)
- Improve measurement of global cancer burden and impact of cancer control interventions (#2)

WCD 2013 – “one overarching goal”

- There will be major reductions in premature deaths from cancer, and improvements in quality of life and cancer survival.

Global surveillance of cancer

“I believe that the fight against cancer, rather than focussing on specific, spectacular news, should aim at viewing the overall global comprehensive picture.

“We should monitor trends if we want to improve that reality.”

Dr Tabaré Vázquez, oncologist
President of Uruguay (2005-10)
A rationale for disease surveillance ...

I believe it is also our job to constantly assess the impact of our activities. One thing I learned from my previous life is this: what gets measured gets done.

Dr Margaret Chan, WHO Director-General, 2007
References

- Abdel-Rahman M, Stockton D, Rachet B, Hakulinen T, Coleman MP. What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? Br J Cancer. 2009 Dec 3;101 Suppl 2:S115-24.


Interesting Cancer Survival Websites

• EUROCARE  www.eurocare.it
• Paul Dickman  www.pauldickman.com
• International Agency for Research on Cancer (IARC)  http://www.iarc.fr/
• UK Cancer Survival Group:  www.lshtm.ac.uk/ncdeu/cancersurvival/
• SEER:  www.seer.gov/cancer
• Statistics Canada:  www.statcan.gc.ca/
• Canadian Partnership Against Cancer:  www.partnershipagainstcancer.ca
Thank You

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The findings and conclusions in this presentation are those of the presenter and do not necessarily represent the official position of the Centers for Disease Control and Prevention.