Death Registration in the 21st Century: Challenges and Opportunities

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CDC

Why am I here?

- Licensed in 3 states to certify cause of death
- Graduate, Cause of Death ‘short course’ (2am, July, 1992, 9200 nurses station, Barnes Hospital, St. Louis, MO)
- ‘Discovered’ the central importance of vital statistics: October, 2009
- It’s mid-August in DC!!

Why do vital statistics matter?

- Public policy
  - Assist in allocation of public health resources
  - Inform design of public health interventions
  - Guide funding for research and development
- Knowledge advancement
  - Measurement of population health status
  - Early detection of epidemics
  - Research
- Impact clinical practice

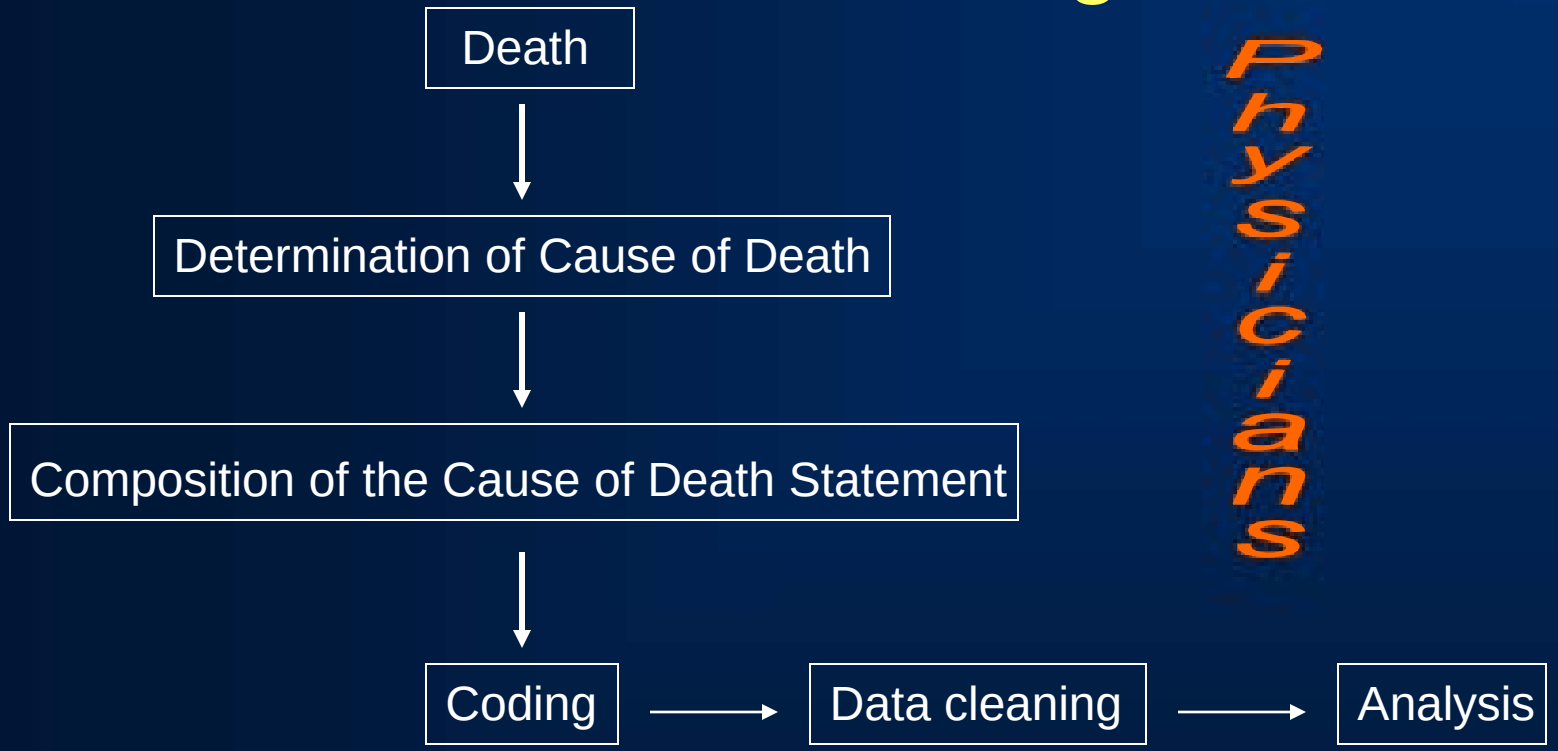
Considerations affecting the integrity of the US Death Registration System

- Data quality
- Timeliness of analyses and reporting
- Recognition of importance by healthcare providers and partners
- Greater understanding of the value by policy makers and the public

Quality of Cause of Death Data

- Numerous studies exist assessing quality of cause of death data
- Error rate varies from 20%-60% depending on the study
  - Differing gold standard
    - Autopsy diagnosis
    - Chart-substantiated diagnosis
  - Variable definitions of error

Cause of Death Information Processing



Physician-generated Errors

- Listing a mechanism as a cause
- Inadequate detail or specificity
- Improper causal sequence
- Competing causes
- Failure to include time intervals
- Incorrect use of Part II

Quality of Cause of Death Data
NYC Experience

- NYC among highest reported heart disease (HD) death rates in US
  - US 2006 : 199/100,000 Population
  - NYC 2006: 255/100,000 Population
- Yet rates of HD risk factors (hypertension, cholesterol, smoking, obesity) largely comparable or better in NYC than nationally.
- 2003 NYC validation study: death certificates over-estimated HD mortality >50% for decedents 35–74 yrs
  - 94% overestimated for decedents 75–84 years
  - 137% overestimated for decedents >85 years

Agarwal et al. (2010) Prev Chronic Dis 7: 1-9

NYC/US Leading Causes of Death with Dissimilar Age-Adjusted Rates (per 100,000)

	NYC		US
Cause of Death	2006		2006
Diseases of heart I00-I09,I11,I13,I20-I51	254.7		199.4
Influenza and pneumonia J10-J18	29.9		17.7
Cerebrovascular diseases I60-I69	19.8		43.6
Chronic lower respiratory diseases J40-J47	16.5		40.4
Septicemia A40-A41	4.5		10.9
Alzheimer's disease G30	2.8		22.7

NYC Health

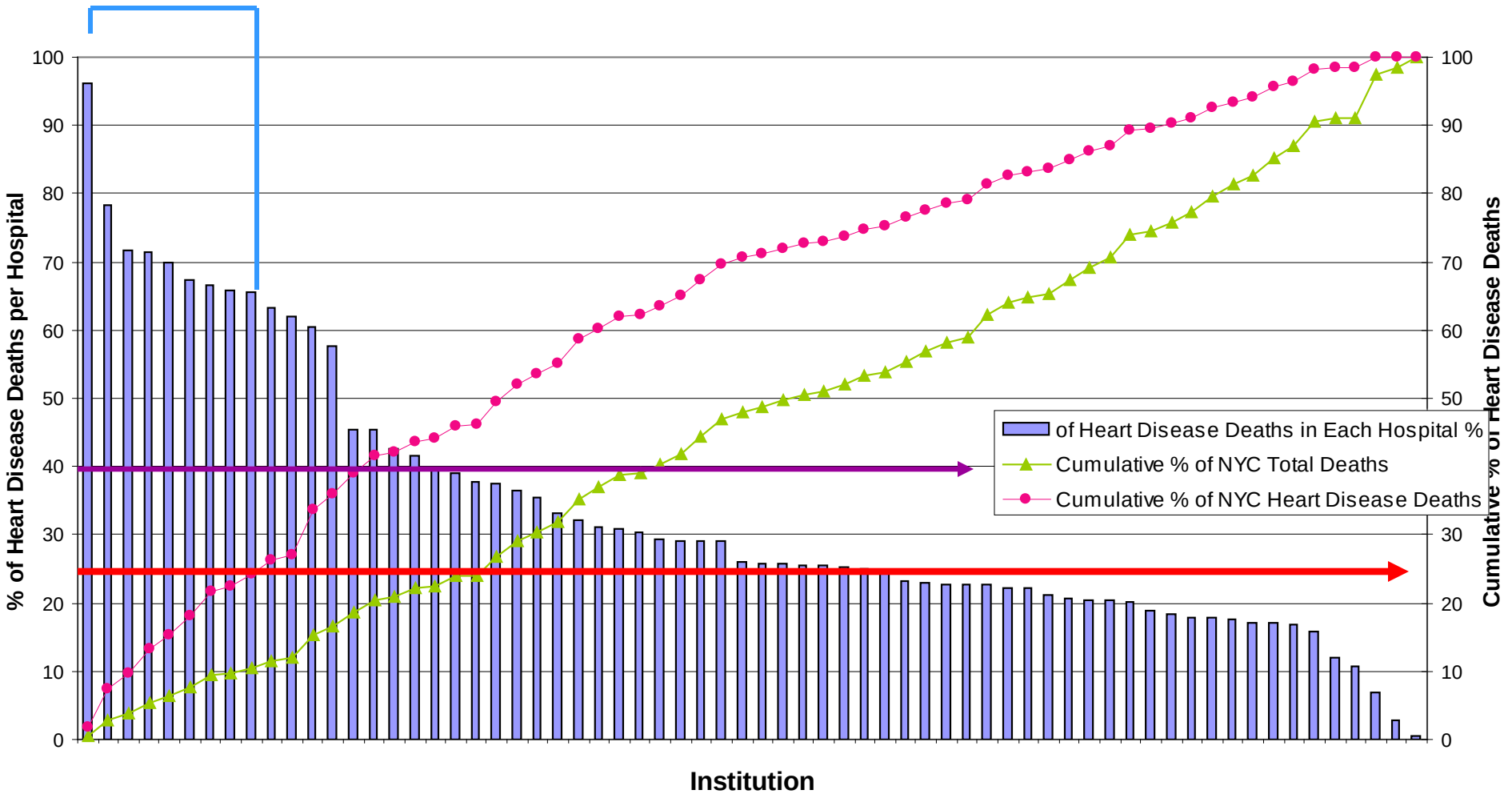
Cause of Death: Literals

Randomly sampled 50 Death Certificates with Heart Disease as underlying cause:

- 64% documented only Heart Disease in Part I and Part II
- 36% documented other contributing causes with an underlying cause of Heart Disease

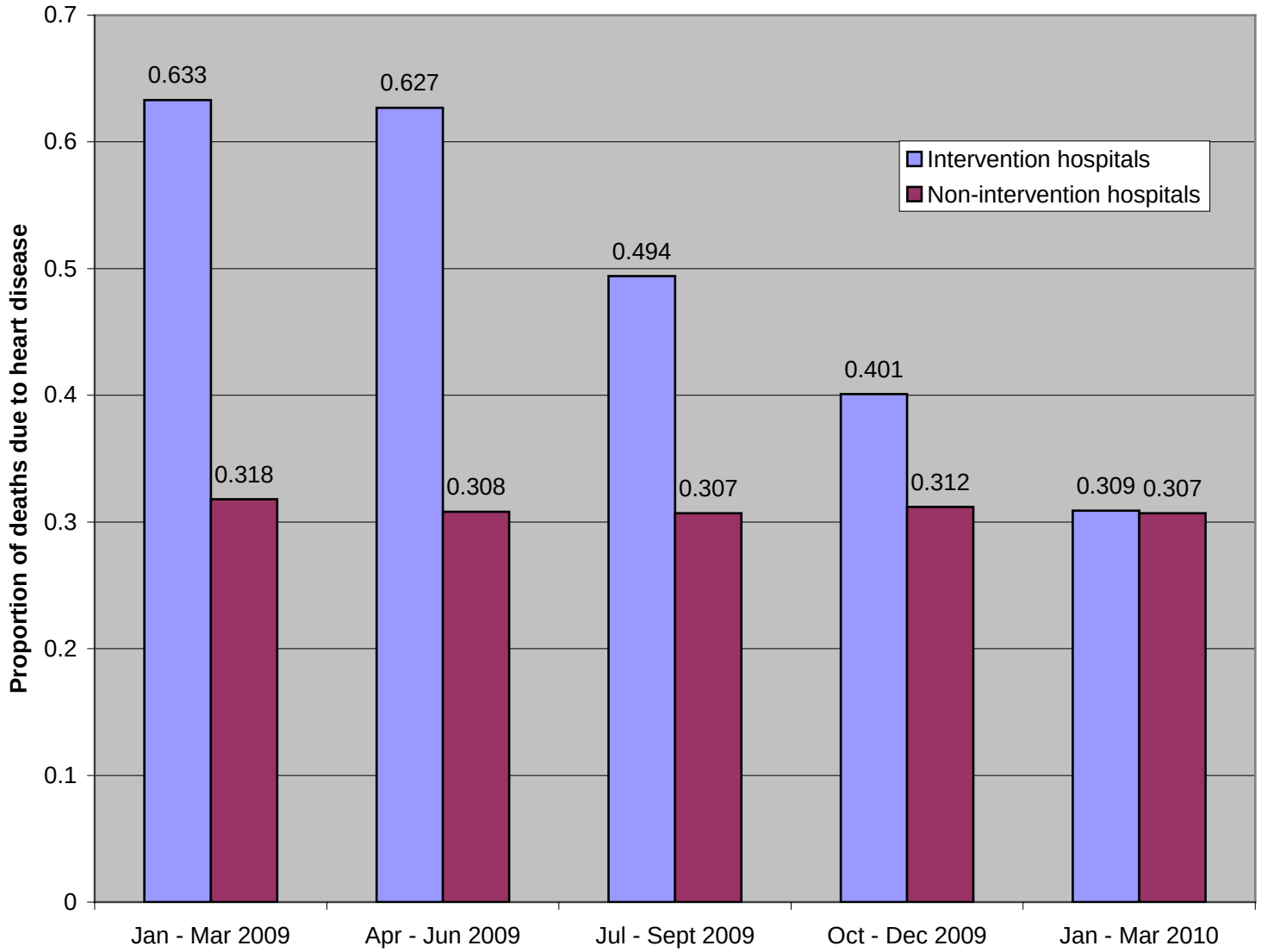
Deaths Due to Heart Disease

by Reporting Institution, 2008



NYC Health

Proportion of Heart Disease Deaths reported at Intervention and Non-intervention Hospitals reporting >50 deaths, NYC 2009–2010



NYC Health

Sources of Physician Error

- Incorrect antemortem diagnosis
  - May be as high as 30%
  - Low autopsy rate makes improvement difficult
- Intentional errors
  - “Protect” family members
  - Poor guidance from associated staff
  - System design flaws
- Unintentional errors

NYC Physician Survey (2009)

- Random sample of 1200 physicians with primary practice site in NYC.
- Questionnaire examining knowledge and use of DOHMH services and resources
  - Only 34% agreed that instructions for recording cause of death were clear
  - Only 36% agreed that the process for electronically certifying cause of death was straightforward

Unintentional Errors: Why is this so hard for clinicians to get?

- No formal training consistently provided in medical school or residency
  - Importance of accurately recording cause of death poorly understood
  - Training usually *ad hoc* and of poor quality
- Resources for accurate guidance limited
- Instructions inconsistent or confusing
- Terminology and format not necessarily intuitive to the clinician

Describe as clearly as possible the events that led to the scene depicted

Would this be your first attempt?

- 155 passengers and crew were safely evacuated onto the wings awaiting rescue
- The pilots skillfully ditched the aircraft in the Hudson River abeam 50th ST
- Seeing no other option, the captain chose to bring the plane down in the river
- The plane hit a flock of birds and lost all power
- US Airways Flight 1549 took off from LGA bound for CLT at 15:24 on January 15, 2009

How do we improve the system??

- Training
- Real time or near real time support
- Audit programs
- Electronic registration systems
- Electronic health records

Training content

- Medical science related to determining cause of death
- Principles of certifying cause of death
- Rules for specific causes of death
- Legal/ethical issues
- General and Specific uses of cause of death data

CDC Core Curriculum or Certifiers of Underlying Cause of Death. 2006 (www.cdc.gov/nchs)

Teaching physicians how to record cause of death

- Monthly publication
- Clinician-friendly guidance on public health topics
- Distributed free to 30,000 NYC physicians
- CME Credit offered

CME Activity Inside and Online
Valid Until October 31, 2009

City Health Information

October 2008 | The New York City Department of Health and Mental Hygiene | Vol. 27(9):71-78

IMPROVING CAUSE OF DEATH REPORTING

- Physicians are responsible for correct completion of death certificates, which provide important mortality data for disease tracking and public health research.
- Cause of death is documented by accurately listing the sequence of events leading to the death.
- Electronic death registration, now replacing paper certificates in New York City, facilitates more accurate and timely reporting for physicians, hospital staff, and funeral directors.

Death certificates are both important legal documents and essential public health tools. The New York City (NYC) Health Department and other government agencies, as well as hospitals, researchers, and community-based organizations, use statistics based on official causes of death recorded on death certificates. These data describe the health of a community, identify priority public health needs, allocate resources, and evaluate interventions. Incomplete or nonspecific reporting can lead to under- or overcounting of causes of death, which can incorrectly affect interventions, policy, and funding. For example, reporting cardiopulmonary arrest as the cause of death without recording its etiology (e.g., renal disease or metastatic breast cancer) may underestimate mortality due to the true underlying illness while overstating the impact of heart disease.[1]

NYC law requires that all deaths be reported within 72 hours. Death certificates provide prompt, accurate information to local and state health departments and, if necessary, the Centers for Disease Control and Prevention (CDC) to identify outbreaks and emergencies, such as pandemic flu or deaths due to excessive natural heat (heat wave deaths).

Rapid reporting also enables families to settle estates quickly and helps government agencies prevent the fraudulent use of birth certificates, driver's licenses, Social Security, and other entitlements.

Because swift and accurate documentation of cause of death (and other significant conditions and events related to that cause) is crucial to public health reporting and surveillance, it is important that physicians have a thorough understanding of how to complete the cause of death section correctly.

TAKE CARE NEW YORK

http://www.nyc.gov/html/doh/downloads/pdf/chi/chi27-9.pdf

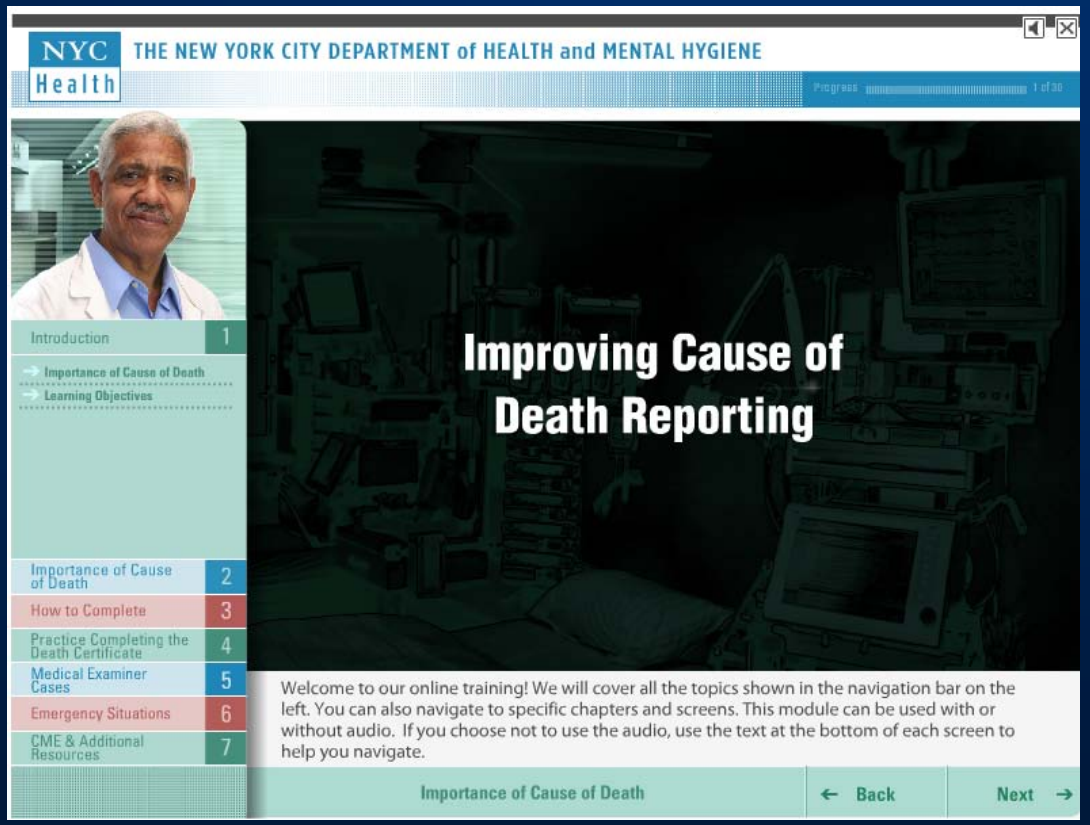
Training format

- Many studies show training leads to significant improvement in accuracy of cause of death statements
- Degree of improvement varies with type of training
  - Printed materials least helpful
  - Interactive approaches associated with the greatest change (≥7 published studies)
- Audit programs helpful, but labor intensive and of questionable sustainability

Teaching physicians how to record cause of death

E-learning Module

- Launched 2008
- Self-paced
- Interactive
- CME credits

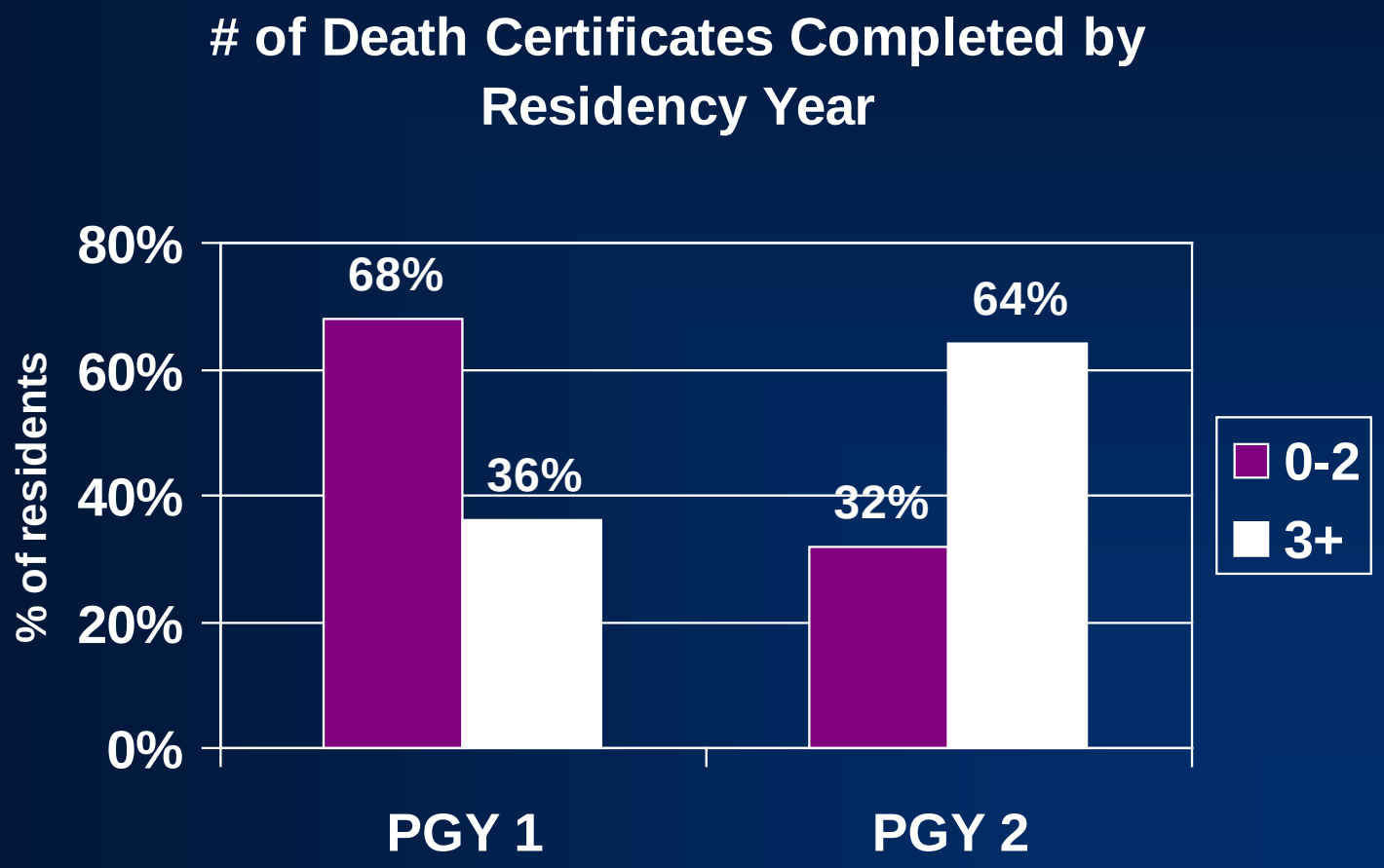


http://www.nyc.gov/html/doh/media/video/icdr/index.html

Evaluation of the NYC Cause of Death E-learning Module

- 114 PGY1 residents (internal medicine; general surgery) sent email with invitation to complete on-line:
  - Pretest
  - Training module
  - Evaluation of module
  - Posttest (same as pretest)
- 113 PGY2 residents (internal medicine; general surgery; emergency medicine) sent email with invitation to complete on-line:
  - Test (same as PGY1 pre/posttest)
  - Survey describing their experience completing death certificates

Experience with Death Certificates

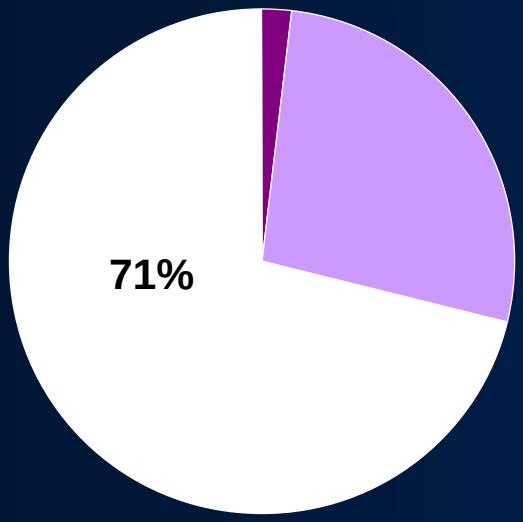


Comparison of Knowledge Test Scores

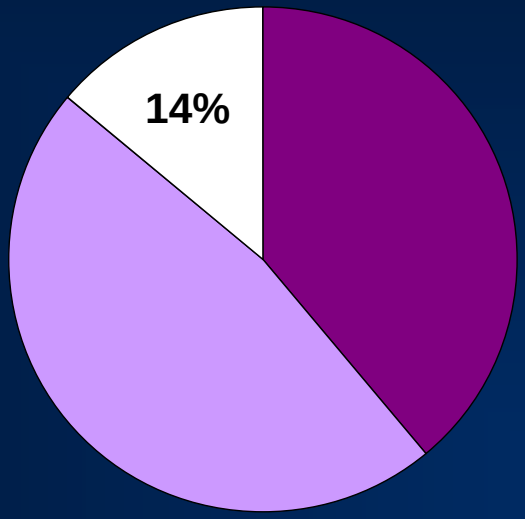
- Prior to course, average knowledge test score was comparable for PGY1 and PGY2 residents (59% vs. 61%, $p=0.89$)

- Post-course, average knowledge test score among PGY1 residents improved significantly (59% to 72%, $p<0.001$)

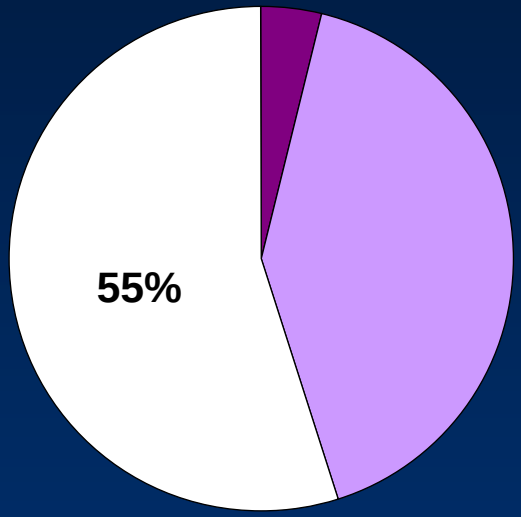
Perceived Expertise Completing Death Certificates



PGY1 Pre-course



PGY1 Post-course



PGY2

Very knowledgeable
Somewhat knowledgeable
Slightly knowledgeable

Improving the e-learning module: Lessons learned

- Clearer, more detailed coverage of frequently misunderstood concepts
  - Mechanisms vs. causes of death
  - Specific vs. non-specific diagnoses
- More sample cases for additional practice
- Cases that cover a broader spectrum of diseases and specialties
- Integrated post-course evaluation

Electronic Death Registration

- Ongoing initiative for development and implementation of EDR across the US
- Once in place could offer a number of benefits:
  - Improved timeliness of death registration
  - Potential for user-friendly data entry
  - Potential for on-line instructions and help
  - Facilitation of real-time q/a review
  - Increased accuracy and timeliness of cause of death analysis and reporting

625 :Test Test SEP-01-2009

Cause of Death

NCHS Recommendations for Entry of Cause of Death

Enter the chain of events- diseases or complications- that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the UNDERLYING CAUSE (disease that initiated the events resulting in death) LAST.

Cause of Death		Approximate Interval Onset to Death
PART I Line a	respiratory failure Immediate Cause (Final disease or condition resulting in death)	
Line b	aspiration pneumonia Due or as a consequence of	
Line c	Parkinson's disease Due or as a consequence of	
Line d	 Due or as a consequence of	
PART II Other significant conditions		

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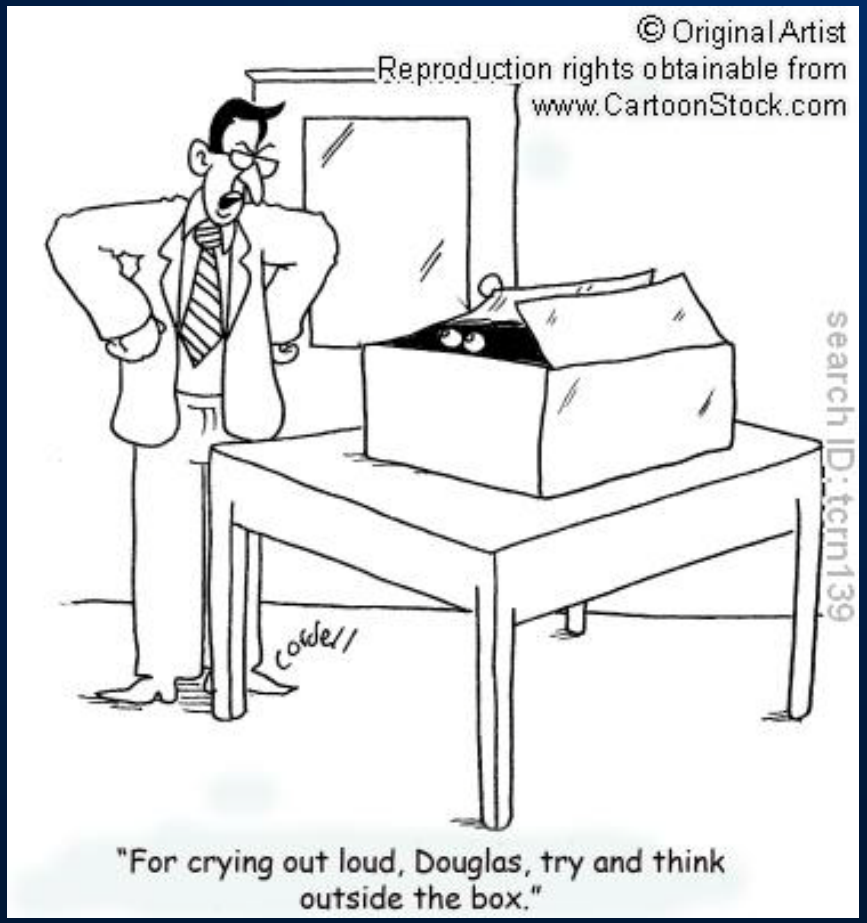
Now for the fun part…



EDR Wish List

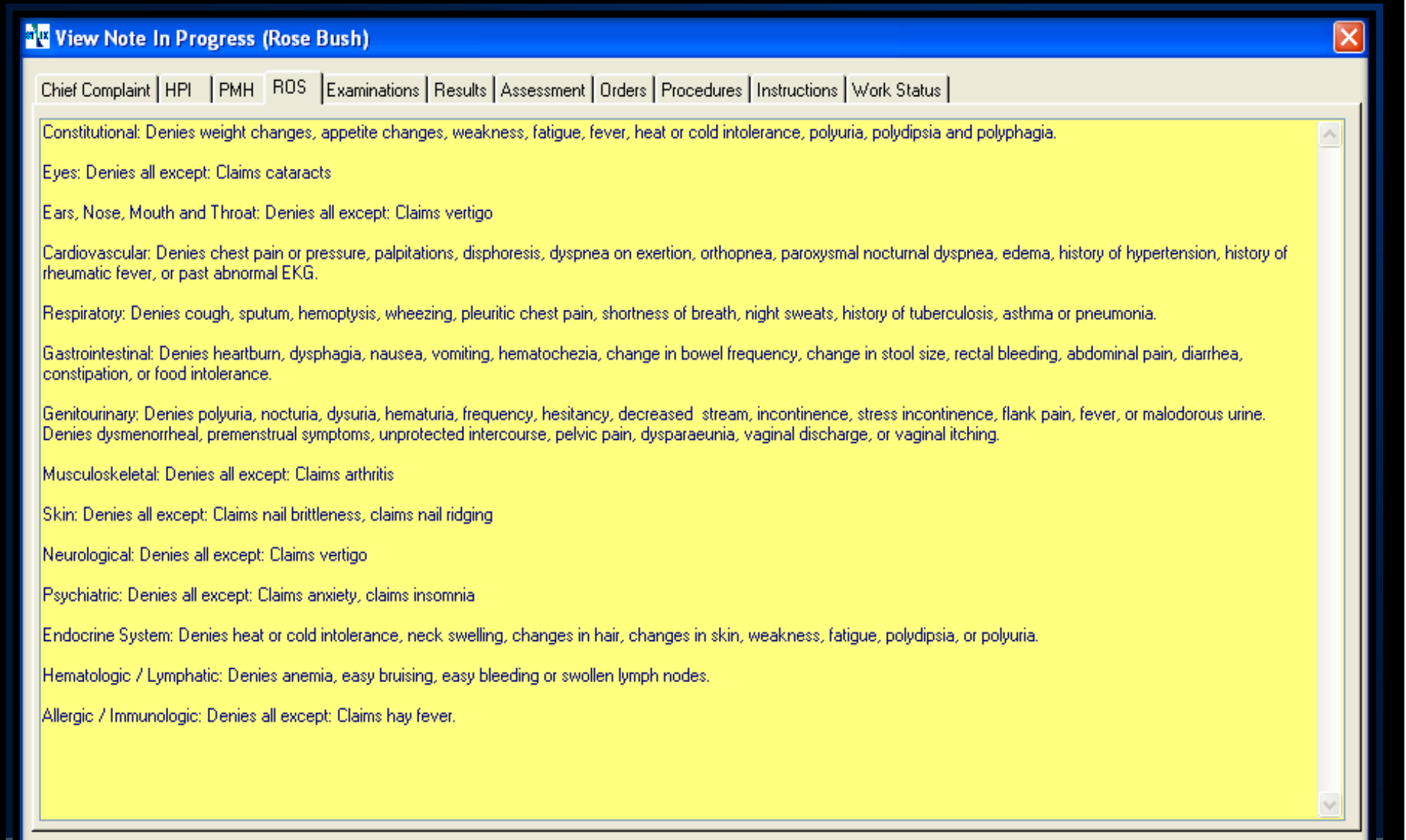
- Instant sequence analysis and coding
- “Smart” search capability for disease terms
- Smart form for cause of death entry

Smart Form

Smart Form Review of Systems

Review of Systems	If a system is entirely Negative, check "All Normal"; otherwise, check each Positive Exception below			
Constitutional: ☐ All Normal	☐ change in appetite	☐ cold intolerance	☐ fatigue	☐ fever
	☐ heat intolerance	☐ polydipsia	☐ polyphagia	☐ polyuria
	☐ weakness	☐ weight gain	☐ weight loss	
Eyes: ☐ All Normal	☐ blurred vision	☐ cataracts	☐ dimness	☐ diplopia
	☐ excess tearing	☐ flashing lights	☐ glaucoma	☐ itching
	☐ pain	☐ redness		
Ears, Nose, Mouth and Throat: ☐ All Normal	☐ bleeding gums	☐ ear discharge	☐ earaches	☐ frequent sore throats
	☐ hearing loss	☐ hoarseness	☐ nasal discharge	☐ sinus problems
	☐ tinnitus	☐ vertigo		
Cardiovascular: ☐ All Normal	☐ chest pain	☐ chest pressure	☐ diaphoresis	☐ dispnea on exertion
	☐ edema	☐ history of hypertension	☐ history of rheumatic fever	☐ orthopnea
	☐ palpitations	☐ paroxysmal nocturnal dyspnea	☐ prior abnormal EKG	
Respiratory: ☐ All Normal	☐ cough	☐ hemoptysis	☐ history of asthma	☐ history of pneumonia
	☐ history of tuberculosis	☐ night sweats	☐ pleuritic chest pain	☐ shortness of breath
	☐ sputum	☐ wheezing		
Gastrointestinal: ☐ All Normal	☐ abdominal pain	☐ blood in stool	☐ change in bowel frequency	☐ change in stool size
	☐ constipation	☐ diarrhea	☐ dysphagia	☐ food intolerance
	☐ hearburn	☐ hematochezia	☐ nausea	☐ vomiting
Genitourinary: ☐ All Normal	☐ decreased stream	☐ dysmenorrheal	☐ dysparaeunia	☐ dysuria
	☐ fever	☐ flank pain	☐ hematuria	☐ hesitancy
	☐ incontinence	☐ malodorous urine	☐ nocturia	☐ pelvic pain

Smart form output



EDR Wish List

- Instant sequence analysis and coding
- “Smart” search capability for disease terms
- Smart form for cause of death entry
- Seamless integration with the electronic medical record

Summary and Conclusions

- Quality of cause of death data is one of several challenges faced by the vital statistics system
- Interactive training is helpful in improving cause of death data quality
- Electronic death registration and electronic medical records have potential in improving the system

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