

From SSS 1977 To SSS 2000: A Preliminary Analysis of the Data Implications of Changes in Registry Item Codes

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Background

- SEER Summary Stage 1977
 - Intended as a derivative of EOD
 - Not updated as EOD evolved
 - Not updated as timing rules changed
- Since then, SSS 1977 Guidelines used for direct coding in many states
 - Instructions incomplete for that task

SEER Summary Stage 2000

- Changes made to EOD since 1977
- Specific timing rules
- Comprehensive instructions amenable to direct coding
- Specific codes for all primary sites and histologies
- No conversion between SSS 1977 and 2000

The Question

- What data implications accompany the transition from SSS 1977 to SSS 2000?

Specific Issues

- Differences in SSS 1977 and SSS 2000 values for same cases
- Quality of existing registry SSS 1977 data
- State-to-state consistency of SSS 1977 coding

Method

- 3 central registries reabstract lung and female breast cancers diagnosed in 2000
 - Sites important to cancer control
 - Sites have large numbers of cases in redefined stages
 - Staging issues differ between the two sites
 - 2000 prior to introduction of SSS 2000, but recent

Method

- Cases:
 - Invasive carcinoma
 - Reported by in-state hospitals that provided first course treatment
 - Random sample of 200 cases from each site selected from eligible cases from each central registry

Method

- Abstracting by Central Registry CTR staff
- Modified AbstractPlus on registry laptops
 - Identification items available to abstractors
 - Coded SSS 1977, SSS 2000, date of surgery, all text fields relevant to those codes
 - Extraction program stripped identifying information used in field to create submission file
- Central registry consolidated information submitted separately and matched for analysis

Notes on Reabstracting Projects in the HIPAA Environment

- Most abstracting took place before HIPAA
- All 3 states provided information from the NAACCR website
- All 3 states provided supporting information from state laws
- 2 facilities required the state to go through IRB procedures

Recommendations for Projects in the HIPAA Environment

- Need to identify the person in the facility who is responsible for receiving supporting information
- State can prepare a form in advance to place in patient record to state who reviewed the record, when and why
- Once at the facility, approach the tumor registrar who can provide introductions

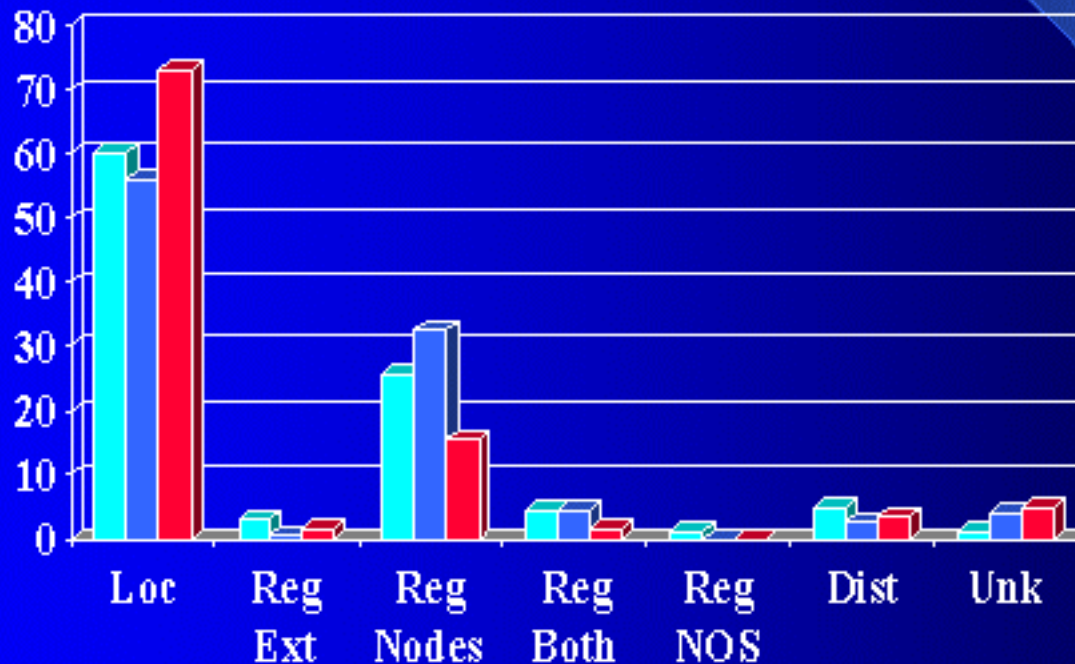
Method

- Central registries
 - Differed in data collection and quality control operations
 - All mature, and all had collected SSS 1977 for several years
 - All used SSS 1977 for publications
 - All collected text during 2000, but it was not available for all cases

What if state registry SSS 1977 distributions were different?

- Unequal proportion unknown
 - committee observed major known/unknown differences in committee member states
 - could represent difference in coding requirements
 - lung: differences in coding or facility work-up?
- Unequal local/regional/distant distribution
 - could represent difference in coding procedures
 - breast: screening effect or differences in coding?

State-to-State Consistency: Registry SSS 1977 Coding Breast Cancer

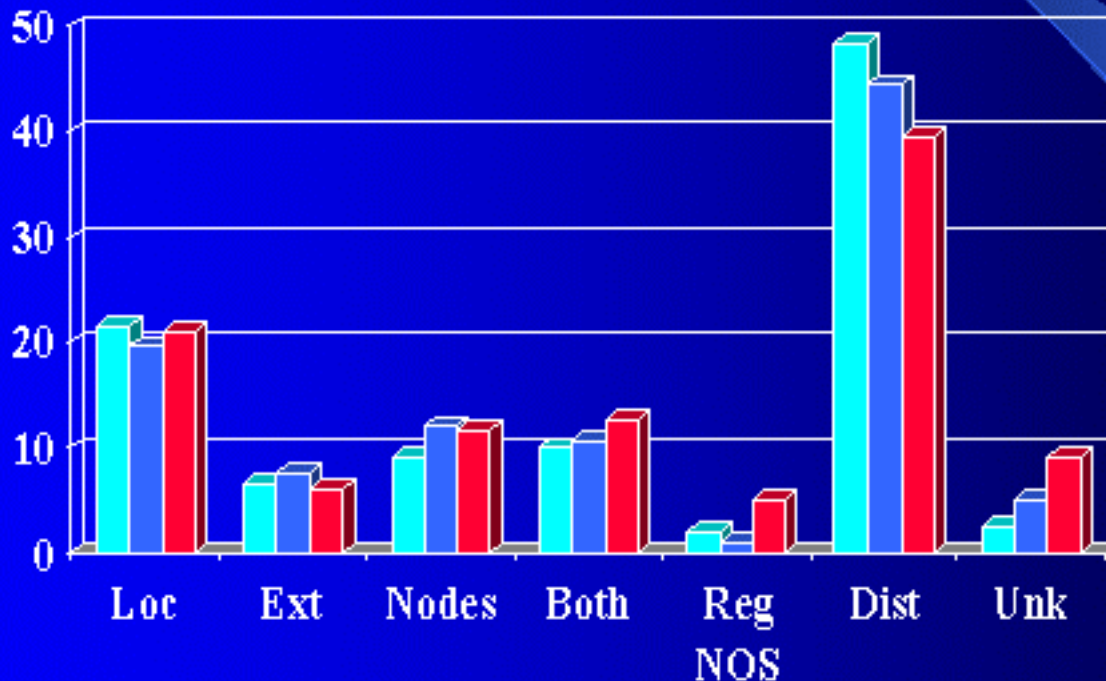


States:
light blue
blue
red

Known/Unknown : no sig difference
Local/Regional/Distant: $p < .05$

State-to-State Consistency: Registry SSS 1977 Coding

Lung Cancer



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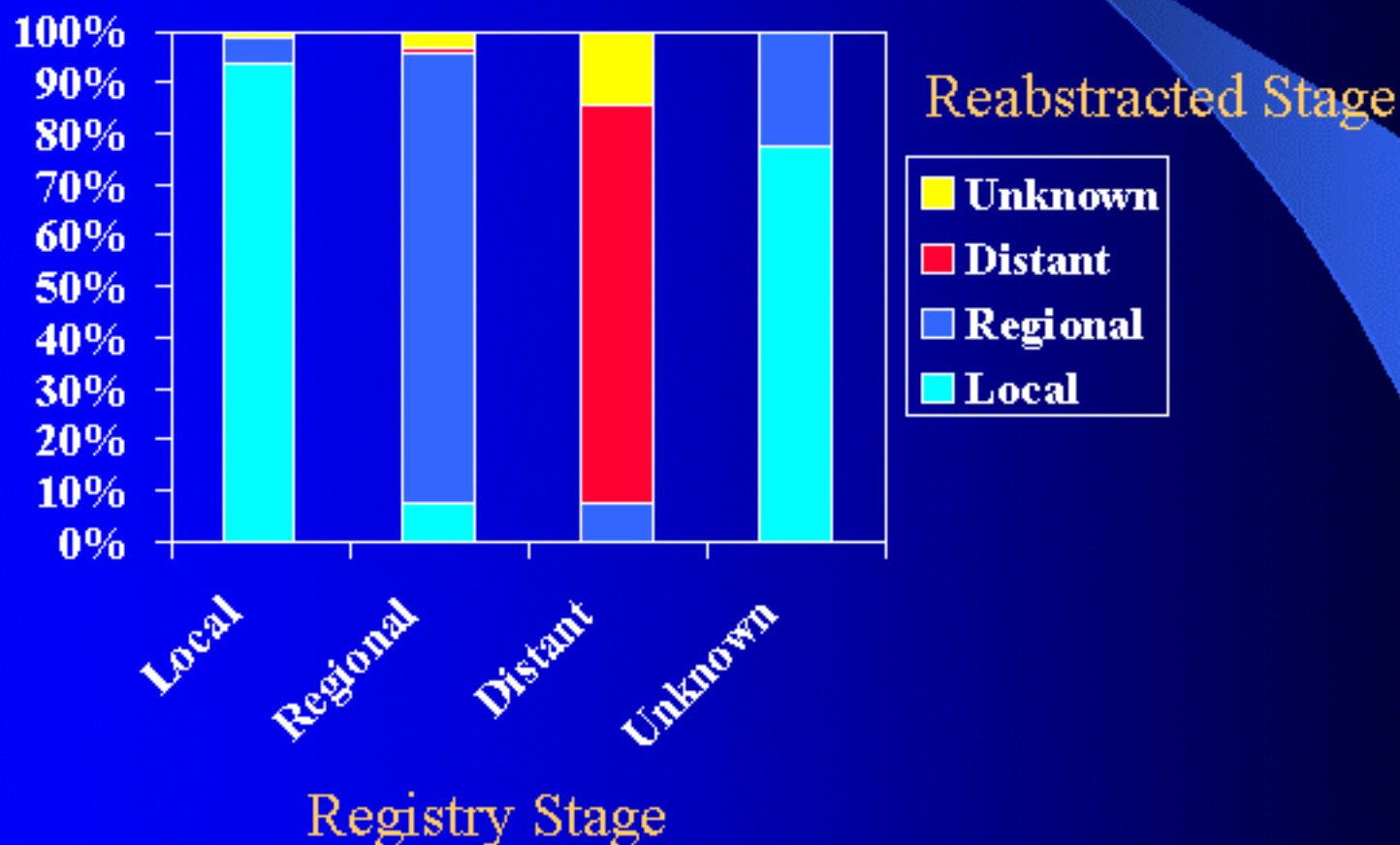
Presenter's note: Due to a series of unavoidable computer problems, one registry had not completed its reabstracting at the time of this presentation. As a consequence, all of the remaining graphics are based data for 2 registries only. All data are to be considered preliminary in this presentation.

What if registry SSS 1977 differed from the reabstracted?

- Coding: were SSS 1977 Guidelines followed when registry data were collected?
 - familiarity with SEER EOD changes
 - “rule of thumb” coding vs. “by the book”
- Registry data are consolidated
 - possible inter-facility discrepancies
 - consolidation procedures themselves

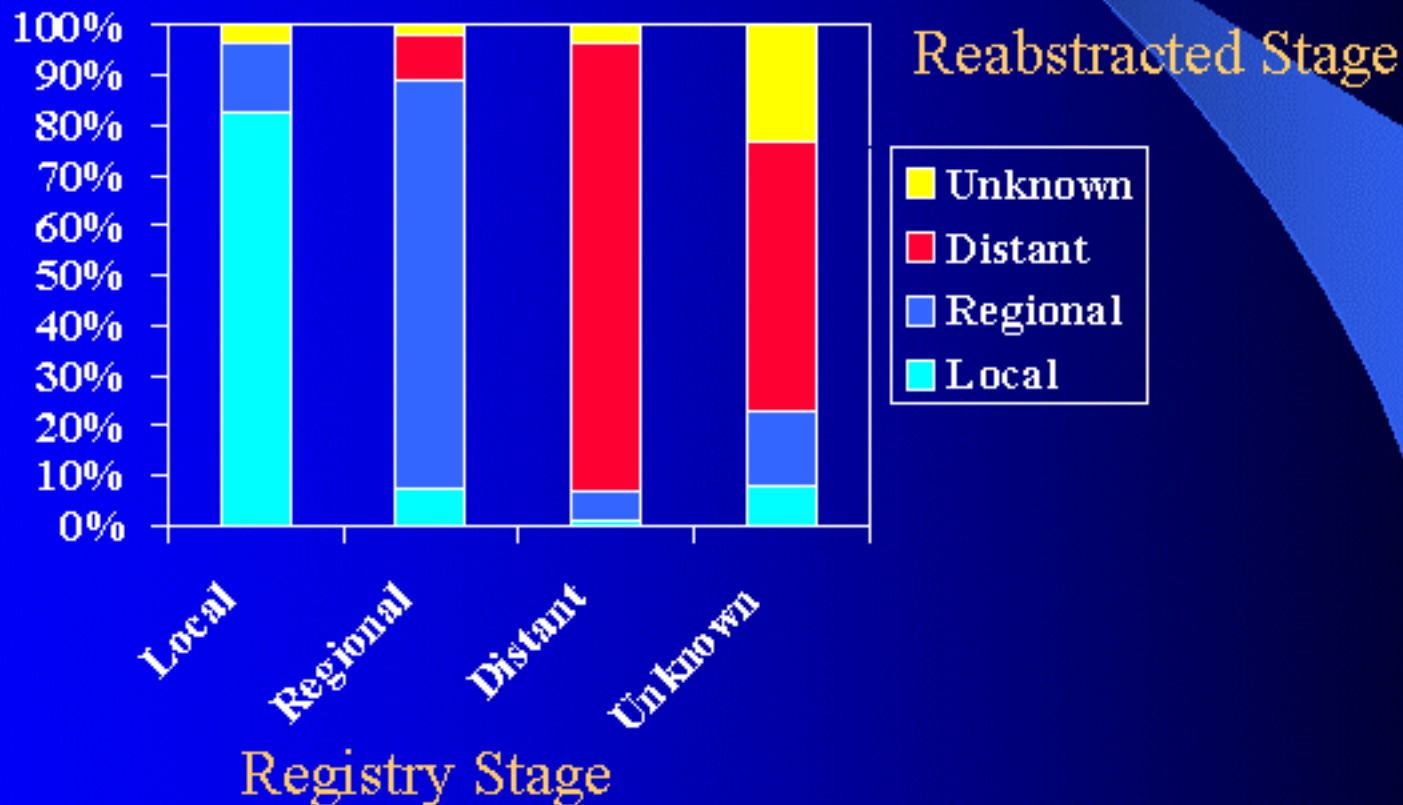
First Look at Registry vs. Reabstract SSS 1977 Stage

Breast



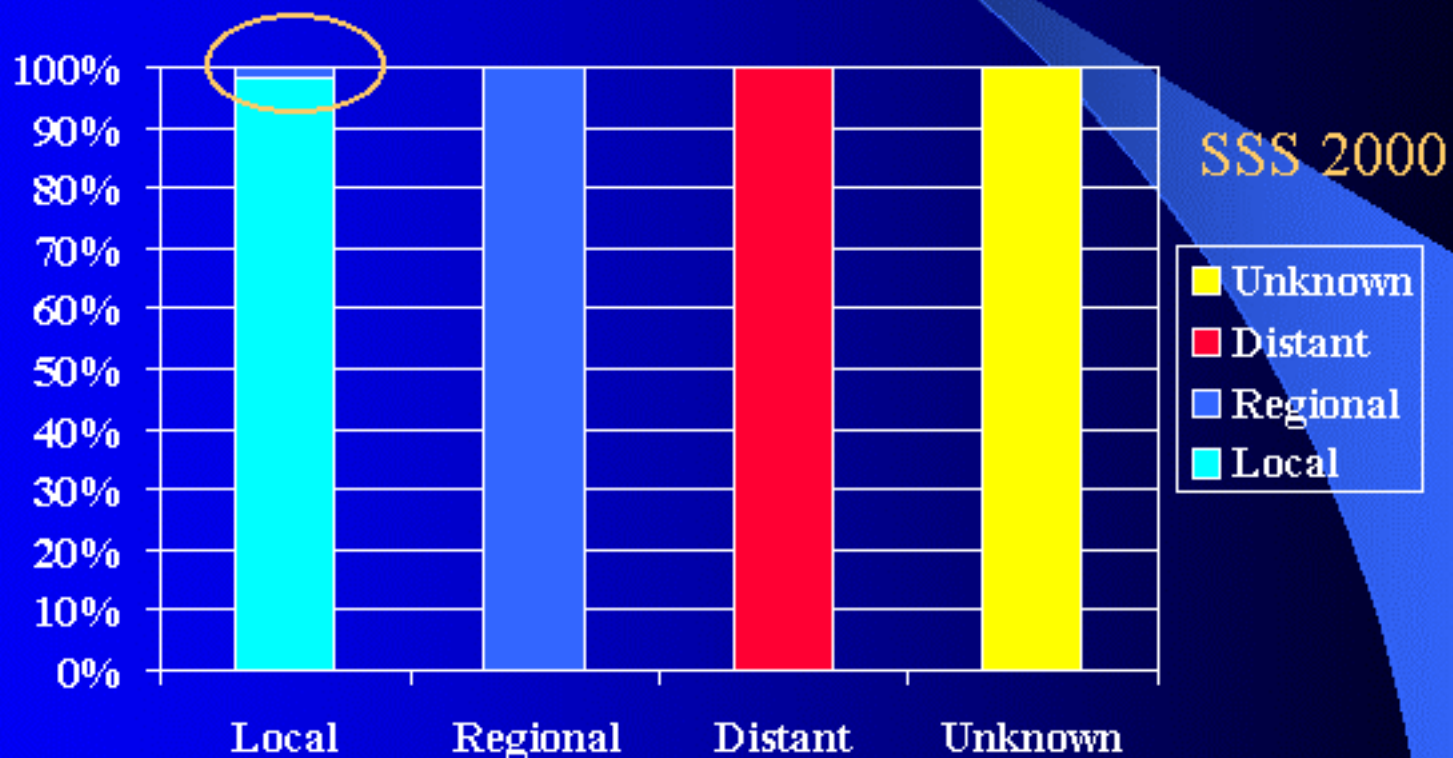
First Look at Registry vs. Reabstract SSS 1977 Stage

Lung



First Look at SSS 2000 Compared to SSS 1977

Breast Cancer



SSS 1977

Breast Cancer Changes

Localized (ignored in the definition) to Regional – Extension

adherence

attachment

fixation

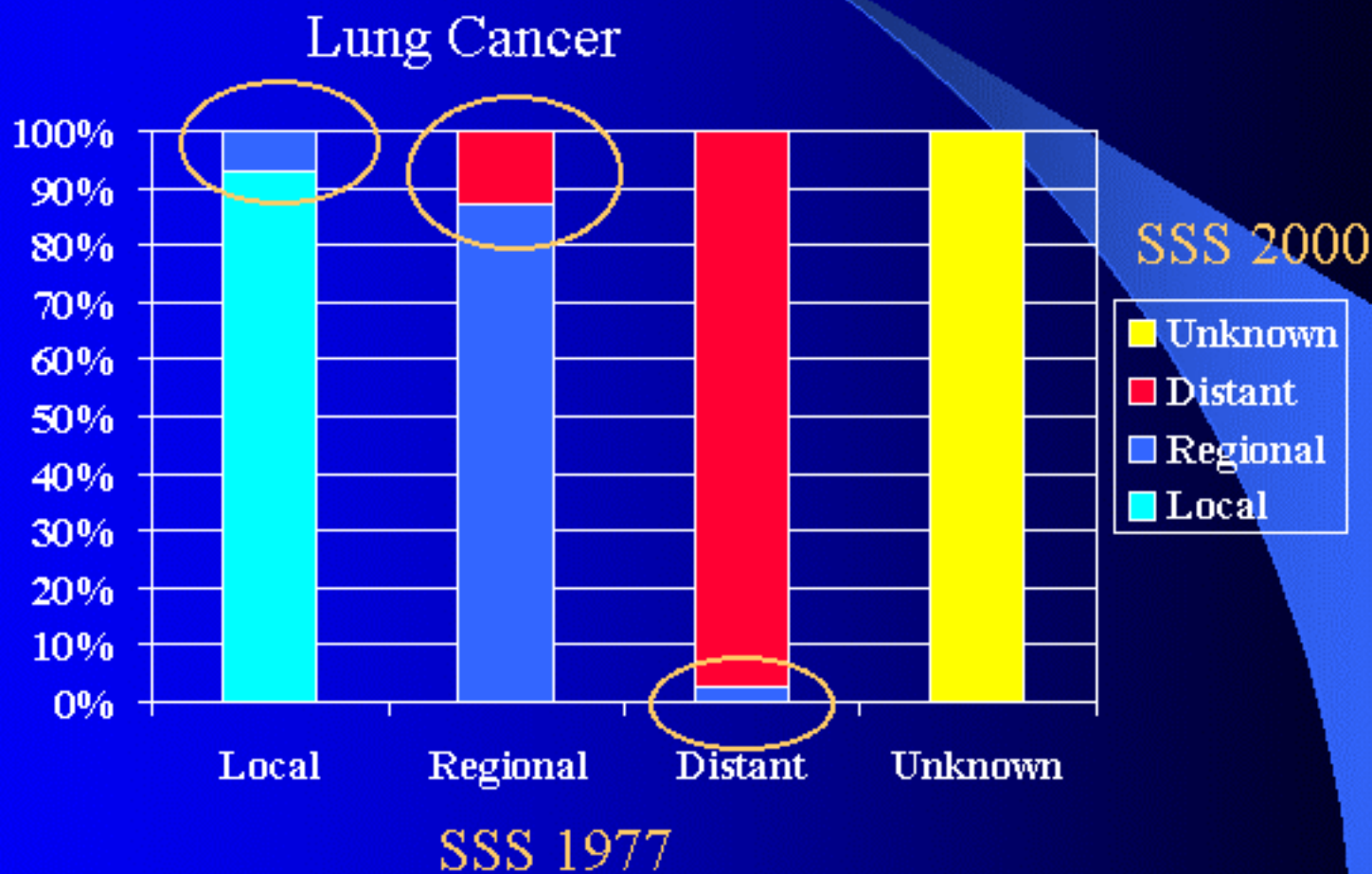
induration

thickening (skin changes)

Distant to Regional – Nodes

ipsilateral infraclavicular (subclavicular)

First Look at SSS 2000 Compared to SSS 1977



Lung Cancer Changes

Localized to Regional:

- multiple masses/separate tumor nodule(s) in the SAME lobe
- tumor of main stem bronchus <2.0 cm from carina

Localized to Distant

- separate tumor nodule(s) in different lobe

Distant to Regional

- aorta

- brachial plexus from superior sulcus

- chest (thoracic) wall

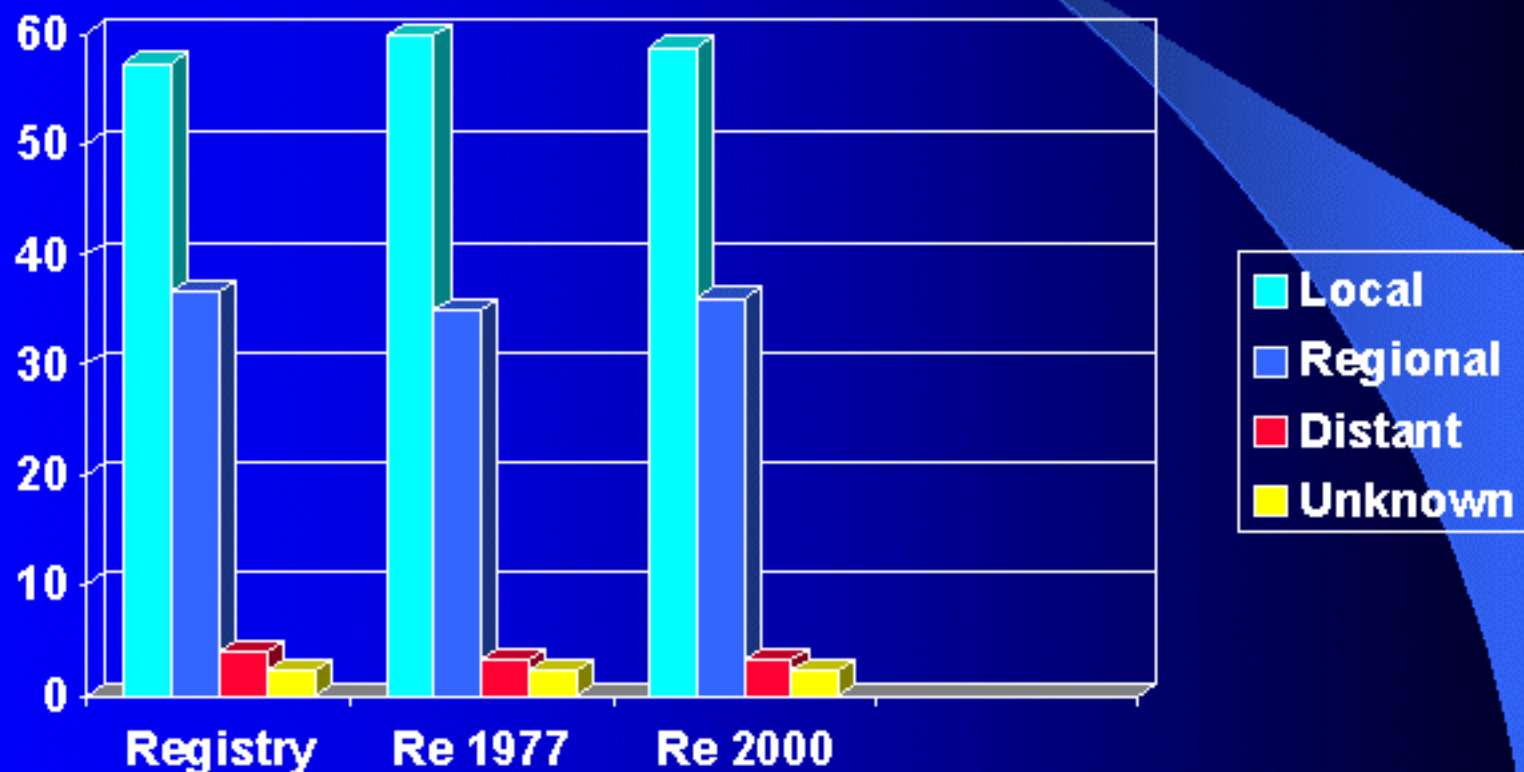
- diaphragm

- pancoast tumor (superior sulcus syndrome)

- parietal (mediastinal) pleura

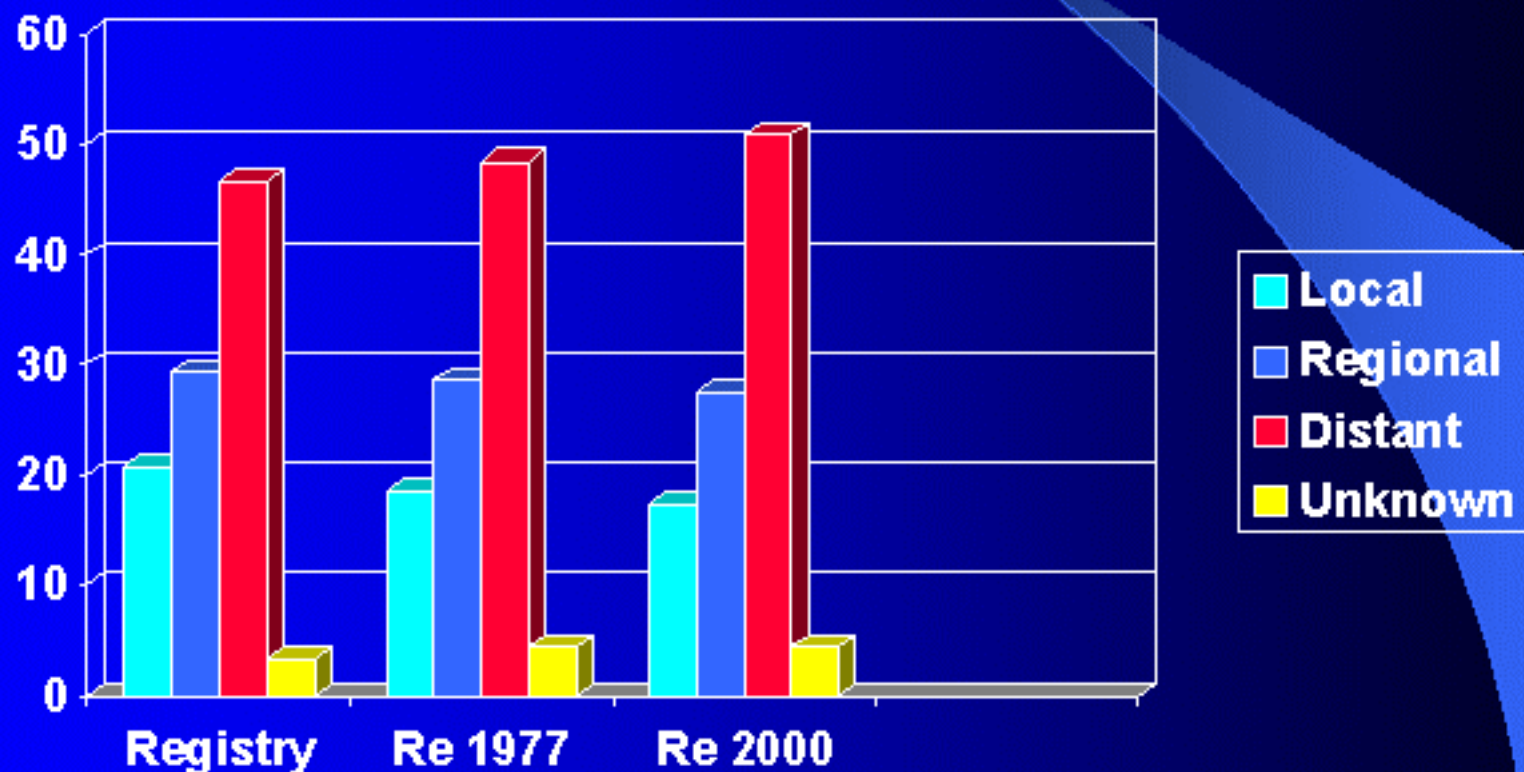
Comparison of Distributions

Breast: 2 Registries



Comparison of Distributions

Lung: 2 Registries



Points to Consider: Preliminary

- The nature of the effect of changing from SSS 1977 to SSS 2000 may depend on your registry's procedures for collecting SSS 1977
- The type and direction of the effect is likely to reflect a compounding of changes and may not be easily deduced from summarized changes in coding definitions
- Specific differences may be few