Variability Among Central Registries in Consolidating Multiple Reports for the Same Individual

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Record Consolidation Test Project

- **GOAL**
  - **Determine whether central registries are consolidating multiple reports on the same patient into the same number of tumors**

Record Consolidation Test Project

OBJECTIVES

- **Create a standardized test file that can be used by all central registries**
  - **Run the test file through their normal (automated and manual) processing**
  - **Export consolidated results**
- **Analyze variability in application of the SEER multiple primary rules**

Methods

- **Contractors created a file of de-identified actual source records**
  - **659 records on 279 patients**
  - **Tested all of the SEER multiple primary rules**
  - **Included a broad range of cancer sites, morphologies, and types of reporting source**
  - **Included records with varying amounts of text**
- **Expert Panel (EP) developed "gold standard" file and determined**
  - **Number of tumors per patient (SEER rules)**
  - **Values for site, histology, behavior, laterality, and date of diagnosis**

Methods, cont.

- **Web text was created to simulate followback to sources**
- **Source record and Expert Panel decision files cleaned up**
  - **Internal consistency**
  - **Pass EDITS**

Technical Issues

Modified source records to pass any registry's edits

- **COC, SEER, NPCR, and NAACCR edits**
- **EOD, TNM, and RX data items**
- **Optional COC data items**
- **Default values for empty data items**
  - **This was the hardest part!**

Technical Issues, cont.

- **Combined test data from 4 contractors**
  - **Used AbstractPlus software**
  - **Printed abstracts for EP to review**
- **Expert Panel reviewed abstracts**
  - **Used answer sheets**
    - **Recorded number of tumors and critical data values**
    - **Specified which rule was used**
    - **Stored in Access Database**

Technical Issues, cont.

Using the test file at a registry

- **Test database recommended, but all records can be identified as test records**
- **Front-End Utility provided**
  - **Updates state, postal code, county, and city**
  - **Updates institutional ID numbers**
  - **Includes option to delete override flags**
- **Split Hospitals Utility provided**

Running the Test

Alpha and beta test of the test file

- **11 central registries**
- **Ran the test file through their normal (automated and manual) processing**

Alpha and Beta Testing Output

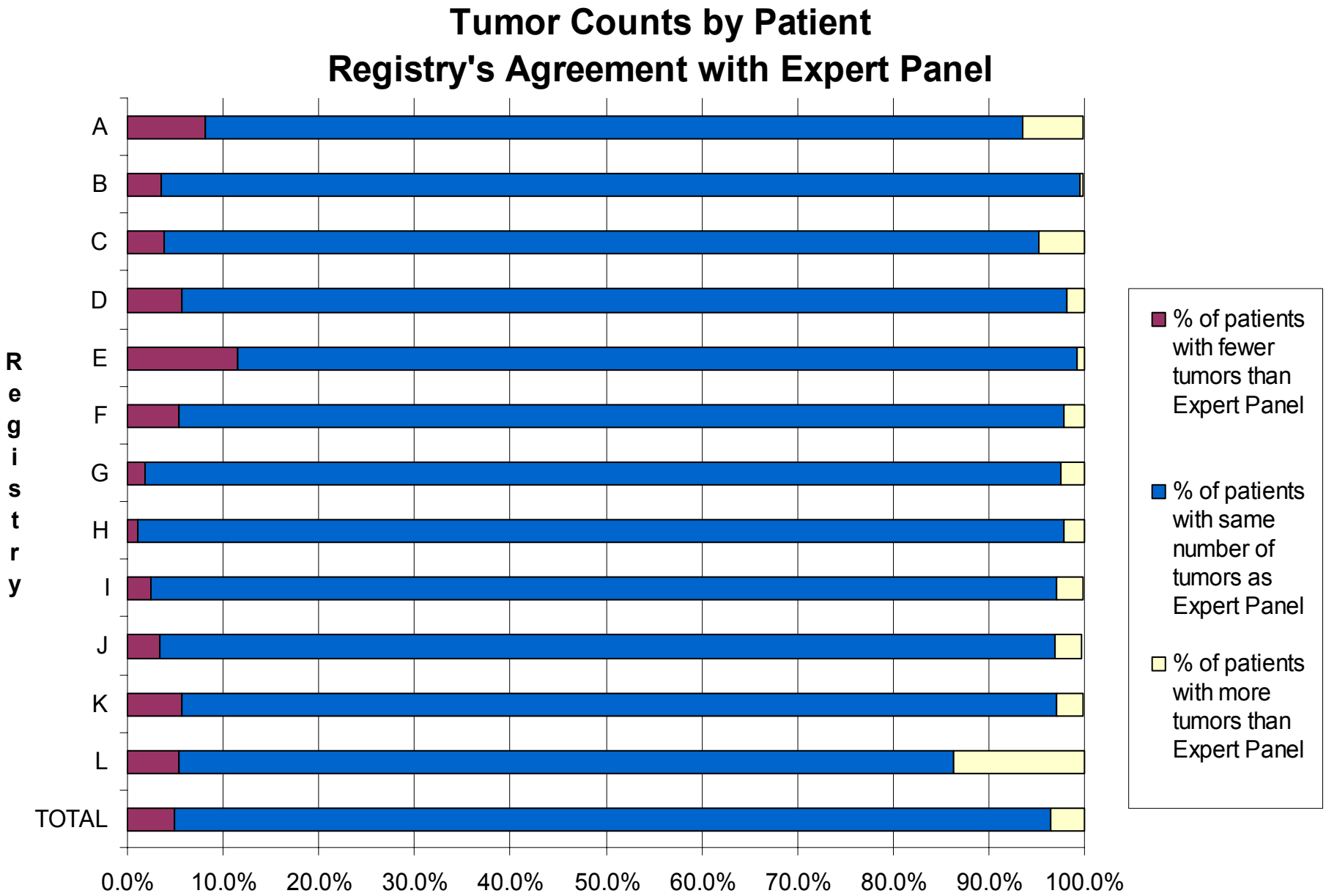
- **12 consolidated files produced by 11 central registries**
  - **Registries A – L in graphs to follow**
- **Compared registry counts to EP decision and to each other**

Profile of Testing Registries

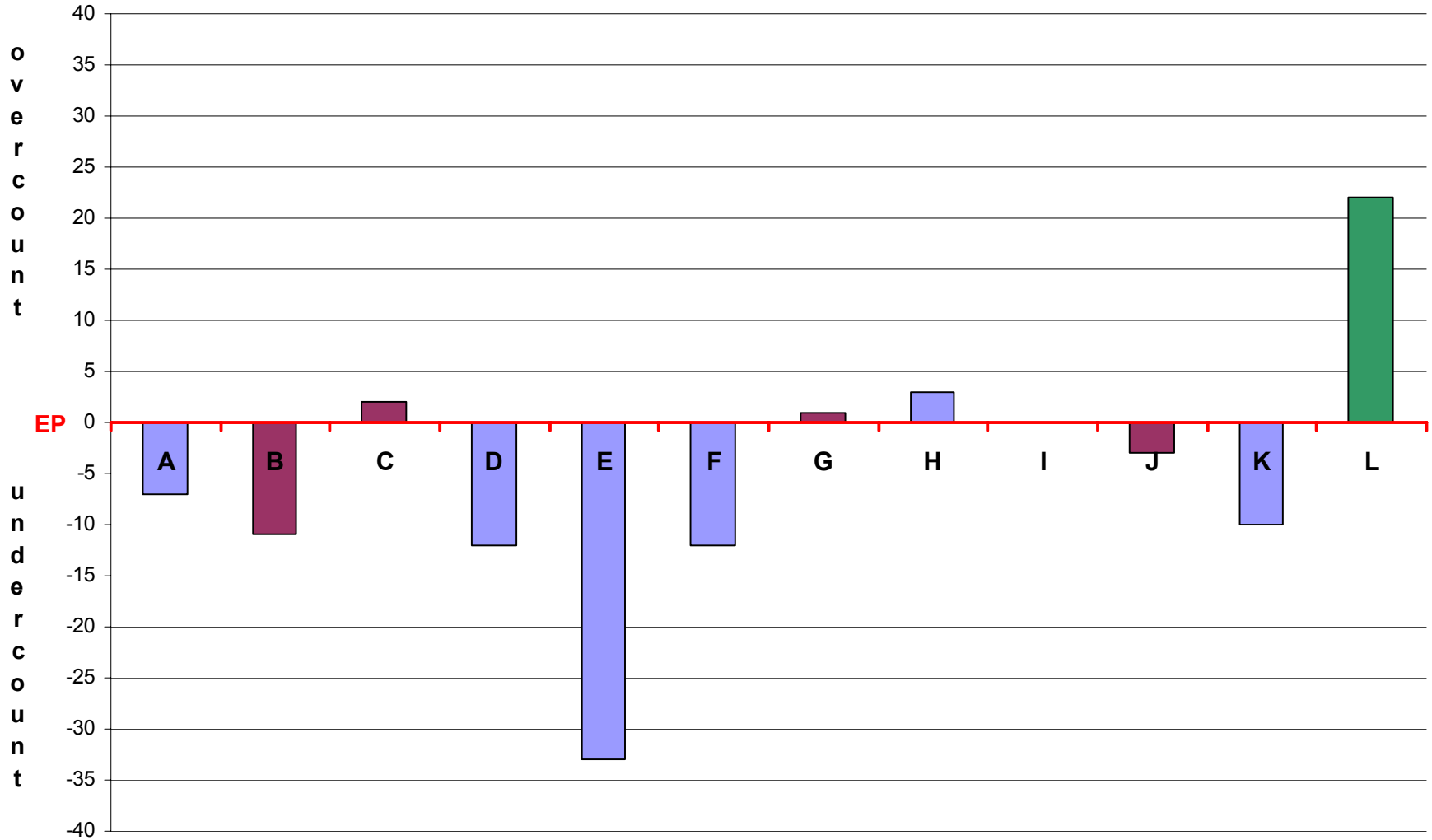
- 11 registries and one automated system (Registry L in graphs to follow)
- Annual caseload 6,000 – 80,000
- 4 SEER (Registries B, C, G, J)
- 0.4 – 7 FTE work on record consolidation
- 1 Registry Plus, 1 IMPATH,
  3 Rocky Mountain Cancer Data System,
  7 own software

Consolidation Test Parameters

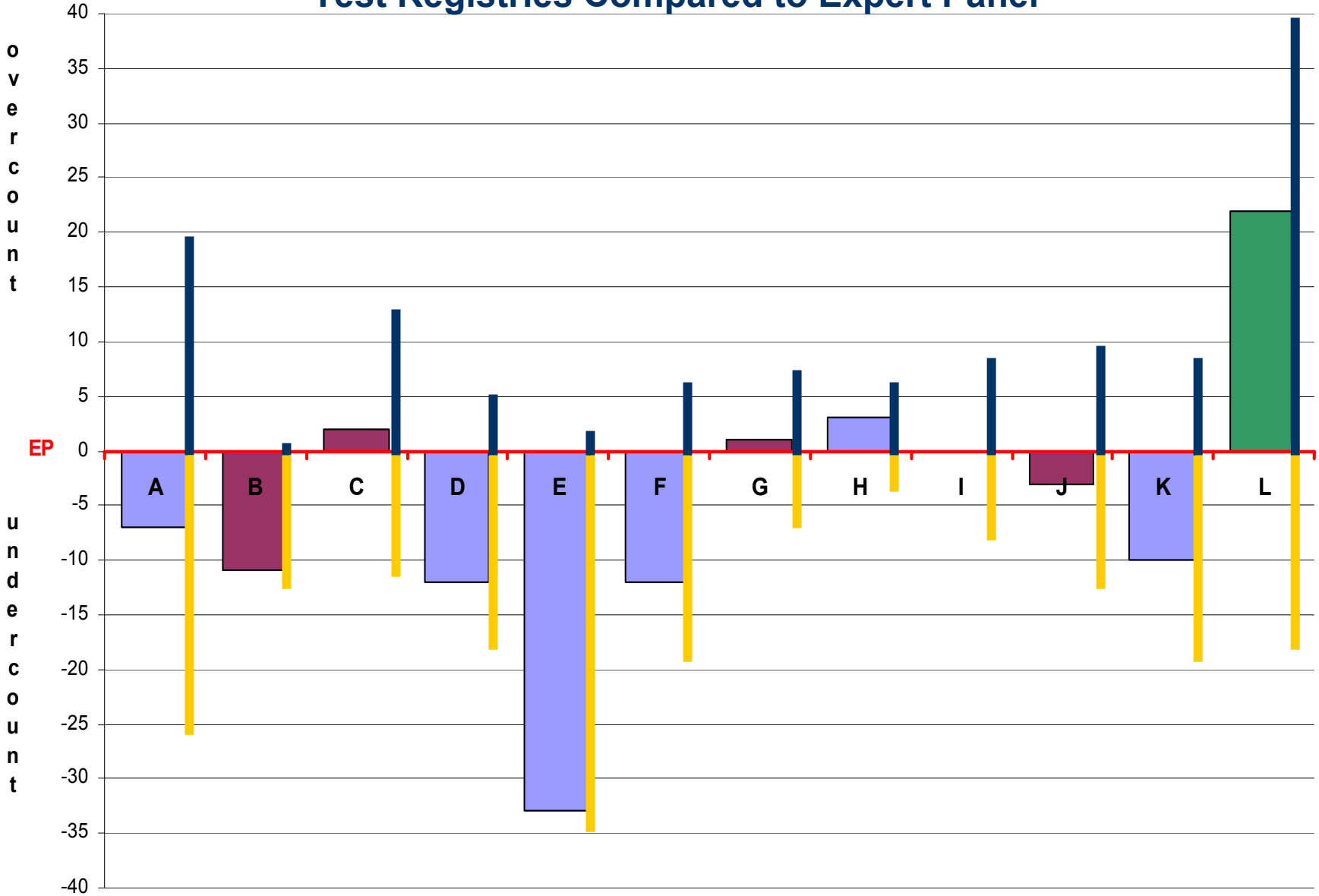
- **File set-up took 0.5 to 20 hours (median 5)**
- **Excluding Registry L,**
  - **Data consolidation took 20 to 180 hours (median 95)**
  - **7 registries were consolidated with 100% manual review**
  - **4 registries were consolidated with 30%, 68%, 70%, and 95% manual review**
- **Registry L (automated system) took 11 minutes to consolidate records, and 100% were completed with no manual review**


Tumor Counts by Patient
Registry's Agreement with Expert Panel
Registry
A
B
C
D
E
F
G
H
I
J
K
L
TOTAL
0.0%
10.0%
20.0%
30.0%
40.0%
50.0%
60.0%
70.0%
80.0%
90.0%
100.0%
% of patients with fewer tumors than Expert Panel
% of patients with same number of tumors as Expert Panel
% of patients with more tumors than Expert Panel

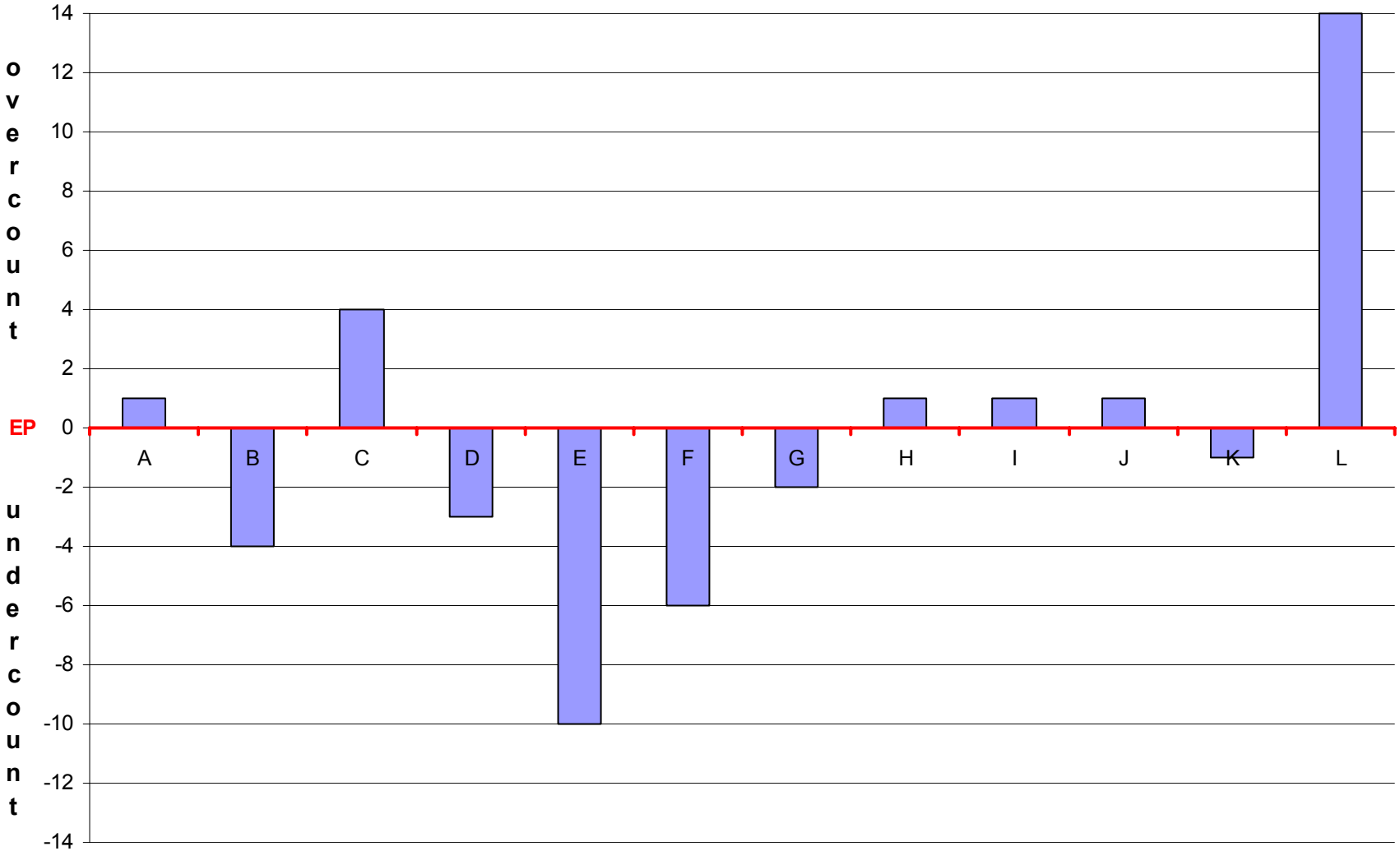
Differences in Total Tumor Counts
Test Registries Compared to Expert Panel



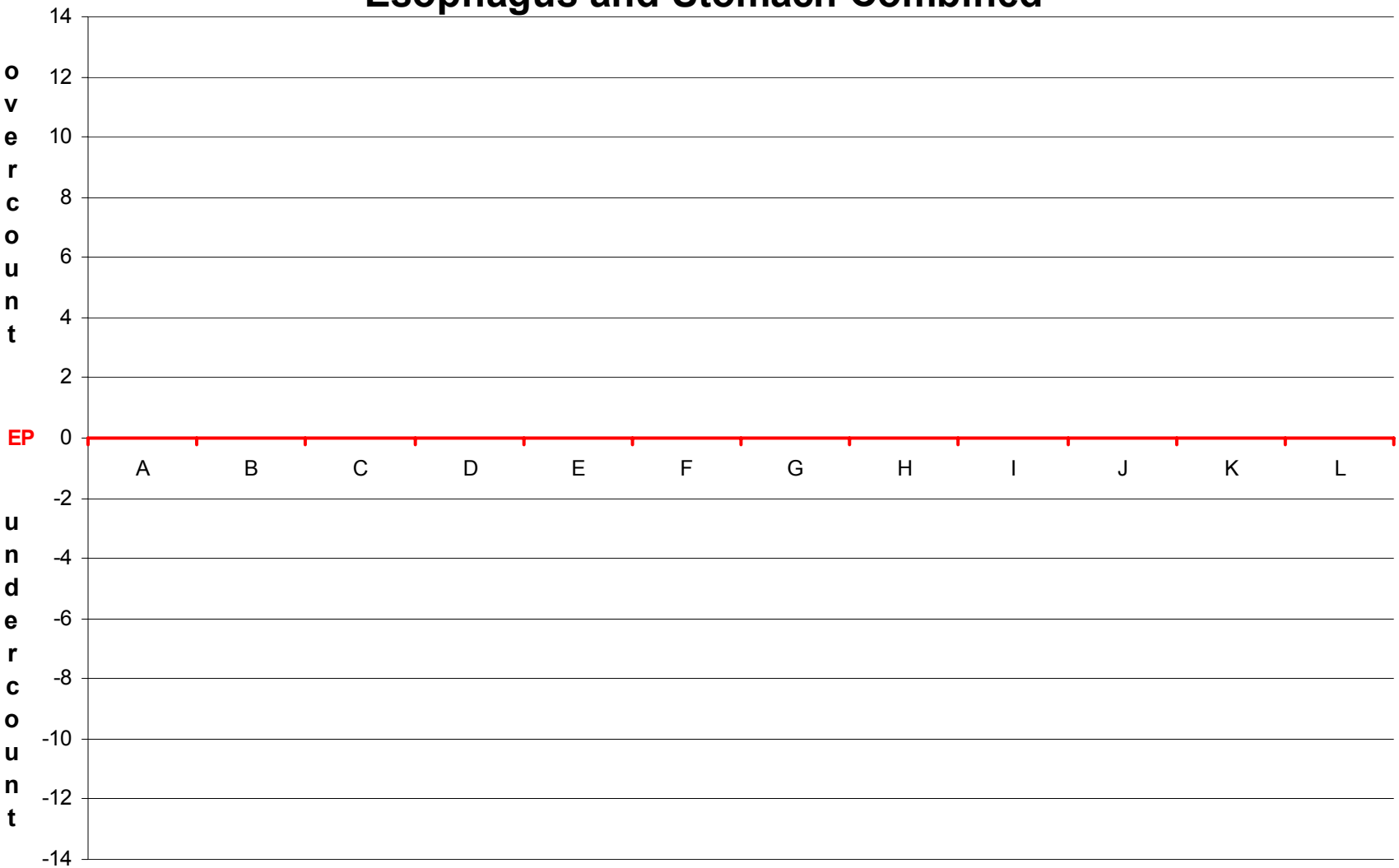
Variability in Total Tumor Counts
Test Registries Compared to Expert Panel

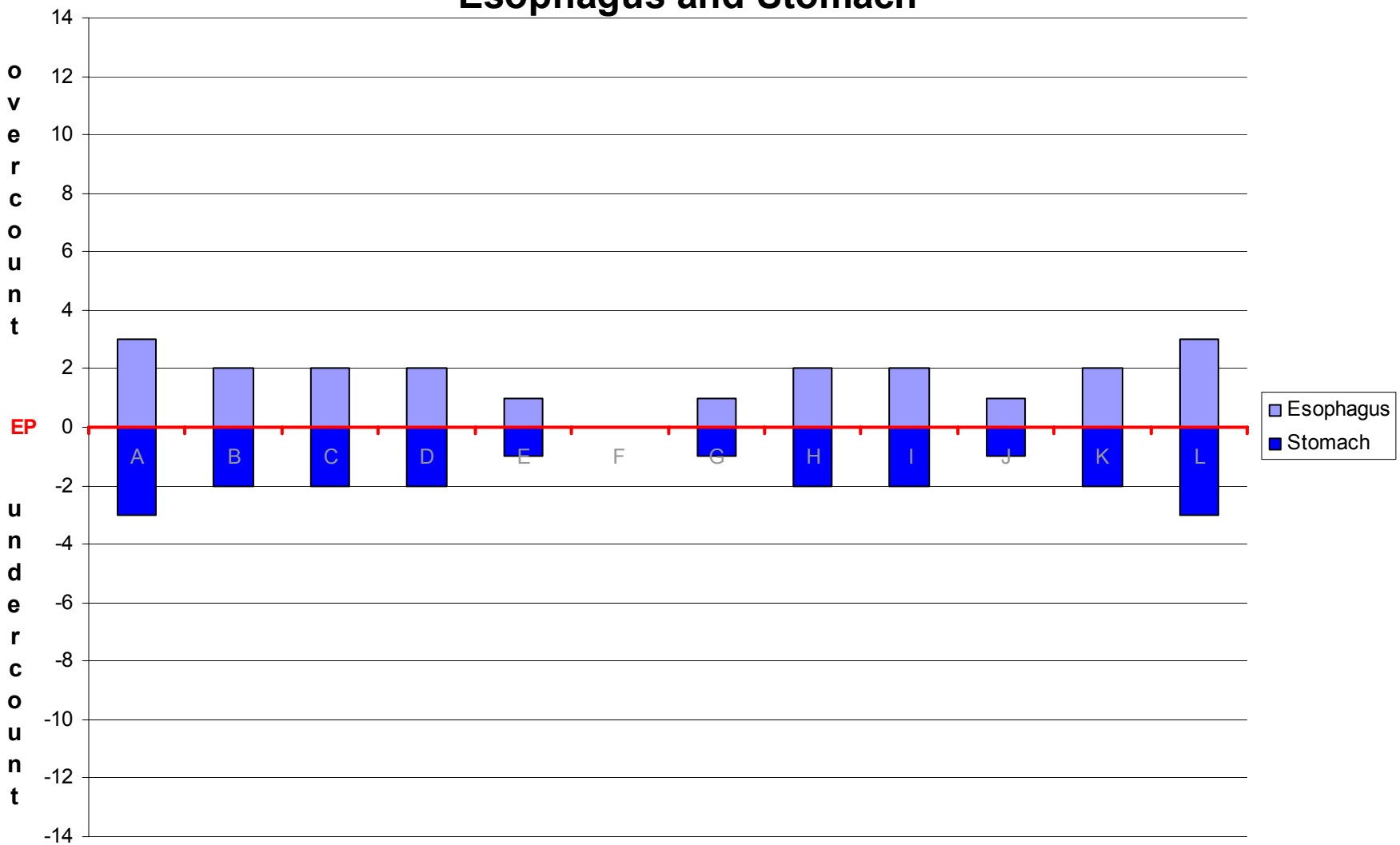


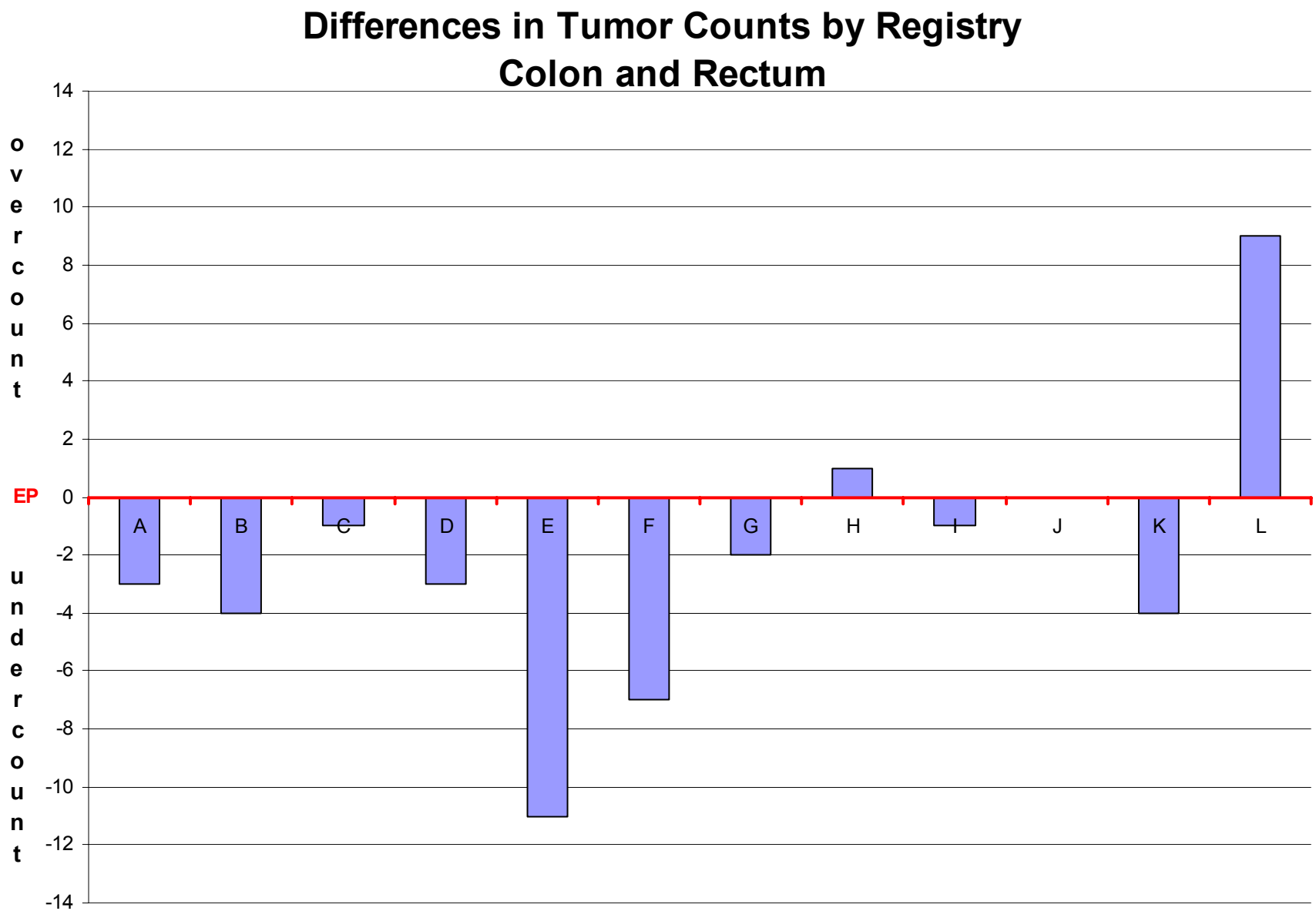
Differences in Tumor Counts by Registry
Digestive System



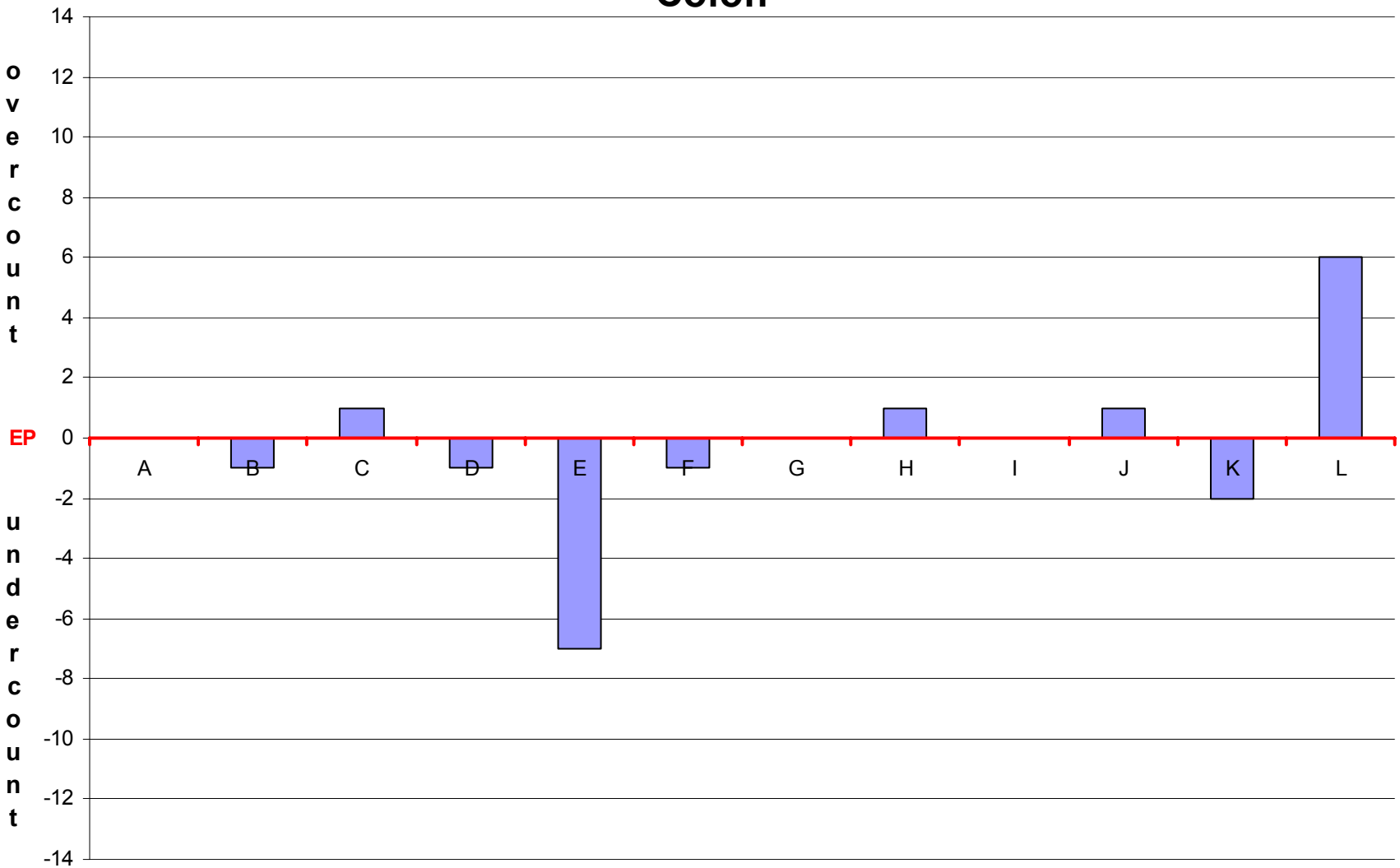
Differences in Tumor Counts by Registry
Esophagus and Stomach Combined

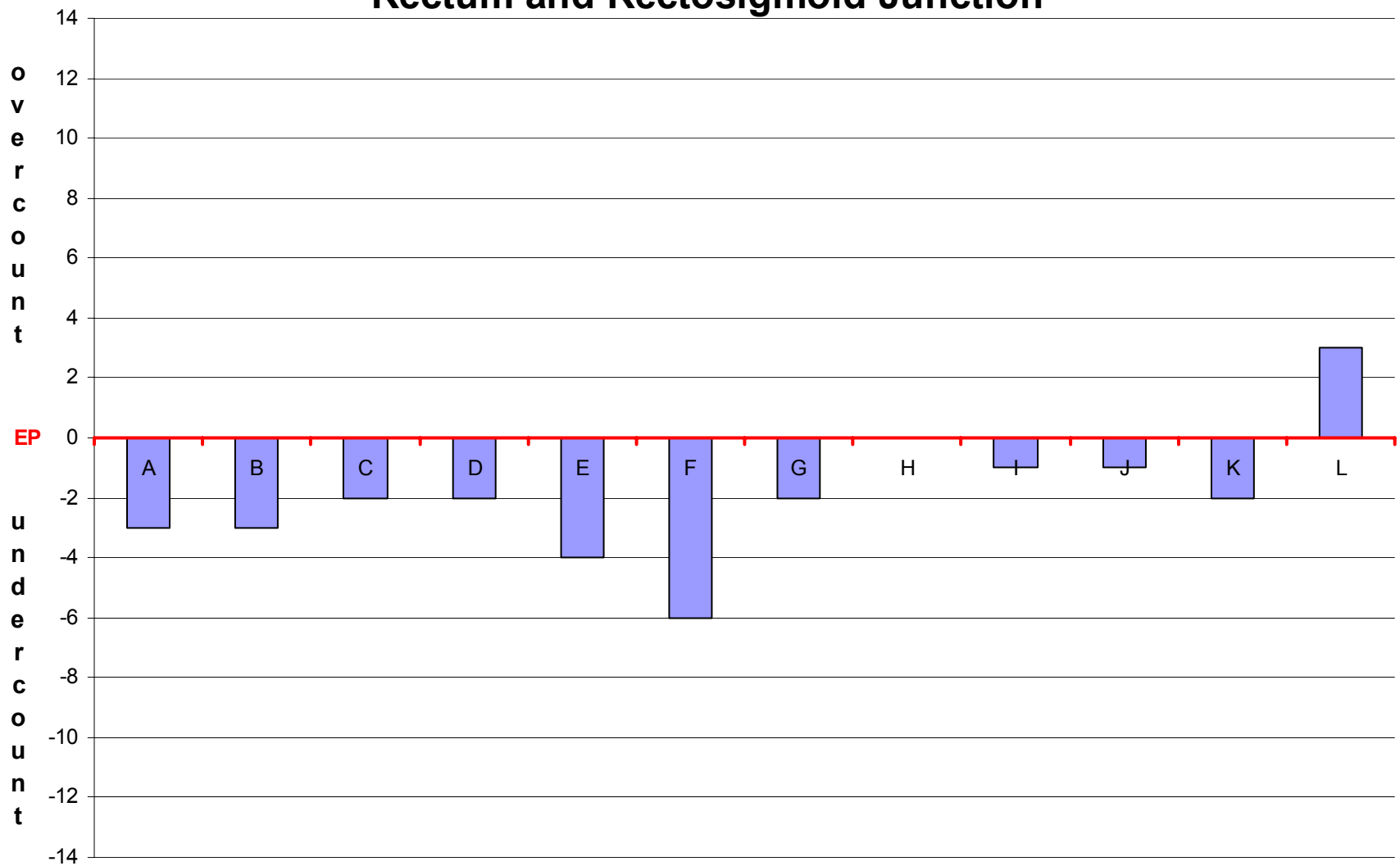



Differences in Tumor Counts by Registry
Esophagus and Stomach
overcount
undercount
EP
14
12
10
8
6
4
2
0
-2
-4
-6
-8
-10
-12
-14
A
B
C
D
E
F
G
H
I
J
K
L
Esophagus
Stomach

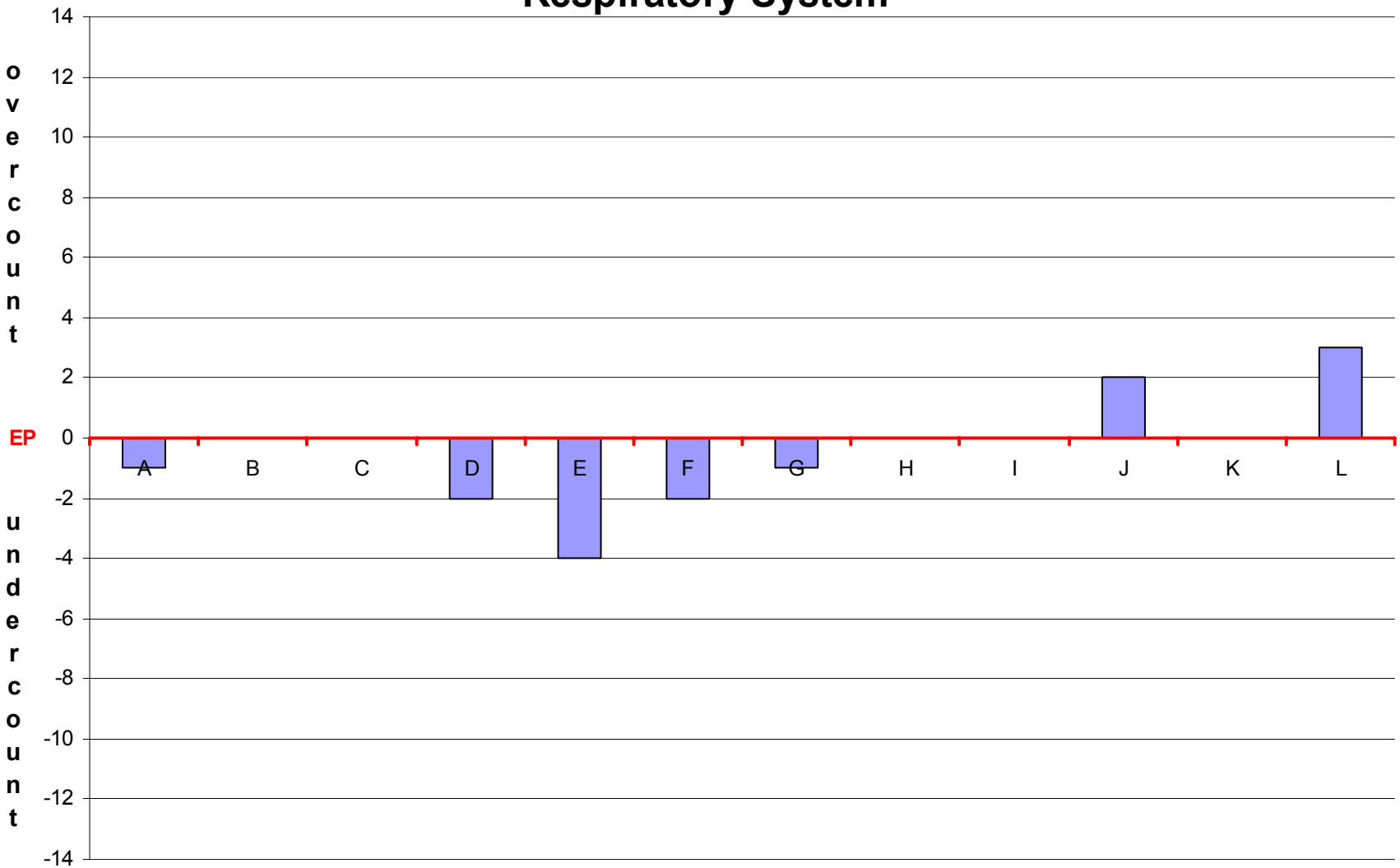

Differences in Tumor Counts by Registry
Colon and Rectum
overcount
undercount
EP
14
12
10
8
6
4
2
0
-2
-4
-6
-8
-10
-12
-14
A
B
C
D
E
F
G
H
I
J
K
L

Differences in Tumor Counts by Registry
Colon

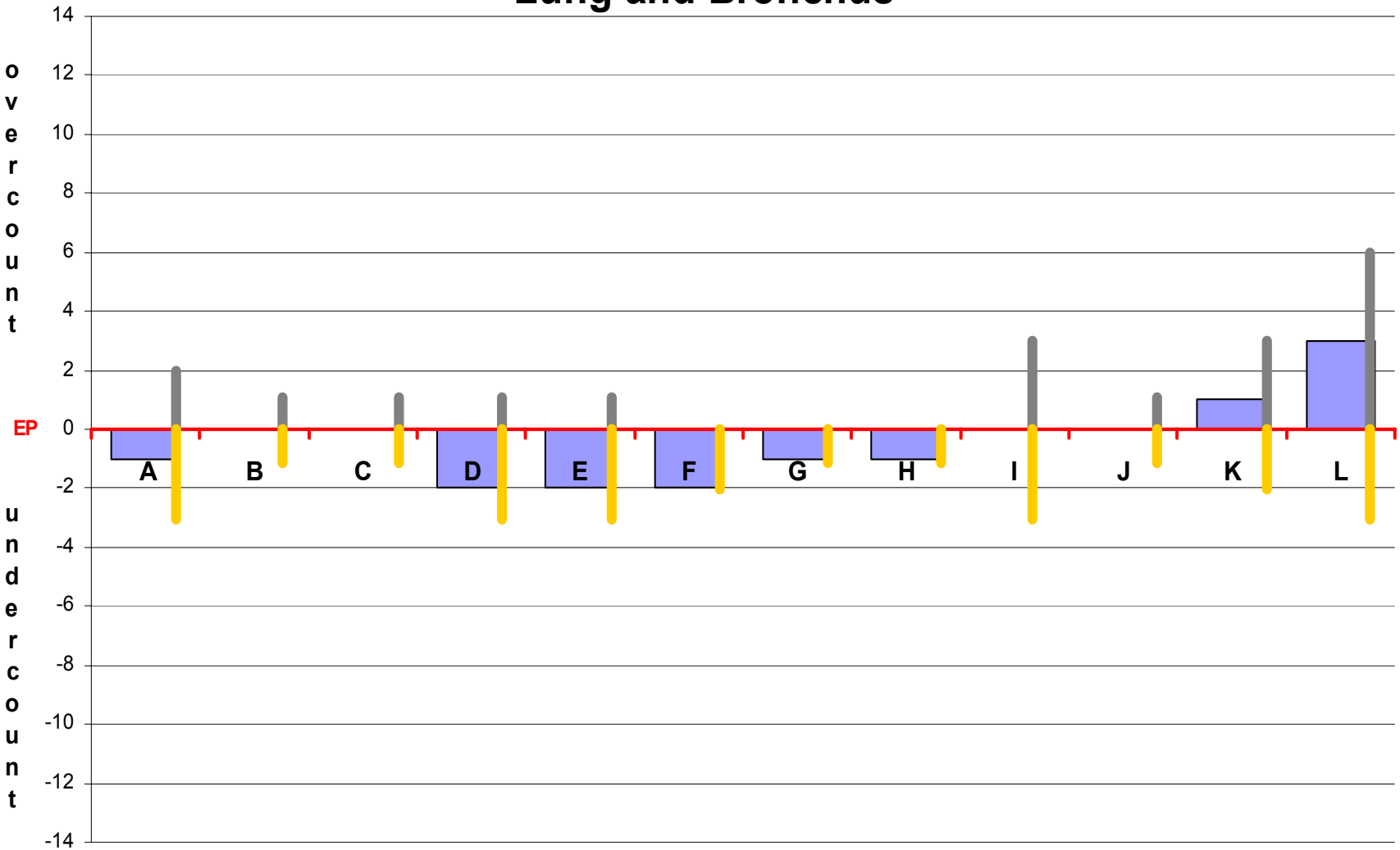


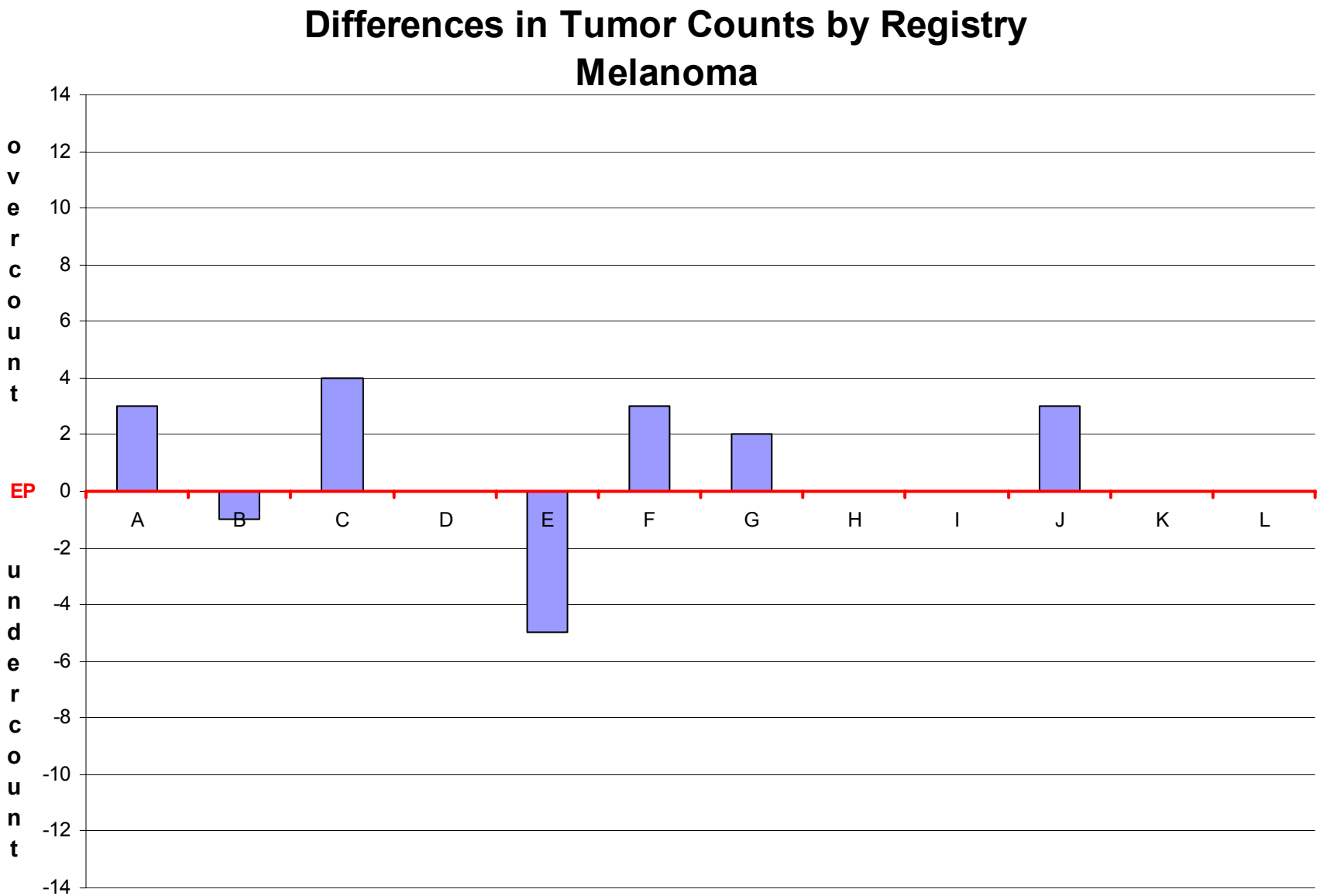

Differences in Tumor Counts by Registry
Rectum and Rectosigmoid Junction
overcount
undercount
EP
14
12
10
8
6
4
2
0
-2
-4
-6
-8
-10
-12
-14
A
B
C
D
E
F
G
H
I
J
K
L

Differences in Tumor Counts by Registry
Respiratory System



Differences in Tumor Counts by Registry
Lung and Bronchus




Differences in Tumor Counts by Registry
Melanoma
overcount
undercount
EP
14
12
10
8
6
4
2
0
-2
-4
-6
-8
-10
-12
-14
A
B
C
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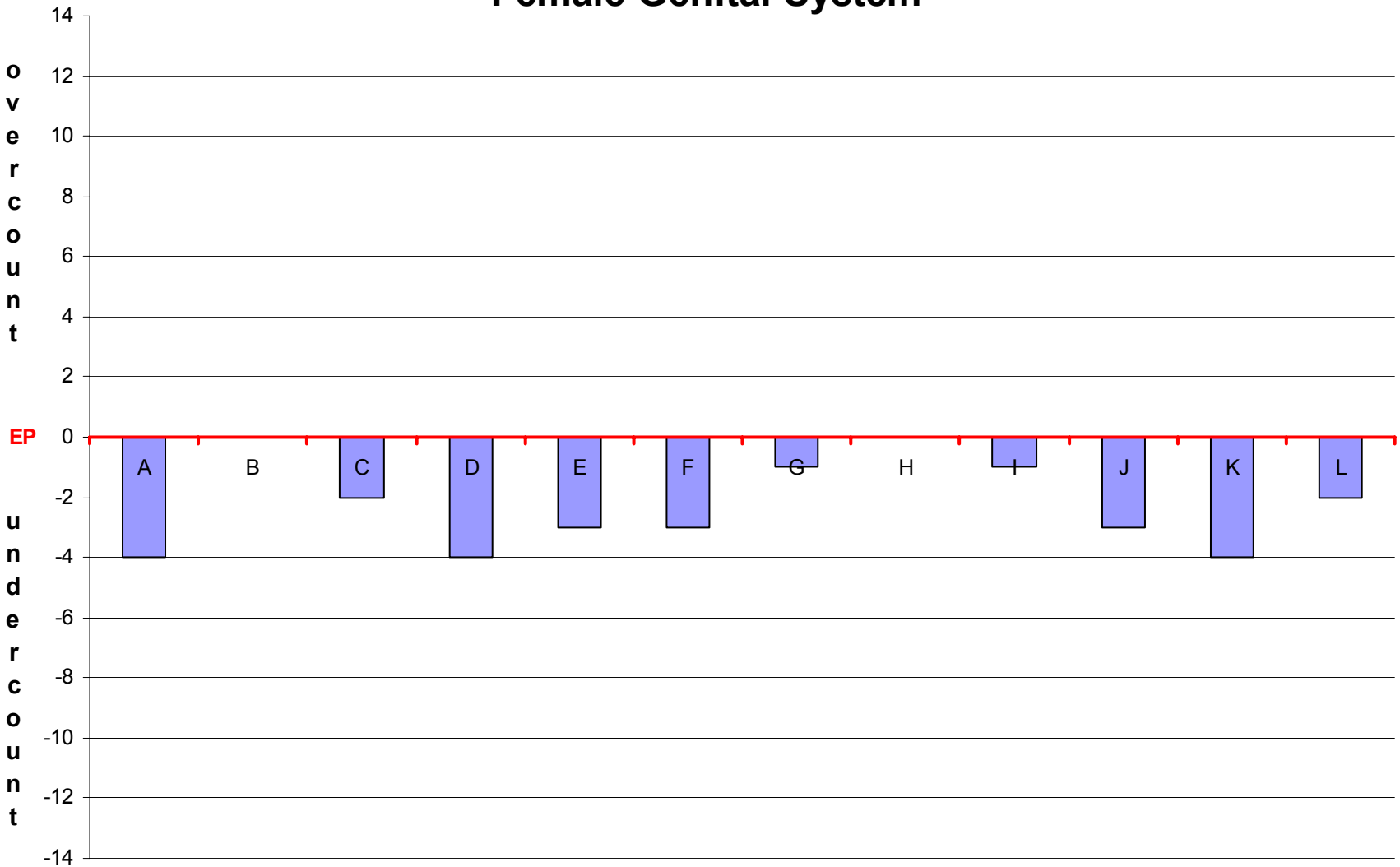
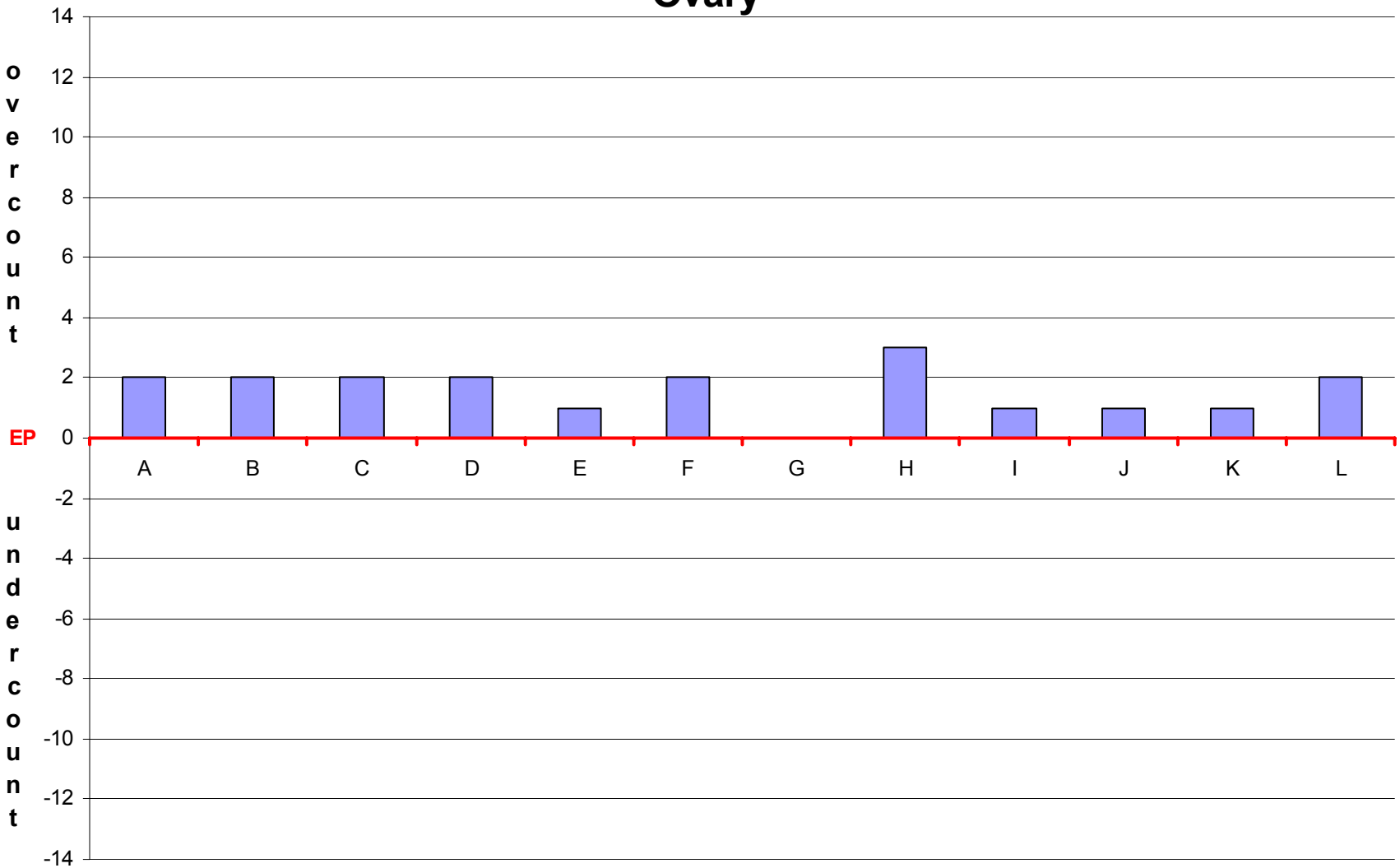
L

Differences in Tumor Counts by Registry
Breast

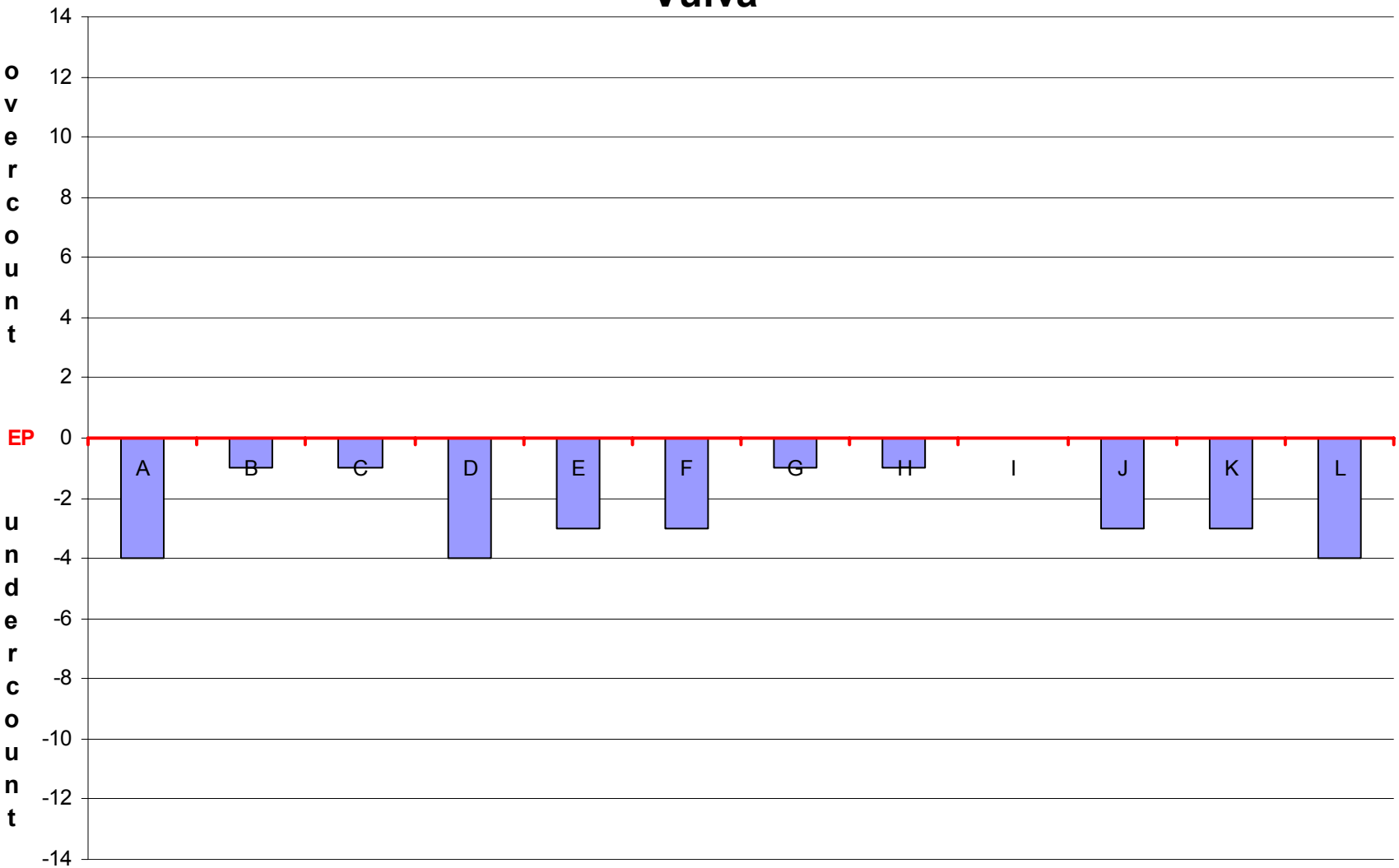
Differences in Tumor Counts by Registry
Female Genital System



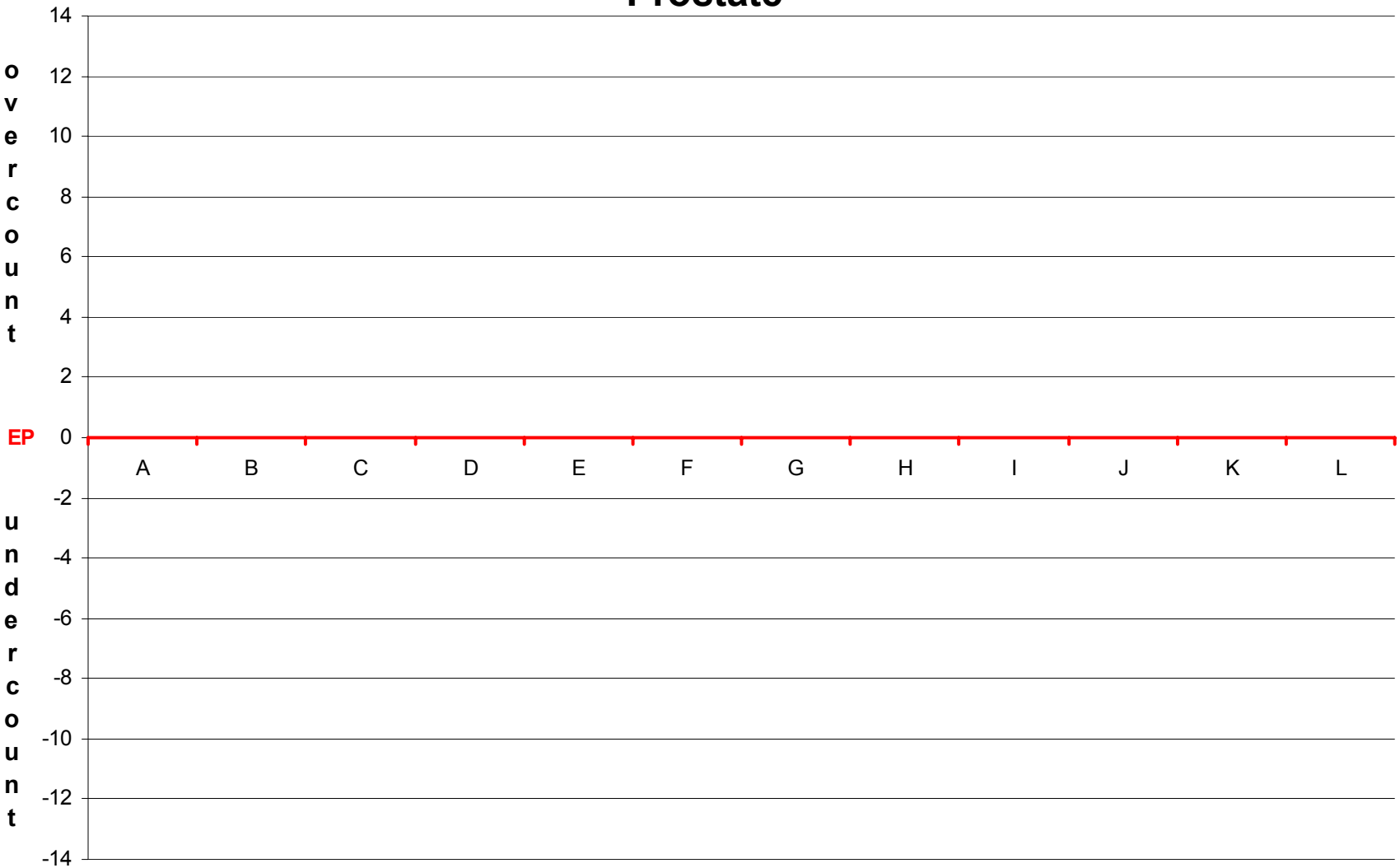
Differences in Tumor Counts by Registry
Ovary



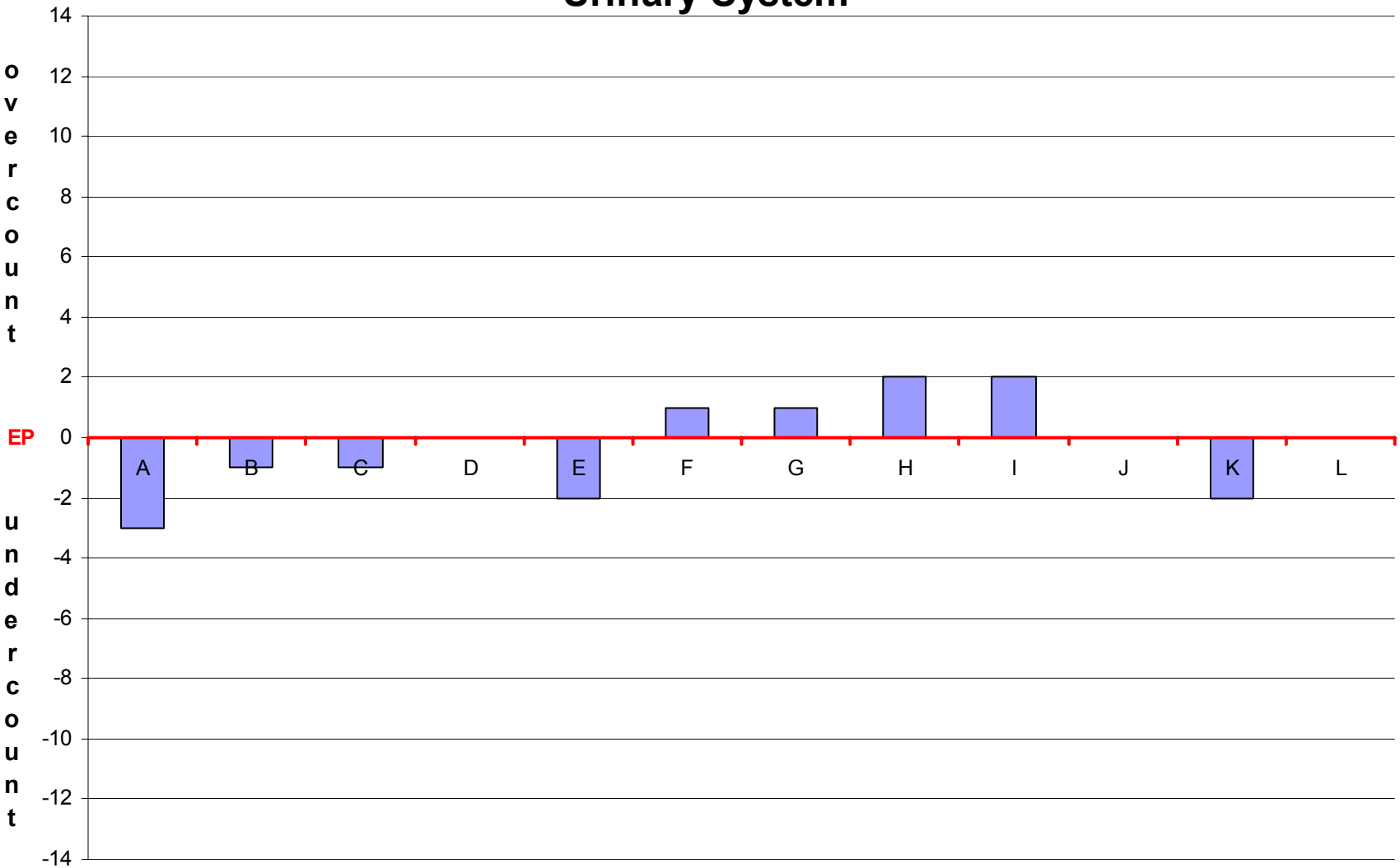
Differences in Tumor Counts by Registry
Vulva



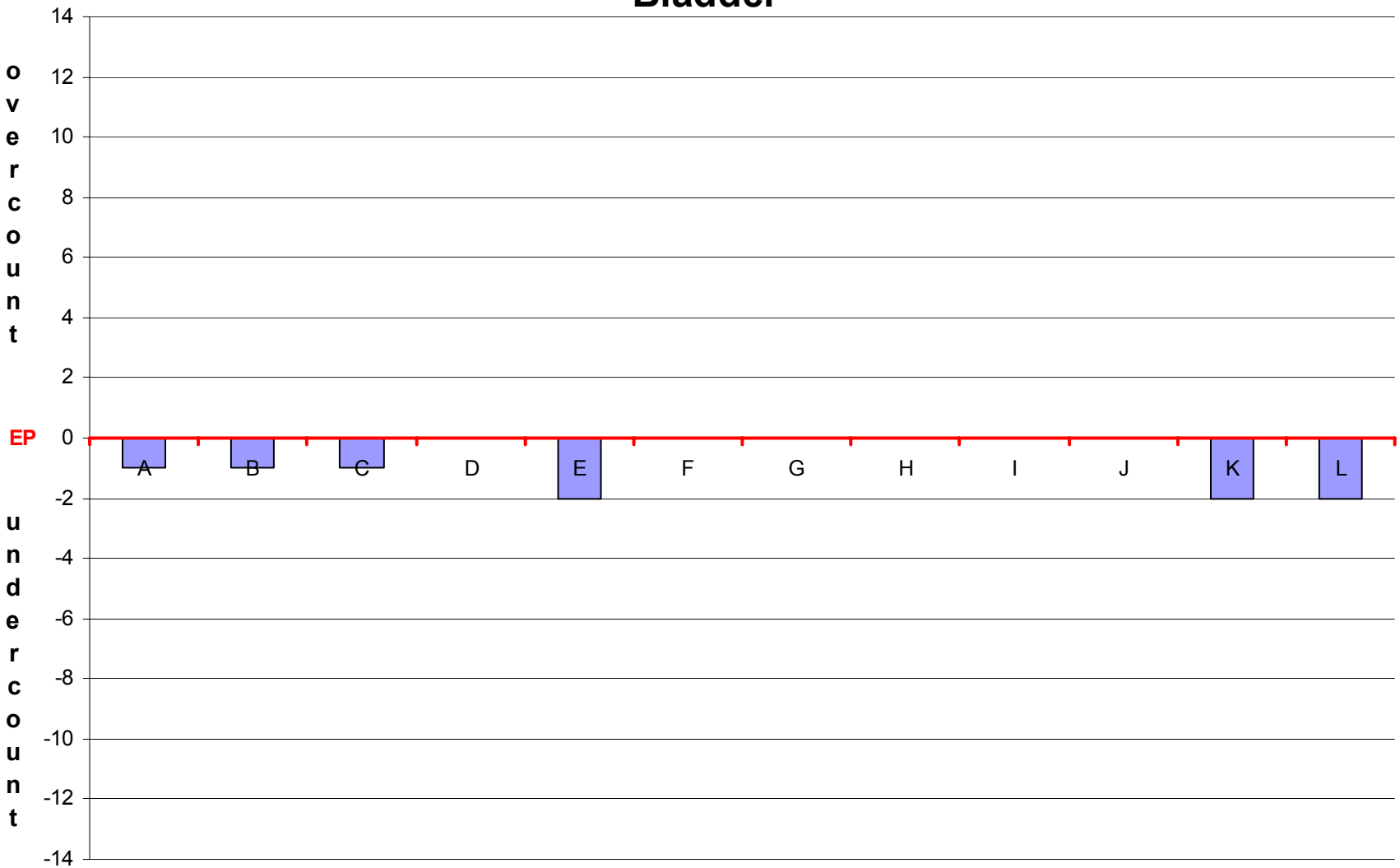
Differences in Tumor Counts by Registry
Prostate



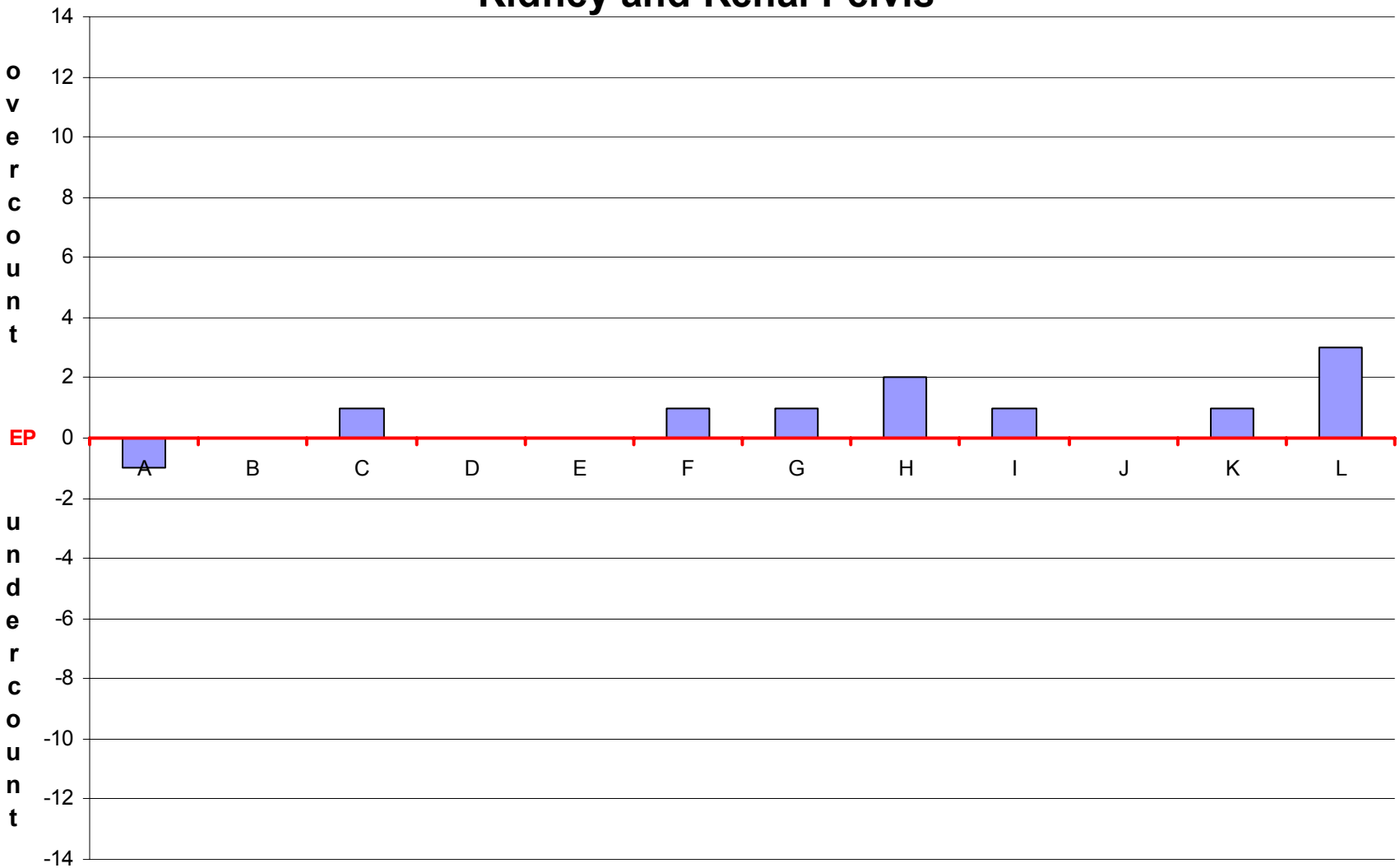
Differences in Tumor Counts by Registry
Urinary System



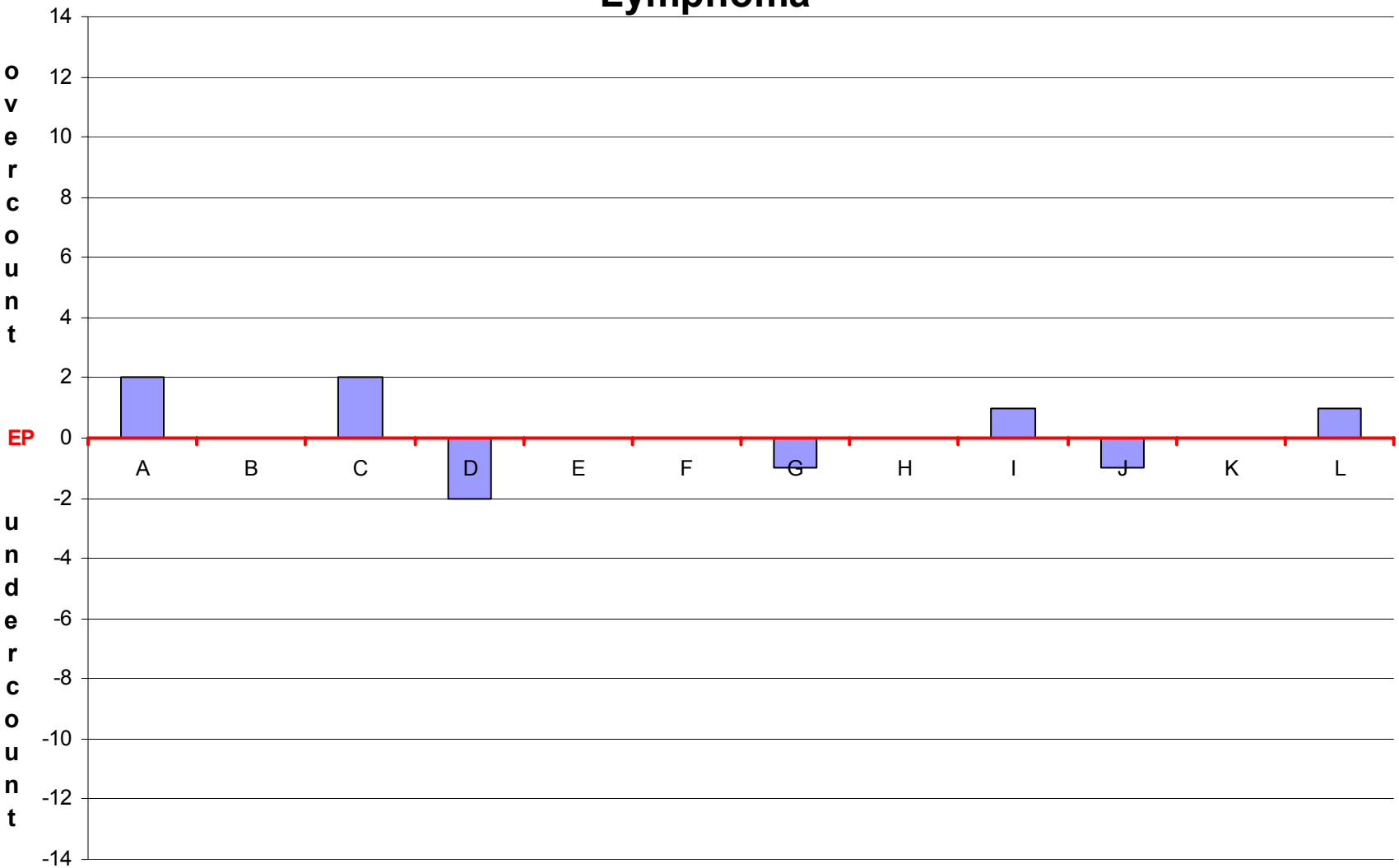
Differences in Tumor Counts by Registry
Bladder



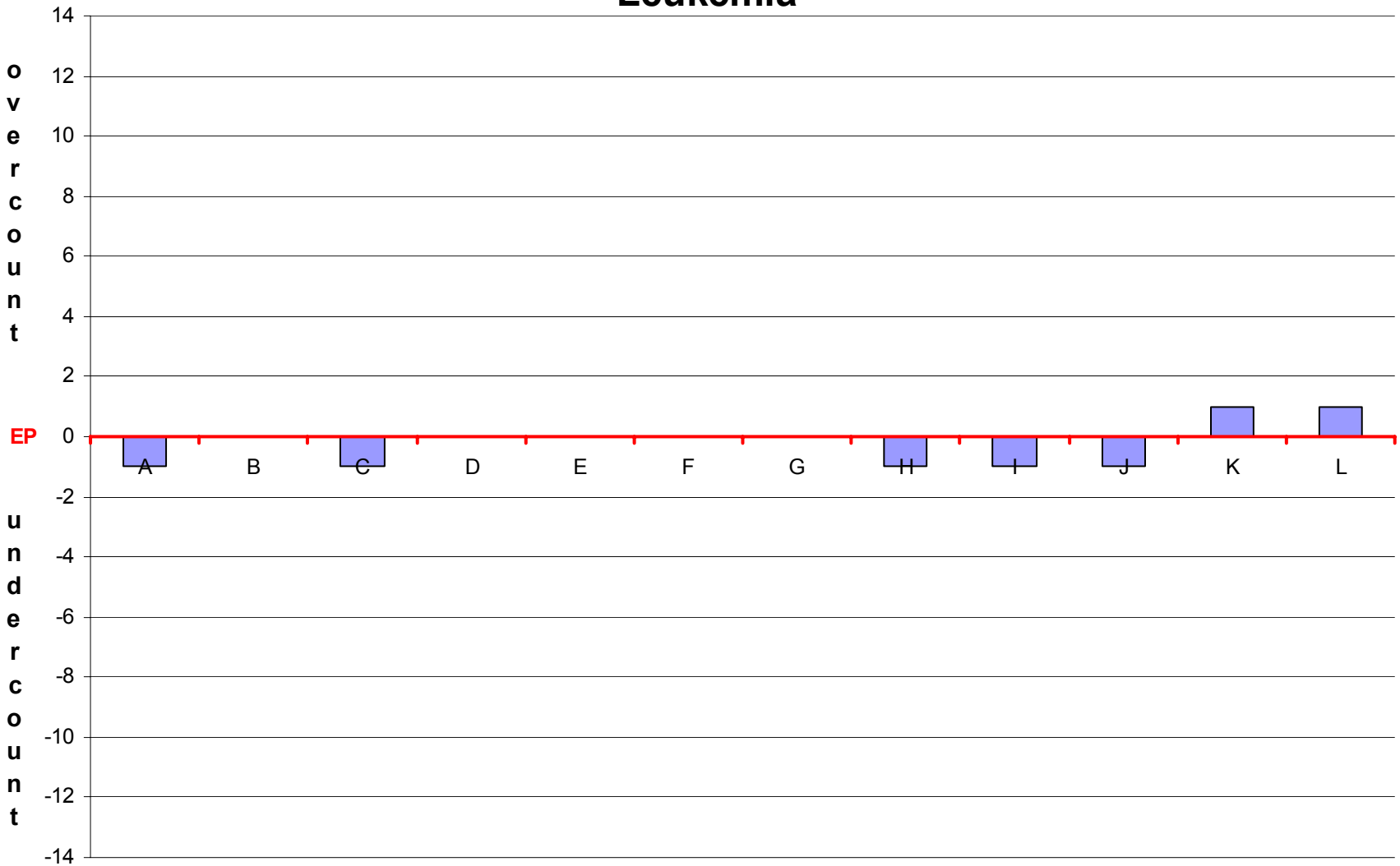
Differences in Tumor Counts by Registry
Kidney and Renal Pelvis



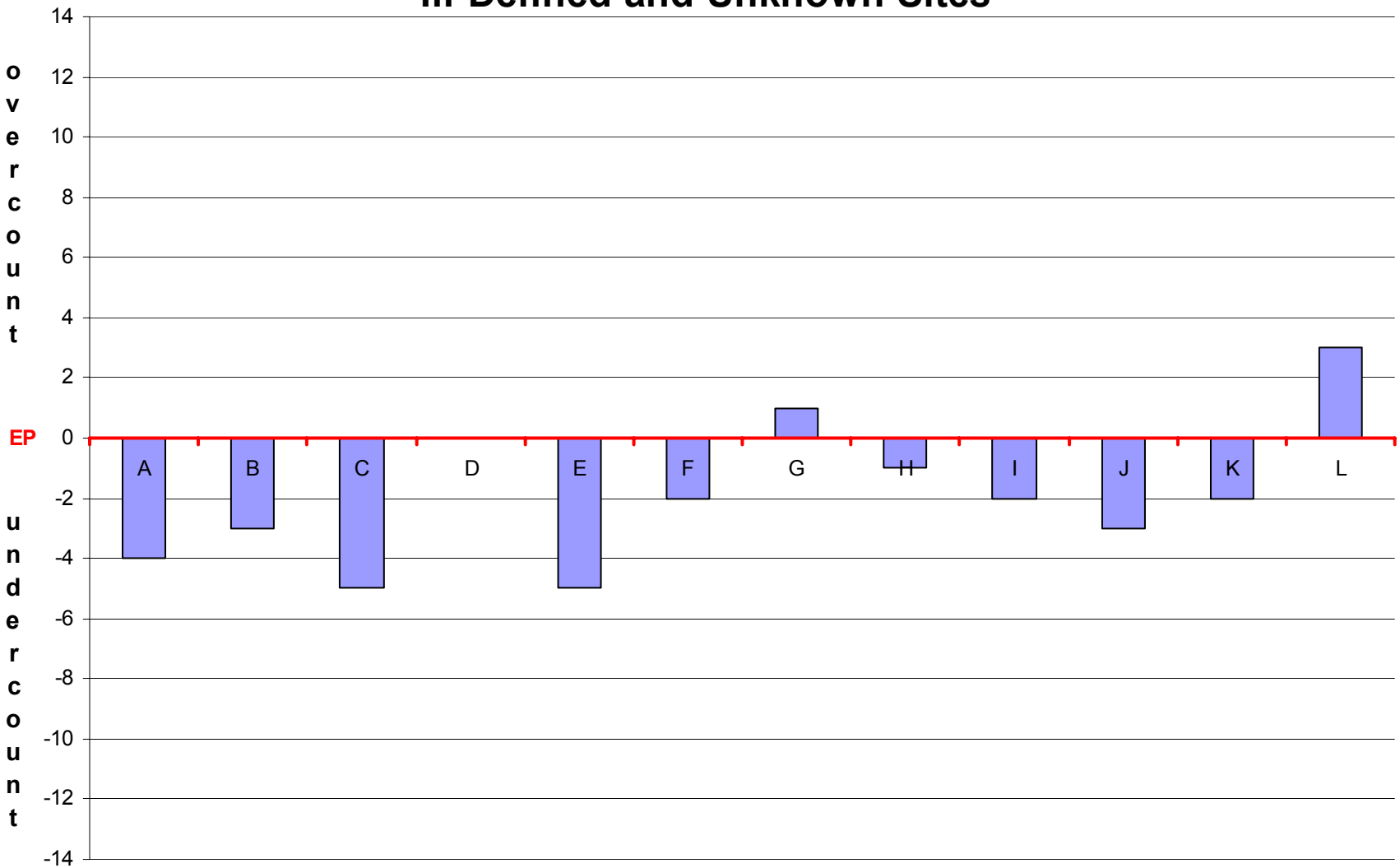
Differences in Tumor Counts by Registry
Lymphoma



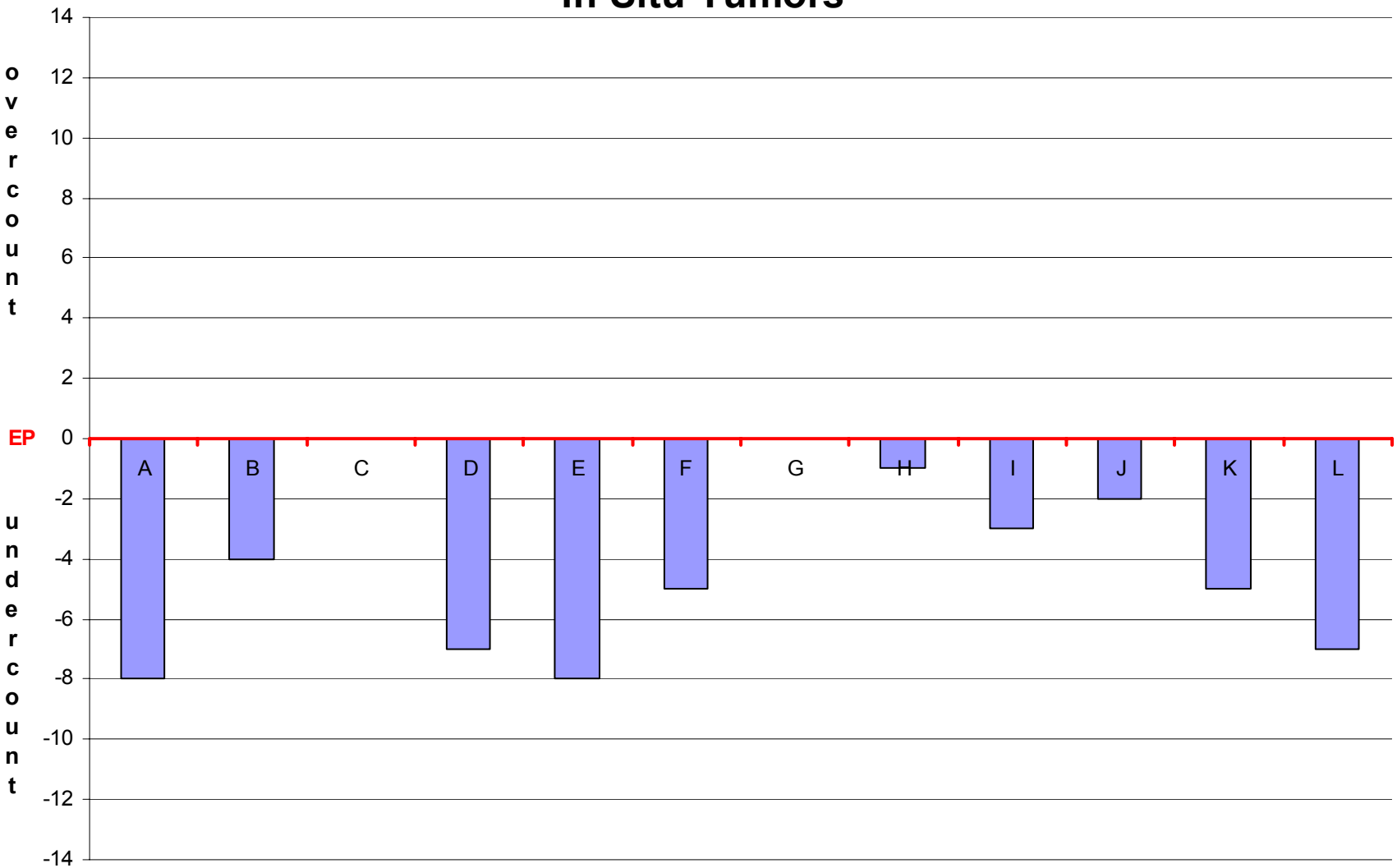
Differences in Tumor Counts by Registry
Leukemia

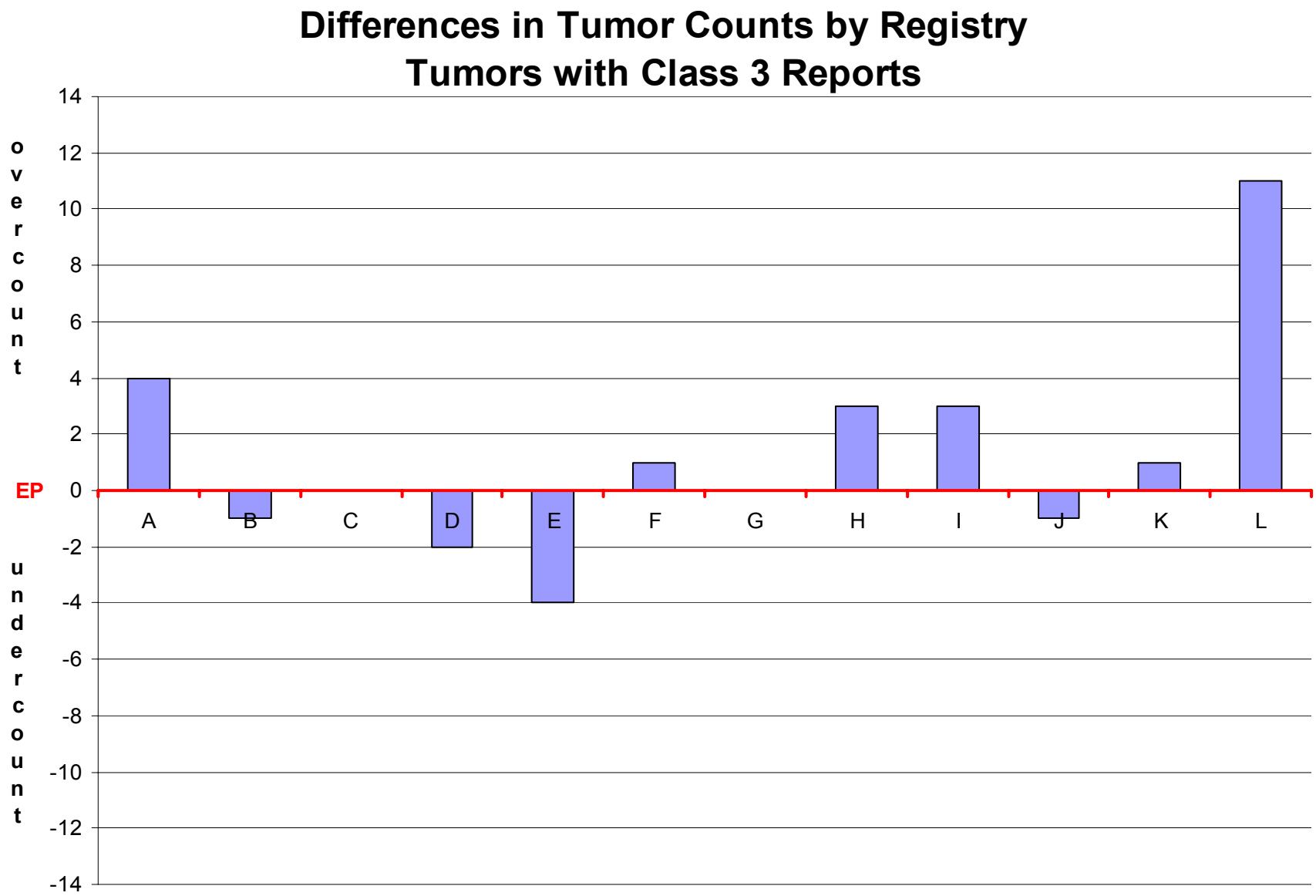


Differences in Tumor Counts by Registry
Ill-Defined and Unknown Sites



Differences in Tumor Counts by Registry
In Situ Tumors




Differences in Tumor Counts by Registry
Tumors with Class 3 Reports
overcount
undercount
EP
14
12
10
8
6
4
2
0
-2
-4
-6
-8
-10
-12
-14
A
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L

Areas of Variability

- **Tumor counts**
  - **Total**
  - **By person**
  - **By site (type) of cancer**
- **Tumor characteristics**
  - **Site, histology, behavior, laterality**
  - **Diagnosis date**

Areas of Variability

- 7 of 11 registries undercounted total number of tumors
- On average, testers agreed with EP on tumor counts for 92% of patients
- Analysis of counts by site is complicated by disagreement over correct site (i.e., lung vs. unknown primary) rather than simply tumor counts

Results and Analysis, cont.

- **Site count discrepancies revealed**
  - **Invasive diagnoses after in situ tumors missed**
  - **Multiple in situ tumors in same site missed**
  - **ACoS rules are different for melanomas, but are being used by some registries**
  - **SEER rules are not being strictly applied in ambiguous situations**

Results and Analysis, cont.

Variability by tumor characteristics:

-Site code discrepancies affect counts by recode groups

-Uncertainty exists on correct site code when multiple tumors in different sites are one primary by definition

-Disagreements on behavior and laterality were minimal and mostly errors

Results and Analysis, cont.

- **Discrepancies on histology and diagnosis date are currently being reviewed.**
- **These important characteristics affect counts, but test results are incomplete and conclusions are not available yet.**

Implications of Variability

- Calculating incidence rates accurately
- Comparing rates among central registries
- Identifying appropriate records for research studies
- Evaluating synchronous and subsequent malignancies in a population
- Evaluating success of cancer control programs

Next Steps

- **Finalize test file and Expert Panel decisions file**
- **Publish file for use by other registries**
- **Request rule clarifications from SEER**
- **Analyze data value discrepancies from beta testing**

File Available for General Use

- **Ready Fall, 2003**
- **Technical assistance and full report provided**

- **Contact Susan Capron**

  scapron@mindspring.com