

Utility of an Early Case Capture Pediatric Cancer Registry

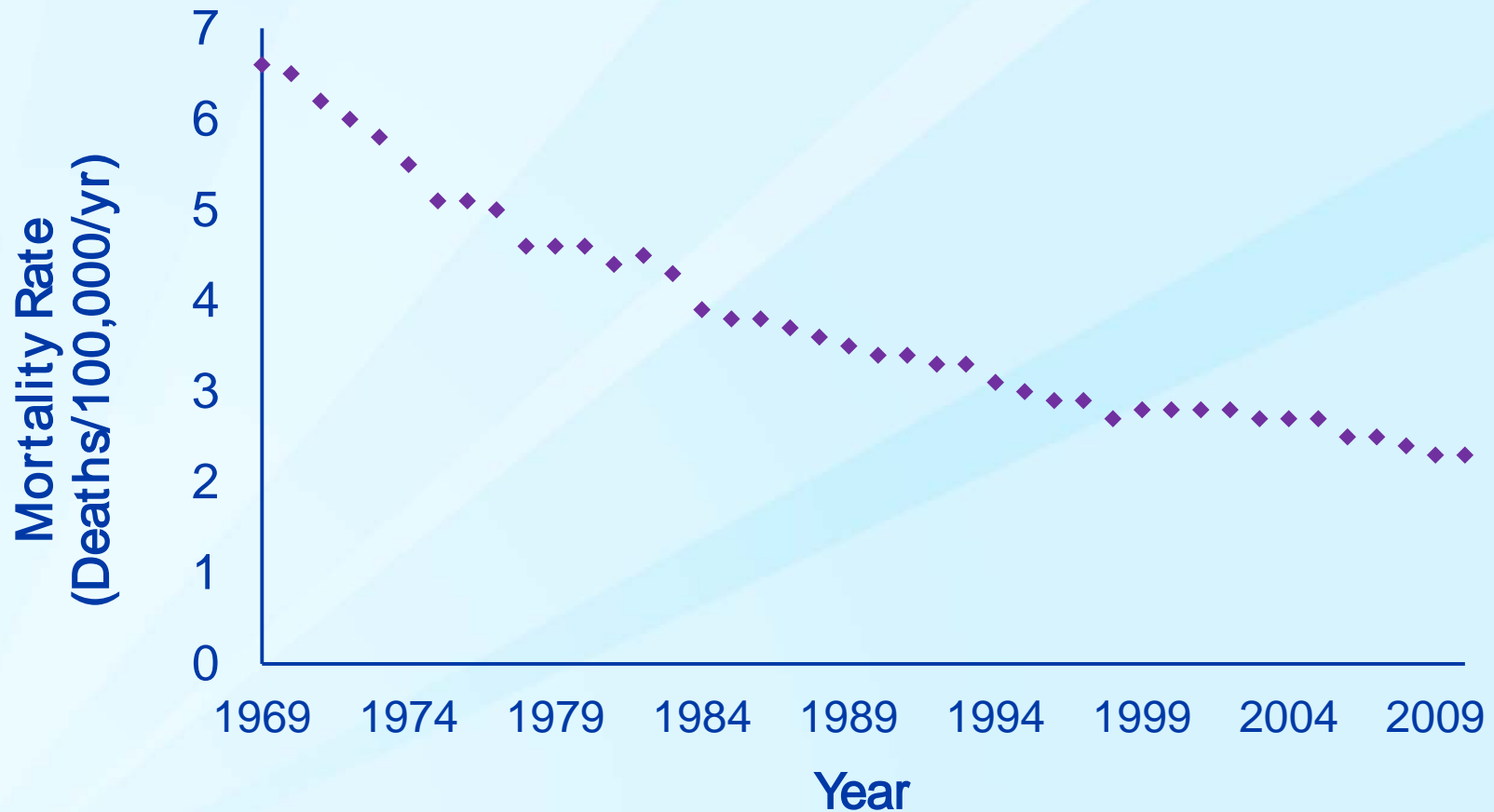
Mary Puckett, PhD

**Epidemic Intelligence Service Officer
Comprehensive Cancer Control Branch**

Pediatric Cancer

- **13,500 children are diagnosed with cancer each year¹**
- **2,100 children die each year from cancer¹**

Cancer Mortality Trends among Children <20 Years of Age, United States, 1969–2009

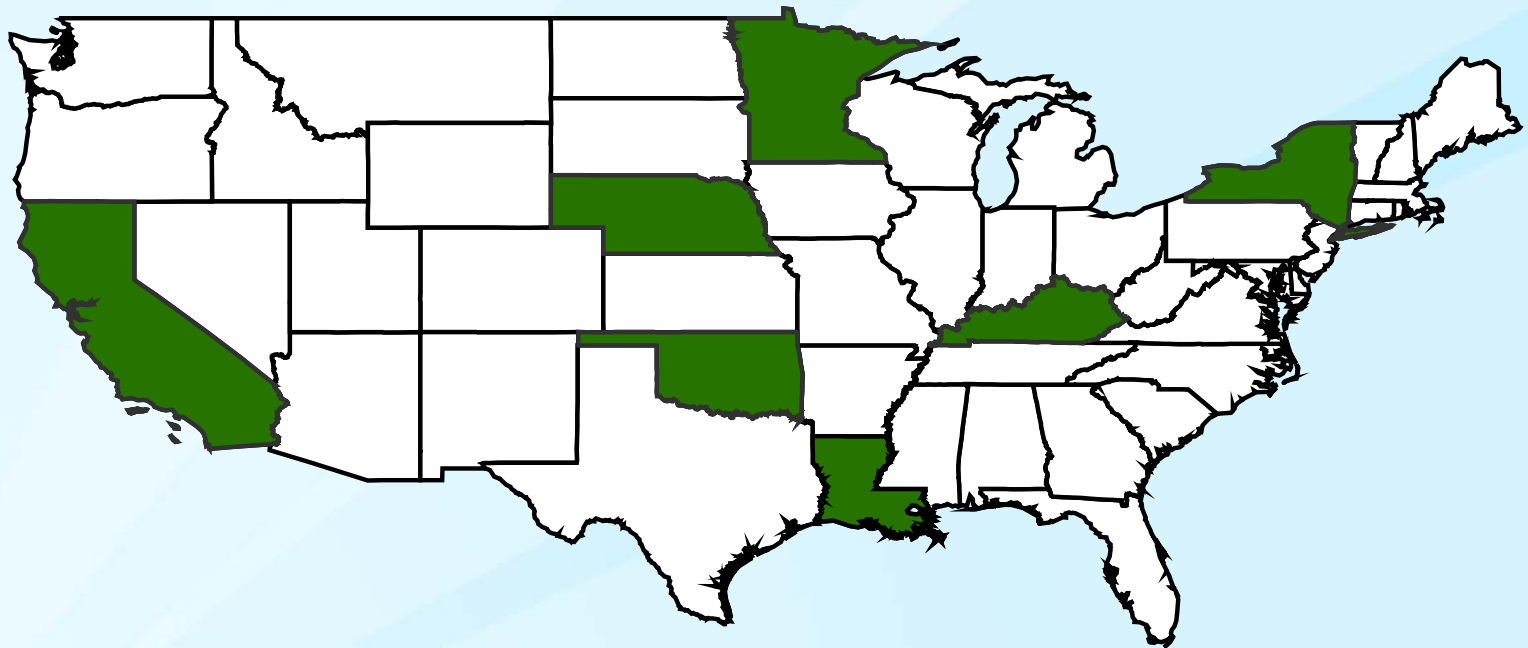


Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov)
Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

Caroline Pryce Walker Conquer Childhood Cancer Act (2008)

- **Advance pediatric cancer research and clinical trials**
- **Ensure public awareness**
- **CDC activities:**
 - Enhance and expand infrastructure to track pediatric cancer
 - Include occurrences of pediatric cancer within weeks of diagnosis

Early Case Capture (ECC) for Pediatric Cancer Pilot Sites



ECC Pediatric Cancer Registry Logic Model

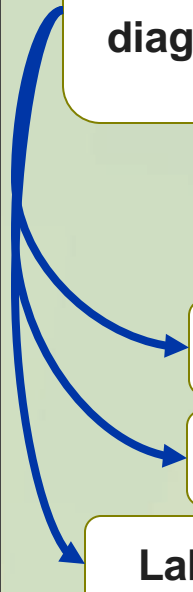
Inputs

**Pediatric
patient
diagnosed with
cancer**

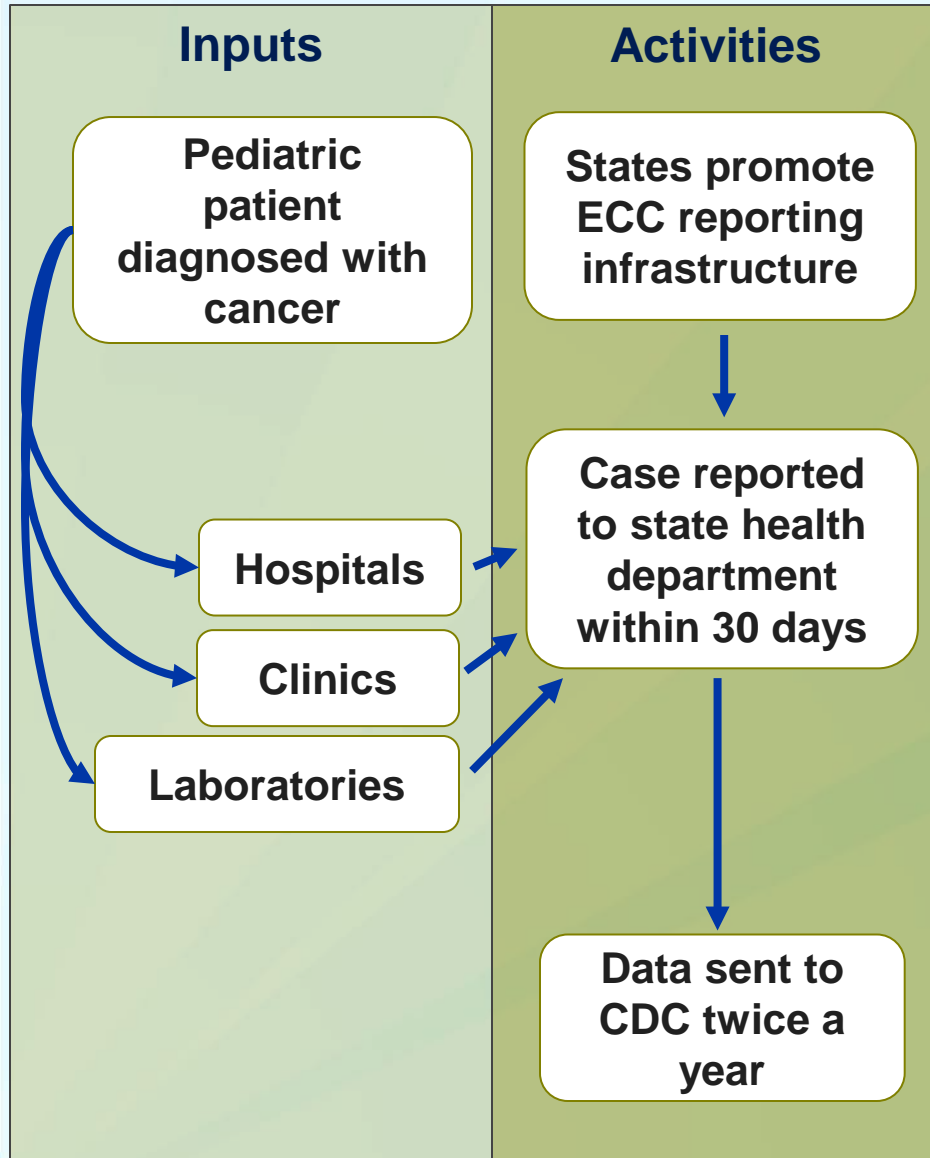
Hospitals

Clinics

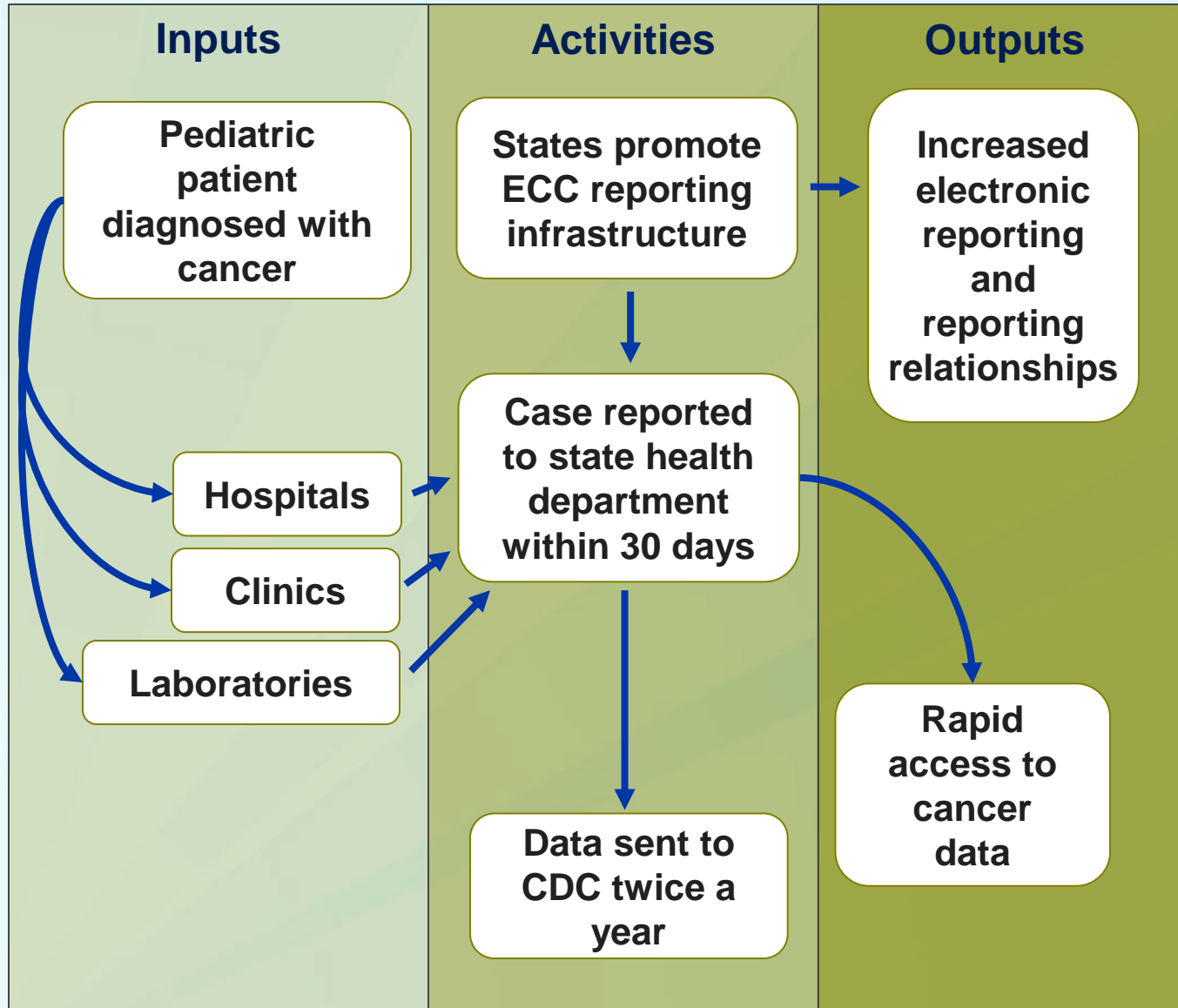
Laboratories



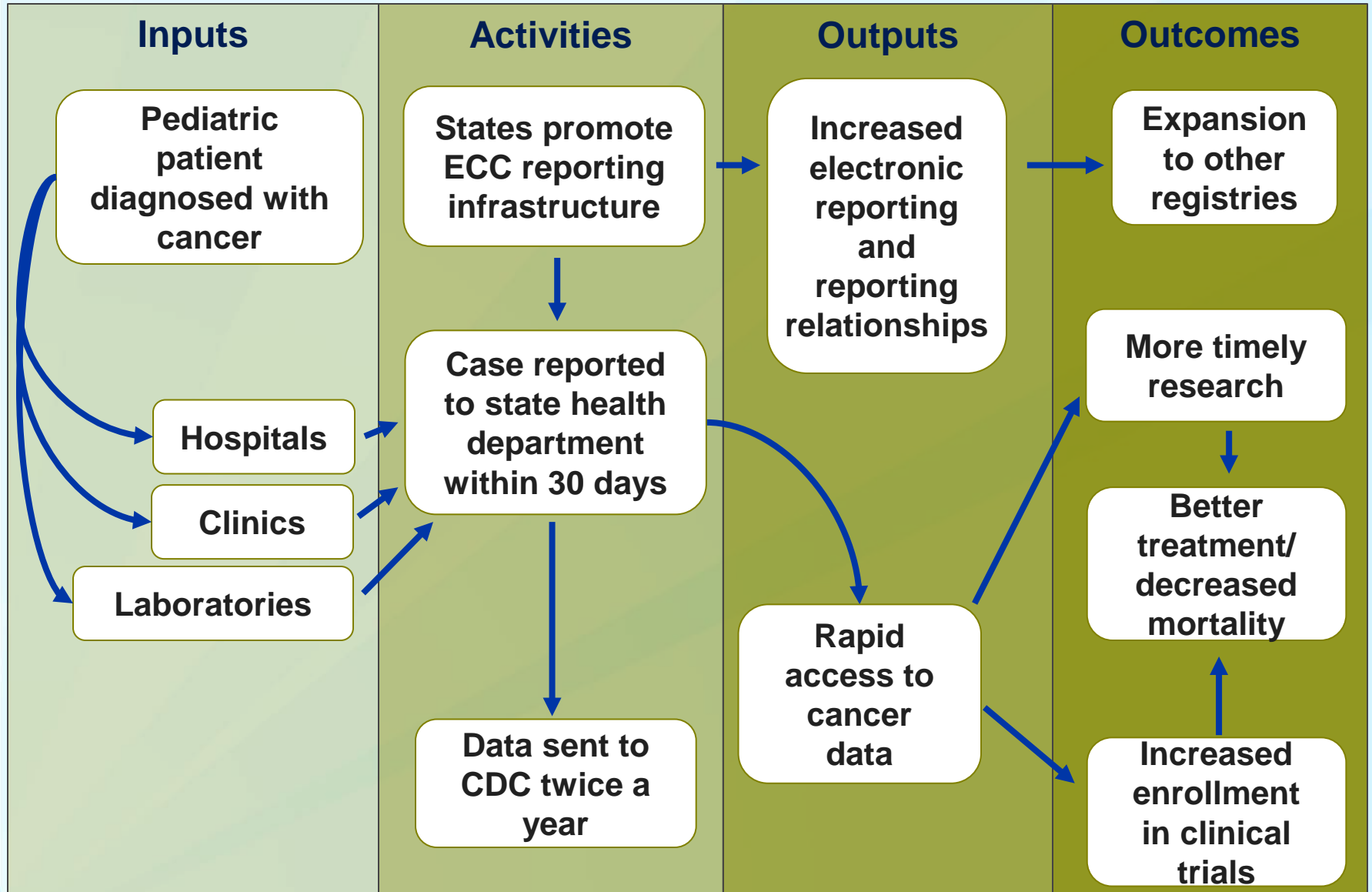
ECC Pediatric Cancer Registry Logic Model



ECC Pediatric Cancer Registry Logic Model



ECC Pediatric Cancer Registry Logic Model



ECC for Pediatric Cancer

- **Research**
 - Increase availability of pediatric data for surveillance activities
- **Public health**
 - Increase electronic reporting (ePath)
- **Clinical**
 - Increase clinical research enrollment
 - Increase follow-up for late effects of disease and treatment

OBJECTIVES AND METHODS

Objectives

- **Assess current ECC practices**
 - Identify challenges with implementation
 - Identify goals for data use
 - Identify benefits
- **Analyze data quality and representativeness**
 - Data submitted at one year
 - Routinely reported national data

Design

**Qualitative
assessment**

**Quantitative
assessment**

**ECC practices
from state
perspective**

**Quality and
usefulness of
data**

**Understand
utility of ECC**



Methods: Quantitative Data Sources

▪ **ECC Data**

- Demographic variables
 - Age at diagnosis
 - Sex
 - Race
 - Ethnicity
- Tumor characteristic variables
 - Primary site
 - Tumor behavior (benign, malignant, etc.)
 - Diagnostic confirmation (microscopically/clinically confirmed)

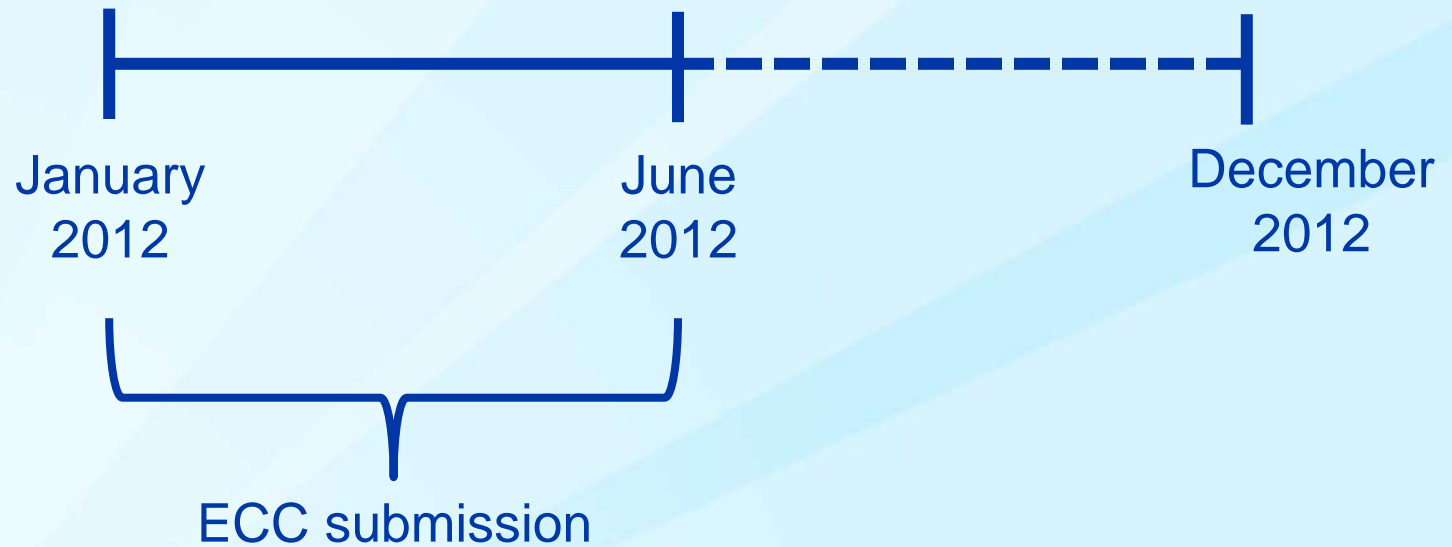
ECC Data



ECC Data

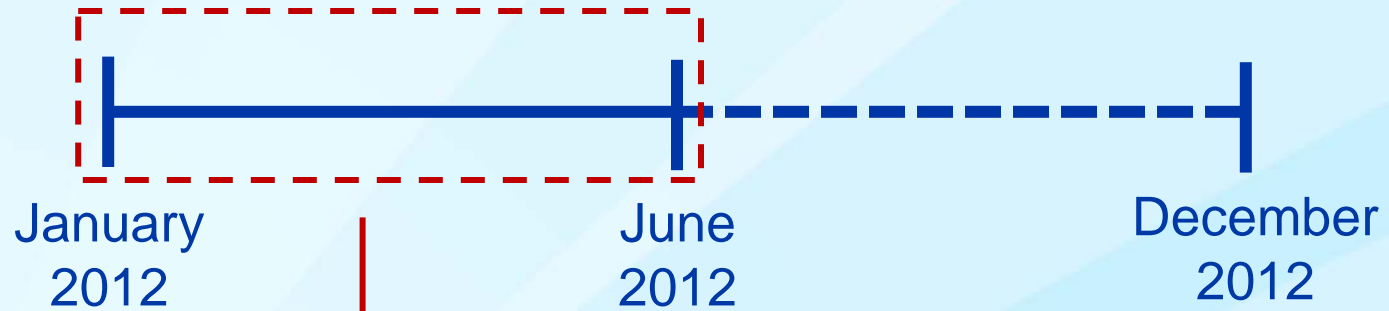


ECC Data



ECC Completeness and Concordance

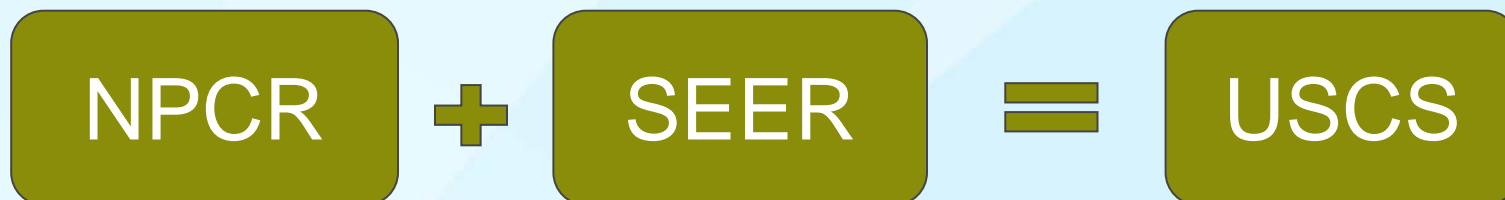
ECC



Full year



United States Cancer Statistics



- **All cases ages 0–19**
- **2006–2010 cases**

ECC Representativeness

ECC



5-yr States



ECC Representativeness

ECC



5-yr USCS



Methods: Quantitative

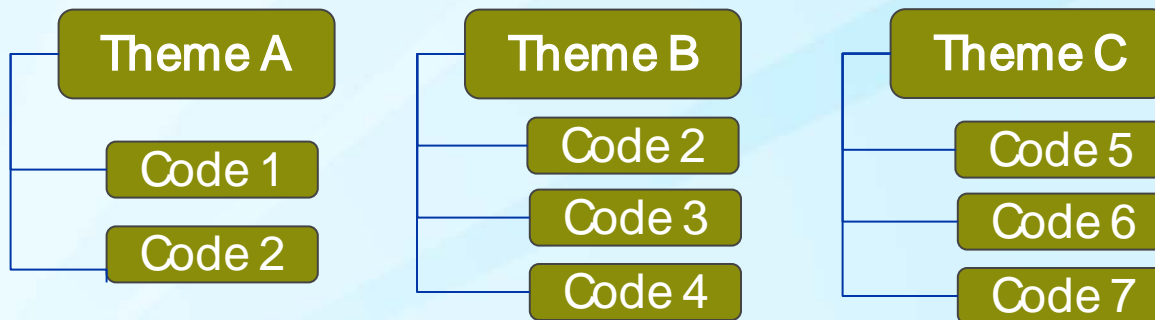
Question	Data Source Compared	Statistical Test
What is the percent of missing data in Jan–June 2012 cases?	Full year submission (Jan–June 2012 cases only)	% Missing
What is the concordance of cases in both Jan–June 2012 datasets?	Full year submission (Jan–June 2012 cases only)	% Concordance
How representative is ECC data of all state-level data?	USCS (ECC states)	X ² , t-test
How representative is ECC data of nationwide data?	USCS (All states)	X ² , t-test

Methods: Qualitative

- **Grounded theory approach¹**
- **Structured focus group telephone interviews**
 - Registry employees in seven states
 - Recorded and transcribed verbatim
- **Codebook developed**
 - Code
 - Brief and full definitions
 - When to use/not to use/rules
 - Example

Methods: Qualitative

- **Transcripts coded and analyzed**
 - Constant comparative method
 - Three independent coders
 - Consensus reached for all codes
- **Codes condensed to themes**



RESULTS

ECC Data Completeness

	% Missing		% Concordance*
	ECC	Full year	
Demographics			
State of Diagnosis	2.7	0	100
County of Diagnosis	3.1	1.9	99.9
Race	18.3	6.1	99.4
Ethnicity	21.2	7.2	99.4
Sex	0.2	0	100
Age at Diagnosis	0	0	100
Date of Birth	0	0	99.6
Tumor Characteristics			
Primary Site	2.5	0	98.6
Laterality	0	0	99.1
Diagnostic Confirmation	0.4	0.5	97.9
Type of Reporting Source	0	0	95.6
Histologic Type	0	0	98.3
Behavior Code	0	0	99.6

*Excludes State E.

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Representativeness of USCS

	<u>ECC*</u>	<u>5-yr States*</u>	<u>p value</u>	<u>5-yr USCS*</u>	<u>p value</u>
Mean Age at Diagnosis (yrs)	9.7	9.9	0.22	9.9	0.33
Sex (% Male)	50.9	53.5	0.22	52.9	0.17
Race			<0.01		<0.01
White (%)	59.0	80.0		80.1	
Black (%)	10.9	10.1		12.4	
Asian/Pacific Islander (%)	3.8	7.1		4.0	
Other (%)	6.3	1.9		2.0	
Unknown (%)	20.1	1.3		1.6	
Ethnicity (% Hispanic)	18.7	31.3	0.01	19.5	<0.01

*Excludes state G

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Ethnicity (% Hispanic)	18.7	31.3	0.01	19.5	<0.01

*Excludes State G

Representativeness of USCS

Site	ECC 5-yr States			5-yr USCS	
	(%)*	(%)*	p value	(%)*	p value
			0.50		0.35
Leukemia/Lymphoma	35.7	36.7		34.2	
Brain & Other Nervous System	17.8	20.4		22.7	
Endocrine System	10.4	10.6		10.6	
Soft Tissue including Heart	6.5	5.5		5.5	
Bones and Joints	5.6	5.1		5.0	
Other	24.0	21.6		22.0	
Diagnostic Confirmation			0.34		0.01
Microscopically Confirmed	97.0	92.4		90.9	
Laboratory/Clinical Diagnosis	2.8	7.1		8.2	
Unknown	0.2	0.5		0.9	
Behavior			<0.01		<0.01
Benign	3.7	6.0		6.0	
Uncertain/Borderline	3.4	4.1		4.2	
In situ	0.8	0.7		0.9	
Malignant (invasive)	92.1	89.2		88.8	

*Excludes State G

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Representativeness of USCS data: State Comparisons

	States						Overall
	A	B	C	D	E	F	
Age	0.42	0.22	0.29	<0.01	<0.01	0.17	0.33
Sex	0.66	0.16	0.27	0.06	<0.01	0.26	0.17
Race	<0.01	0.01	0.39	0.62	<0.01	0.96	<0.01
Site	0.06	0.11	0.74	0.15	<0.01	0.99	0.35
Diagnostic Confirmation	<0.01	0.65	0.09	0.32	0.85	0.21	0.01
Behavior	0.32	0.26	0.31	0.27	<0.01	0.93	<0.01

Representativeness of USCS data: State Comparisons

States

	A	B	C	D	E	F	Overall
Age	0.42	0.22	0.29	<0.01	<0.01	0.17	0.33
Sex	0.66	0.16	0.27	0.06	<0.01	0.26	0.17
Race	<0.01	0.01	0.39	0.62	<0.01	0.96	<0.01
Site	0.06	0.11	0.74	0.15	<0.01	0.99	0.35
Diagnostic Confirmation	<0.01	0.65	0.09	0.32	0.85	0.21	0.01
Behavior	0.32	0.26	0.31	0.27	<0.01	0.93	<0.01

Qualitative Results

Challenges	Benefits	Data Use	Facilitators
<p><i>Staffing issues</i></p> <ul style="list-style-type: none"> • Lack of Qualified Staff • Staff Turnover • Training 	<p>Improved Data in Overall Registry</p> <p>Electronic Reporting</p>	<p>Data Dissemination</p> <p>Potential Data Use</p>	<p>CDC TA</p> <p>Existing Resources</p> <p>Relationships</p>
<p><i>Increased Commitment</i></p> <ul style="list-style-type: none"> • Work Burden • Manual Abstraction • Race Data • Reinforcement-Reminders • Timeliness 			

Qualitative Results

Challenges	Benefits	Data Use	Facilitators
<p data-bbox="227 315 529 358"><i>Staffing issues</i></p> <ul data-bbox="100 422 587 615" style="list-style-type: none"> <li data-bbox="100 422 587 465">• Lack of Qualified Staff <li data-bbox="100 508 436 551">• Staff Turnover <li data-bbox="100 572 320 615">• Training <p data-bbox="139 651 620 694"><i>Increased Commitment</i></p> <ul data-bbox="100 729 529 1065" style="list-style-type: none"> <li data-bbox="100 729 417 772">• Work Burden <li data-bbox="100 793 529 836">• Manual Abstraction <li data-bbox="100 843 369 886">• Race Data <li data-bbox="100 901 455 986">• Reinforcement-Reminders <li data-bbox="100 1029 369 1072">• Timeliness 	<p data-bbox="697 294 1025 386">Improved Data in Overall Registry</p> <p data-bbox="668 422 1054 465">Electronic Reporting</p>	<p data-bbox="1122 294 1392 379">Data Dissemination</p> <p data-bbox="1170 401 1344 486">Potential Data Use</p>	<p data-bbox="1557 315 1711 358">CDC TA</p> <p data-bbox="1450 422 1818 465">Existing Resources</p> <p data-bbox="1499 508 1769 551">Relationships</p>

Qualitative Results

Challenges	Benefits	Data Use	Facilitators
<p>“There is a shortage of registry staff across the nation, and so we’re contemplating trying to figure out other ways to complete the activities, perhaps with contractors.”</p>	<p>Improved Data in Overall Registry</p> <p>Electronic Reporting</p>	<p>Data Dissemination</p> <p>Potential Data Use</p>	<p>CDC TA</p> <p>Existing Resources</p>
			<p>Relationships</p>

Qualitative Results

Challenges	Benefits	Data Use	Facilitators
<p>“We’re doing extra things to get race because they aren’t on the path reports.”</p>	<p>Improved Data in Overall Registry</p> <p>Electronic Reporting</p>	<p>Data Dissemination</p> <p>Potential Data Use</p>	<p>CDC TA</p> <p>Existing Resources</p>
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Common Themes

- **ECC involves a significant work burden**
 - Increased time commitment
 - Staffing issues
 - Collection of race information
- **Electronic reporting increased ECC utility**
 - Facilitated reporting when in place
 - Addition benefited all registry reporting
 - Added sustainability to ECC

DISCUSSION

Summary

- **Data completeness**

- Three variables do not meet standards
- High concordance with full year submission

- **Representativeness**

- Highly representative of full year submission data
- Moderately representative of USCS data
- Only two states were not representative for more than one variable
- Main issues observed were collection of race and some tumor information

Summary

▪ Common themes

- Rapid reporting places additional work burden on registries and reporting facilities
- Staffing issues and training can adversely affect ECC progress
- Manual abstraction of cases is time and labor intensive
- Electronic reporting facilitated timeliness
- Electronic reporting infrastructure improves registry
- Low current data usage but great potential

Limitations

- **Only 7 states participated in ECC**
 - 2 states were excluded from parts of the quantitative analysis
- **Only data from first ECC submission was analyzed**
- **Due to the lag time in cancer reporting, direct ECC-USCS comparisons could not be made**
- **Qualitative analysis was limited to interviews with state cancer registry staff**

Public Health Impact

- **Pediatric cancer is the 2nd leading cause of mortality in children**
- **Pediatric ECC has potential to**
 - Increase the pool of timely data available for research
 - Improve comprehensive cancer control planning in states
 - Increase enrollment on clinical trials
 - Improve identification of childhood cancer survivors
- **ECC could serve as a model for future rapid reporting programs**

Recommendations

- **Increase number of states involved**
 - Improve representativeness and completeness
- **Develop training modules**
- **Encourage ePath in all facilities**
- **Communicate data availability**
- **Promote and evaluate data use**
 - Clinical research enrollment
 - Academic research
- **Expand ECC to adult cancers**

Acknowledgements

- **Division of Cancer Prevention and Control**
 - Comprehensive Cancer Control Branch
 - Dr. Antonio Neri
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 - Dr. Christie Ehemann
 - Dr. Blythe Ryerson
- **State Cancer Registries**
 - California
 - Kentucky
 - Louisiana
 - Minnesota
 - Nebraska
 - New York
 - Oklahoma
- **Macro International**

Thank you

For more information please contact Centers for Disease Control and Prevention. You may contact me at mpuckett1@cdc.gov .

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Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348

Visit: www.cdc.gov | Contact CDC at: 1-800-CDC-INFO or www.cdc.gov/info

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