CDC Cancer Registry Data Access for Research Project

Cancer Registry Research Approval Process: Classification of States by Level of Approval Required

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National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Definition of Terms

Approval process: The approval process for research requests for access to confidential data is specific to each state cancer registry. The approval process may require cancer registry, institutional review board (IRB) and/or regulatory group approvals.

Levels of approval: The levels of review for approval range from one to four or more levels of review that may include the cancer registry, affiliated IRB, and affiliated regulatory groups.

Sponsorship: Clarifies if sponsorship from a local epidemiologist or state-based researcher is required for any research request to access confidential data.

Committee: This term represents any regulatory body or group, board, or review group different from the IRB, from whom approval is required.

Epidemiologist: This term represents a cancer registry-affiliated epidemiologist.

Cancer registry IRB: This term represents an institutional review board affiliated with the cancer registry.

Level of complexity scale: The level of complexity for gaining approval to access confidential data is based on factors including the number of levels of approval, time frame for approval, pediatric special requirements, fees, sponsorship requirement, a limit on the number of studies allowed by the cancer registry or the IRB, and whether physician/patient authorization is required.

States That Require One Level of Approval

State	One level of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Alaska	Committee	No	No	Varies	No	No	No	Not applicable	Not applicable	Not applicable	No	Less
Colorado	Cancer registry IRB	No	No	2–6	No	Yes	Yes	Physician	Physician	Not applicable	No	More
Connecticut	Cancer registry IRB	No	No	<2	No	Yes	Yes	Not applicable	Not applicable	Physician	No	Middle
District of Columbia	Cancer registry IRB	No	No	<2	No	No	Yes	Varies	Varies	Varies	No	Middle
Georgia	Cancer registry IRB	No	Yes	2–3	Yes	No	Yes	Physician and patient	Physician and patient	Not applicable	No	More
Idaho	Committee	Yes	Yes	<2	No	No	Yes	Physician and patient	Physician and patient	Not applicable	No	More
Illinois	Cancer registry IRB	No	Yes	Varies	No	Yes	Yes	Patient	Not applicable	Not applicable	No	Middle
Indiana	Committee	No	No	<2	No	No	Yes	Not applicable	Not applicable	Physician	No	Less
Kentucky	Committee	No	Yes	<2	No	No	Yes	Patient	Not applicable	Not applicable	No	Less
Massachusetts	MDPH IRB	No	No	<2	No	Yes	Yes	Patient	Not applicable	Not applicable	No	Less
Mississippi	Committee	No	Yes	<2	No	No	Yes	Patient	Not applicable	Not applicable	No	Less
Nevada	Cancer registry IRB	No	Yes	2–6	No	No	Yes	Varies	Varies	Varies	No	More
Pennsylvania	Committee	No	Yes	<2	No	No	Yes	Not applicable	Not applicable	Patient	No	Less
Wisconsin	Committee	No	Yes	Varies	No	No	Yes	Not applicable	Not applicable	Patient	No	Middle

States That Require Two Levels of Approval (up to two levels of approval depending on the research)

State	Two levels of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Alabama	• Advisory council • Cancer registry IRB	Yes	Yes	Varies	No	No	Yes	Physician	Physician	Not applicable	Yes	Middle
Arizona	• Committee • Cancer registry IRB	No	No	Varies	No	No	Yes	Not applicable	Not applicable	Physician	No	Middle
Florida	• Committee • Cancer registry IRB	No	Yes	<2	No	Yes	Yes	Not applicable	Not applicable	Patient	No	Less
Hawaii	• Committee • Cancer registry IRB	No	Yes	<2	Yes	Yes	Yes	Patient	Not applicable	Not applicable	No	More
Louisiana	• Committee • Cancer registry IRB	No	Yes	<2	No	Yes	Yes	No	Yes	Yes	Yes	More
Maine	• Cancer registry director • Cancer registry IRB	No	Yes	2–6	No	Yes	Yes	Not applicable	Not applicable	Physician	No	More
Minnesota	• Peer review committee (after registry staff review to ensure compliance with legal requirements) • Commissioner	Yes, insofar as involvement of children elevates scrutiny; no specific requirement	No app. fee; cost recovery for work if approved	2–6	Yes	No, but approval by researcher's IRB is required	Yes	Physician and patient (in-state researchers can contact patients after physician permission)	Not applicable	Not applicable	No	More
Montana	• Cancer registry committee • Legal counsel	No	No	<2	No	No	Yes	Not applicable	Not applicable	Patient	No	Less

State	Two levels of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
New Hampshire	• Committee • Cancer registry IRB	Yes	No	<2	No	No	Yes	Not applicable	Not applicable	Physician	No	More
New Jersey	• Committee • Cancer registry IRB	No	Yes	Varies	No	Yes	Yes	Patient	Not applicable	Not applicable	No	Middle
New Mexico	• Cancer registry director • Cancer registry IRB	No	Yes	Varies	Yes	Yes	Yes	Physician and patient	Physician and patient	Not applicable	No	More
New York	• Committee • Cancer registry IRB	No	Yes	2–6	No	No	Yes	Not applicable	Physician and patient	Not applicable	No	Middle
North Dakota	• Committee • Committee	No	No	2–6	No	No	Yes	Varies	Varies	Varies	No	Middle
Ohio	• Cancer registry • Ohio Department of Health IRB	No	No	2–6	No	No	Yes	Not applicable	Not applicable	Physician	No	Middle
Rhode Island	• Cancer registry director • Health department IRB	Yes	No	2–6	No	No	Yes	Not applicable	Not applicable	Patient	No	More
Tennessee	• Cancer registry director • Cancer registry IRB	No	No	<4	No	Yes	Yes	Patient	Not applicable	Not applicable	Yes	More
Utah	• Investigator's institution's IRB • Review committee	No	Yes	Varies	No	Yes	Yes	Patient	Not applicable	Not applicable	No	More

State	Two levels of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Virginia	• Health department IRB • Commissioner	No	Varies	Varies	No	Yes	Varies	No	No	Varies	No	More
Washington	• Cancer registry IRB • Assistant secretary	No	No	Varies	No	No	Yes	Patient	Not applicable	Not applicable	No	Middle
West Virginia	• Cancer registry director • Committee	No	Yes	2–6	No	No	Yes	Varies	Varies	Varies	Yes	More
Wyoming	• Committee • Cancer registry IRB	Yes	No	<2	No	No	Yes	Varies	Varies	Varies	No	More

States That Require Three Levels of Approval (up to three levels of approval depending on the research)

State	Three levels of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Delaware	• Epidemiologist • Committee • Cancer registry IRB	No	No	2–6	No	No	Yes	Not applicable	Not applicable	Patient	No	Middle
Iowa	• Epidemiologist • Cancer registry IRB • Committee	Yes	Yes	<2	No	Yes	Yes	Not applicable	Physician and patient	Not applicable	No	Less
Michigan	• Cancer registry IRB • Scientific committee • Dept. of health director	Yes	Yes	2–6	No	Yes	Yes	Physician and patient	Not applicable	Not applicable	No	More
Missouri	• Cancer registry senior statistician and staff • Cancer registry director • Dept. of health IRB	No	Yes	Varies	Yes	Yes	Yes	Patient	Not applicable	Not applicable	Yes	More
Nebraska	• Cancer registry director • Committee • Administrator	No	Yes	<2	No	No	Yes	Patient	Not applicable	Not applicable	No	Less
North Carolina	• Cancer registry director • SCHS director • Committee chair	No	Yes	<2	No	No	Yes	Physician	Physician	Patient	No	Less

State	Three levels of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Oklahoma	• Cancer registry • Cancer registry IRB • Commissioner	No	Yes	2–6	No	Yes	Yes	Physician and patient	Not applicable	Not applicable	No	Middle
Oregon	• Cancer registry manager • Cancer registry advisory committee • Public health IRB	Yes	Yes	2–6	Yes	No	Yes	Physician and patient	Physician and patient	Not applicable	No	More
Puerto Rico	• Cancer registry director and coordinator • Cancer registry IRB • Committee	Yes	No	2–6	No	Yes	Yes	Not applicable	Not applicable	Physician	No	More
South Carolina	• Cancer registry • Committee • Department of Health IRB	No	Yes	2–6	Yes	Yes	Yes	Physician and patient	Physician and patient	Not applicable	No	Middle
South Dakota	• Cancer registry director • Cancer registry committee • Executive committee	No	Yes	<2	No	No	Yes	Not applicable	Not applicable	Physician	No	Less

State	Three levels of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
United States Pacific Islands	Specific Territory: • Cancer registry director • Committee • Official/local IRB Regional: • Cancer registry director • Committee	No	No	2–6	No	No	Yes	Not applicable	Not applicable	Physician	No	Middle
Vermont	• Cancer registry director • Committee • Cancer registry IRB	No	Yes	2–6	No	Yes	Yes	Physician and patient	Physician and patient	Not applicable	No	Middle

States That Require Four Levels of Approval (up to four levels of approval depending on the research)

State	Four levels of approval	Pediatric special require-ments	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Arkansas	• Epidemiologist • Committee • State board of health • Administration	No	Yes	2–6	No	No	Yes	Patient	Not applicable	Not applicable	No	Middle
California	• Committee • Epidemiologist • Cancer registry IRB • Cancer registry director	Yes	Yes	2–6	No	No	Yes	Not applicable	Not applicable	Patient	No	More
Kansas	• Cancer registry director • Cancer registry data release board • University and/or state IRB • Secretary of KDHE	No	Yes	Varies	Yes	Yes	Yes	Patient	Not applicable	Not applicable	No	Middle
Maryland	• Cancer registry director • Cancer registry officials • Cancer registry IRB • Secretary	No	No	Varies	No	No	Yes	Patient	Not applicable	Not applicable	No	Middle
Texas	• Cancer registry manager • Cancer registry IRB • Committee • Commissioner	No	No	2–6	No	Yes	Yes	Not applicable	Not applicable	Patient	No	More

Level of Complexity by State Cancer Registry

Less Complex Process	Middle Complex Process	More Complex Process
• Alaska • Florida • Indiana • Iowa • Kentucky • Massachusetts • Mississippi • Montana • Nebraska • North Carolina • Pennsylvania • South Dakota	• Arizona • Arkansas • Connecticut • Delaware • District of Columbia • Kansas • Maryland • New Jersey • New York • North Dakota • Ohio • Oklahoma • South Carolina • United States Pacific Islands • Vermont • Washington • Wisconsin	• Alabama • California • Colorado • Georgia • Hawaii • Idaho • Illinois • Louisiana • Maine • Michigan • Minnesota • Missouri • Nevada • New Hampshire • New Mexico • Oregon • Puerto Rico • Rhode Island • Tennessee • Texas • Utah • Virginia • West Virginia • Wyoming

Appendix: Classification and Analysis Tables

Cancer registries' human subject protection policies and procedures classification category definitions

Classification Category	Definition
1. Requires initial cancer registry contact prior to application submission	How to initiate the data request process: clarifies if the researcher should contact the cancer registry representative or the IRB as a first step in the process.
2. State cancer registry allows release of state residents' identifiable data to researchers	State cancer registry allows identifiable and confidential data to be released to researchers as long as the researcher meets all required state cancer registry-specific confidentiality requirements and obtains the necessary approvals.
3. Requires sponsorship from local researcher	Clarifies if sponsorship from a local epidemiologist or state-based researcher is required.
4. Requires cancer registry-specific human subject protection training	This section clarifies if the IRB of record or the cancer registry has specific human subject protection training requirements.
5. Requires IRB approval from requested state and/or researcher's affiliated institution	Clarifies and identifies the number of IRBs that need to review and approve the research project.
6. Special requirements for pediatric research	Clarifies if the state has special requirements for pediatric research.
7. Patient contact, authorization, and consent required for release of confidential data	State-specific requirements for contacting patients and obtaining consent for research purposes.
8. Detail and number of steps in the approval process	Identifies the number of regulatory bodies and process of review and approval required for research studies. Categories include one to four or more levels.
9. Frequency of IRB and other regulatory committee meetings	Categories include weekly, monthly, quarterly, bi-monthly, semi-monthly, other, and unknown.
10. Charges a fee	Provides information regarding the cost of a data request.
11. Time frame for the approval process	The length of time generally required for data request processes and research approvals.
12. Limit on number of studies	The number of active projects a researcher may have open with the cancer registry.
13. Involvement of cancer registry director or senior official in approval process	Clarifies if cancer registry administrators and senior officers are involved in the research review and approval process. In general, involvement of cancer registry officials is considered a positive feature.

1. Requires initial cancer registry contact prior to application submission

No Initial Contact Required (7)	Initial Contact Required (48)
Arizona, California, Connecticut, Massachusetts, Nevada, North Carolina, Virginia	Alabama, Alaska, Arkansas, Colorado, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Washington, West Virginia, Wisconsin, Wyoming

2. State cancer registry allows release of state residents' identifiable data to researchers

Does Not Allow Release (0)	Allows Release (53)
None	Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, North Carolina, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin*, Wyoming

*Wisconsin allows access to identifiable data under very strict circumstances.

3. Requires sponsorship from local researcher

No Sponsorship Required (46)	Sponsorship Required (7)
Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Virginia, Washington, Wisconsin, West Virginia, Wyoming	Georgia, Hawaii, Kansas, Minnesota, Missouri, New Mexico, Oregon

4. Requires human subject protection training

No Human Subject Protection Training Required (33)	Human Subject Protection Training Required (20)
Alabama, Alaska, Arizona, Arkansas, California, Delaware, District of Columbia, Georgia, Idaho, Illinois, Indiana, Kentucky, Maine, Maryland, Minnesota, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New York, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, South Dakota, U.S. Pacific Islands, Washington, West Virginia, Wisconsin, Wyoming	Colorado, Connecticut, Florida, Hawaii, Iowa, Kansas, Louisiana, Massachusetts, Michigan, Missouri, New Jersey, New Mexico, Oklahoma, Puerto Rico, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia

5. Requires IRB approval from requested state and/or researcher's affiliated institution

IRB Approval Requirement	Total	States
IRB approvals from both researcher's and registry-affiliated institution	28	Alabama, California, Connecticut, Delaware, District of Columbia, Illinois, Iowa, Kansas, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, New Hampshire, New Jersey, New Mexico, New York, Ohio, Oklahoma, Oregon, Puerto Rico, South Carolina, Tennessee, U.S. Pacific Islands, Vermont, Virginia, Washington
Only IRB approval from researcher-affiliated institution	17	Alaska, Arkansas, Idaho, Indiana, Kentucky, Minnesota, Mississippi, Montana, Nebraska, Nevada, North Carolina, North Dakota, Pennsylvania, South Dakota, Utah, West Virginia, Wisconsin
Only IRB approval from registry-affiliated institution	6	Arizona, Florida, Georgia, Rhode Island, Texas, Wyoming
IRB approval from registry-affiliated institution but information not available if IRB approval required from researcher-affiliated institution	2	Colorado, Hawaii

6. Special requirements for pediatric research

Special Requirements for Pediatric Research (11)	No Special Requirements for Pediatric Research (42)
Alabama, California, Idaho, Iowa, Michigan, Minnesota, New Hampshire, Oregon, Puerto Rico, Rhode Island, Wyoming	Alaska, Arizona, Arkansas, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin

Notes: Alabama, Iowa, Rhode Island, and Utah require parental and/or physician consent.

Alaska, New Hampshire, Puerto Rico, and Utah have never handled pediatric study requests.

California, Michigan, Minnesota, Oregon, Utah, and Wyoming have a more difficult approval process or require more oversight.

Idaho requires a case-by-case review.

North Carolina prefers initial cancer registry contact prior to application submission to discuss data release charges to be included in the application.

Utah specifically does not have any special requirements for research involving children, but the IRB would have special requirements.

Virginia does not allow patient contact either directly or indirectly, through providers.

7. Patient contact, authorization, and consent required for release of confidential data

7a. Cancer registry requests authorization from physician and/or patient

State-Specific Requirement for Requesting Authorization	Total	States
Patient authorization required	14	Arkansas, Hawaii, Illinois, Kansas, Kentucky, Maryland, Massachusetts, Mississippi, Missouri, Nebraska, New Jersey, Tennessee, Utah, Washington
Both physician notification and patient authorization required (passive physician consent)	9	Georgia, Idaho, Iowa, Louisiana, New Mexico, New York, Oregon, South Carolina, Vermont
Both physician and patient authorization required (active physician consent)	4	Indiana, Michigan, Minnesota, Oklahoma
Physician notification required (passive consent)	3	Alabama, Colorado, North Carolina
Physician authorization required (active consent)	1	Alabama (pediatric)

Notes: In Alabama, active physician consent is required for pediatric studies.

The Louisiana Tumor Registry (LTR) sends the notification letter to the physician first to check whether there are any medical reasons that we should not contact the patient. If the physician does not respond within two weeks, the LTR can contact patients.

In North Carolina, the registry must obtain passive physician consent when the research study is within one year of participant diagnosis.

In Washington, authorization may be waived by the IRB.

Virginia does not allow patient contact either directly or indirectly, through providers.

7b. Researcher requests authorization from physician and/or patient

State-Specific Requirement for Requesting Authorization	Total	States
Physician authorization required (active consent)	8	Connecticut, Indiana, Maine, New Hampshire, Ohio, Puerto Rico, South Dakota, U.S. Pacific Islands
Physician authorization required (passive consent)	2	Arizona, Louisiana
Patient authorization required	8	California, Delaware, Florida, Montana, North Carolina, Pennsylvania, Rhode Island, Texas

Notes: Louisiana needs to inform physician first (provide physician with the researcher's name, institution and contact information). Then, LTR notifies the patient with his/her permission before giving his/her information to researcher.

Virginia does not allow patient contact either directly or indirectly, through providers.

7c. Who consents patient for participation in the study?

State-Specific Requirement for Consenting Patients	Total	States
Researcher contacts and consents	40	Alabama, Arizona, California, Colorado, Connecticut, Delaware, Florida, Georgia, Idaho, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Vermont, Wisconsin
Options on consent	7	District of Columbia, Iowa, North Dakota, New Jersey, Utah, Washington, Wyoming
Cancer registry contacts and consents	2	Arkansas, Hawaii
Strict conditions for patient contact studies	2	Nevada, West Virginia
No patient contact	2	Alaska, Virginia

Notes: Delaware, Montana, Nevada, and West Virginia require the researcher to have prior informed consent from the patient.

Texas requires the researcher to send a courtesy note to the physician.

Virginia does not allow patient contact directly or indirectly, through providers.

8. Detail and number of steps in the approval process

8a. One level of approval

State (14)	One Level of Approval
Alaska	Alaska Cancer Registry Internal Review Committee
Colorado	Colorado Department of Public Health and Environment IRB
Connecticut	Connecticut Department of Public Health Human Investigations Committee IRB
District of Columbia	District of Columbia IRB for the Public Health
Georgia	Georgia Department of Public Health IRB
Idaho	Idaho Cancer Analysis Work Group
Illinois	Illinois Department of Public Health IRB
Indiana	Indiana State Cancer Registry Data Release Committee
Kentucky	Kentucky Cancer Registry Scientific Advisory Committee
Massachusetts	Massachusetts Department of Public Health IRB and Data Access Committee
Mississippi	Mississippi Cancer Registry Review Committee
Nevada	Nevada Central Cancer Registry IRB
Pennsylvania	Bureau of Health Statistics and Research
Wisconsin	Department of Health Services Data Governance Board

8b. Two levels of approval (up to two levels of approval depending on the research)

State (21)	Two Levels of Approval
Alabama	• Alabama Statewide Cancer Registry Advisory Council • Alabama Department of Public Health IRB
Arizona	• Arizona Cancer Registry Committee • Arizona Department of Health Services Human Subjects Review Board IRB
Florida	• Florida Cancer Registry Program (programmatic acknowledgement must be received prior to applying to the Florida DOH IRB) • Florida Department of Health IRB
Hawaii	• University of Hawaii Committee on Human Studies IRB • Commission on Cancer of the Hawaii Medical Association IRB
Louisiana	• Louisiana State University Health Sciences Center IRB • Institutional Bio-Safety Committee
Maine	• Maine Cancer Registry Director • Maine Center for Disease Control and Prevention, Department of Health and Human Services IRB
Minnesota	• Minnesota Cancer Surveillance System Administrative Review Group • Peer Review Committee
Montana	• Montana Central Tumor Registry Data Use Review Committee • Legal Counsel of the Department of Public Health and Human Services
New Hampshire	• Health Statistics and Data Management Data Review Committee • New Hampshire Department of Health and Human Services IRB
New Jersey	• Scientific Review Board of the Cancer Institute of New Jersey • University of Medicine and Dentistry of New Jersey IRB
New Mexico	• New Mexico Cancer Registry Principal Investigator • Human Research Review Committee
New York	• New York State Department of Health Administrative Approval • New York State Department of Health IRB
North Dakota	• North Dakota Department of Health HIPAA Privacy Office • North Dakota Department of Health Privacy Board
Ohio	• Ohio Cancer Incidence Surveillance System Data Group • Ohio Department of Health IRB
Rhode Island	• Rhode Island Cancer Registry Program Director • Rhode Island Department of Health IRB
Tennessee	• Tennessee Department of Health IRB • Tennessee Cancer Registry Director
Utah	• University of Utah IRB • Utah Cancer Registry Advisory Research Committee
Virginia	• Virginia Department of Health IRB • Virginia Department of Health Commissioner of Public Health
Washington	• Washington State IRB • Washington State Department of Health Assistant Secretary
West Virginia	• West Virginia Cancer Registry Director and West Virginia State Epidemiologist • Cancer Advisory Committee

State (21)	Two Levels of Approval
Wyoming	• State Epidemiologist • Wyoming Department of Health IRB

8c. Three levels of approval (up to three levels of approval depending on the research)

State (13)	Three Levels of Approval
Delaware	• Chronic Disease Epidemiologist • Delaware Division of Public Health Privacy Board • Delaware Human Subjects Review Board
Iowa	• Iowa Cancer Registry Epidemiologist • University of Iowa IRB • Iowa Department of Public Health
Michigan	• Michigan Department of Community Health IRB • Scientific Advisory Panel • Director of Department of Community Health
Missouri	• Missouri Cancer Registry and Research Center Review Committee • Vital Records Registrar • Missouri Department of Health and Senior Services IRB
Nebraska	• Nebraska Cancer Registry Program Director • Department of Health and Human Services Public Health Support Unit Administrator • Department of Health and Human Services Legal Department
North Carolina	• North Carolina Department of Health, Cancer Registry Director • North Carolina Department of Health, State Center for Health Statistics Director • North Carolina Department of Health, State Cancer Advisory Board
Oklahoma	• Oklahoma Central Cancer Registry • Oklahoma State Department of Health IRB • Commissioner of Health
Oregon	• Oregon Department of Human Services, Public Health IRB • Oregon State Cancer Registry Program Director • Oregon State Cancer Registry Advisory Committee
Puerto Rico	• Puerto Rico Cancer Registry Program Director and Coordinator of Analysis and Research Unit • University of Puerto Rico Medical Sciences Campus IRB • Puerto Rico Cancer Registry Advisory Committee
South Carolina	• Cancer registry • Committee • Department of Health IRB
South Dakota	• South Dakota Cancer Registry Program Director • A Committee of the South Dakota Cancer Registry • Executive Management (Secretary of Health and three division directors)
U.S. Pacific Islands	If specific territory, up to three senior-level officials: • Pacific Regional Central Cancer Registry Program Director • Senior-level ranking official • Local IRB If regional level, two senior-level officials: • Pacific Regional Central Cancer Registry Program Director • Pacific Islands Health Officers Association
Vermont	• Vermont Cancer Registry Program Chief • Vermont Department of Health Legal Department • Vermont Agency of Human Services IRB

8d. Four or more levels of approval (up to four levels of approval depending on the research)

State (5)	Four Levels of Approval
Arkansas	• Chief Epidemiologist • Scientific Advisory Committee • State Board of Health • Administration (MOA required)
California	• Committee for the Protection of Human Subjects IRB • California Cancer Reporting and Epidemiologic Studies Research Program Director • Cancer registry IRB • California Department of Public Health Cancer Registry Director
Kansas	• Kansas Cancer Registry Director • Kansas Cancer Registry Data Release Board • University of Kansas Medical Center (KUMC) IRB and/or Kansas Department of Health and Environment (KDHE) IRB • Secretary, KDHE Protection
Maryland	• Maryland Cancer Registry Program Director • Three senior-level Department of Health and Mental Hygiene officials • Department of Health and Mental Hygiene IRB • Secretary of the Department of Health and Mental Hygiene
Texas	• Texas Cancer Registry Director • Texas Department of State Health Services IRB • Texas Department of State Health Services Executive Oversight Committee • Texas Department of State Health Services Commissioner

9. Frequency of IRB and other regulatory committee meetings

Frequency	Total	States
Weekly	1	Iowa
Monthly	15	Arizona, Connecticut, District of Columbia, Georgia, Hawaii, Maryland, New Hampshire, Ohio, Oklahoma, Oregon, Tennessee, Texas, Vermont, Washington, Wyoming
Quarterly	6	Colorado, Kansas, Maine, South Carolina, Virginia, West Virginia
Bimonthly	5	California, Florida, New York, Massachusetts, Missouri
Semimonthly	2	Indiana, Puerto Rico
As needed	2	Alabama, Idaho
5–6 per month	1	Utah
Unknown	21	Alaska, Arkansas, Delaware, Illinois, Kentucky, Louisiana, Michigan, Minnesota, Mississippi, Montana, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Pennsylvania, Rhode Island, South Dakota, U.S. Pacific Islands, Wisconsin

10. Charges a fee

No Fee (20)	Charges a Fee (33)
Alaska, Arizona, Colorado, Connecticut, Delaware, District of Columbia, Indiana, Maryland, Massachusetts, Montana, New Hampshire, North Dakota, Ohio, Puerto Rico, Rhode Island, Tennessee, Texas, U.S. Pacific Islands, Washington, Wyoming	Alabama, Arkansas, California, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, Utah, Vermont, Virginia,* West Virginia, Wisconsin

*Virginia may charge a fee, depending on the study.

11. Time frame for the approval process

Time Frame	Total	States
<2 months	19	Connecticut, District of Columbia, Hawaii, Idaho, Indiana, Iowa, Kentucky, Louisiana, Massachusetts, Mississippi, Montana, Nebraska, New Hampshire, North Carolina, Pennsylvania, South Dakota, Wyoming
2–6 months	20	Alabama, Arkansas, California, Colorado, Delaware, Georgia, Maine, Michigan, Minnesota, Nevada, New York, North Dakota, Ohio, Oklahoma, Oregon, Puerto Rico, Rhode Island, South Carolina, Texas, U.S. Pacific Islands, Vermont, West Virginia
Varies	14	Alaska: Time frame unknown, never processed request for access to identifiable data Arizona: Complexity of the research, patient contact study Florida: Depends on the complexity of the research project and if the researcher submits in a timely fashion additional documentation if requested by the Cancer Registry Program and DOH IRB Illinois: Complexity of the research Kansas: Complexity of the research, type of research, type of data requested Maryland: Project needs, cancer registry priorities, IRB schedule Missouri: Can take a long time, several months minimum New Jersey: Complexity of the research and staffing New Mexico: Complexity of the research Tennessee: Time frame unknown; approval process changing, previous requests took 6 months Utah: Depends on the details of the project Virginia: Depends on the complexity of the project, time of year, other priorities, and staffing; typically one week to four months Washington: Complexity of the research Wisconsin: Time of year, other priorities, staffing; typically 1 week to 3–4 months

12. Limit on number of studies

Does Not Limit Studies (50)	Limits Studies (3)
Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Virginia, Washington, Wisconsin, Wyoming	Louisiana, Missouri, West Virginia

Notes: Louisiana: Registry limits number of contact studies per patient to minimize patient burden. No patient can be contacted by more than one study regardless of researcher.

Missouri: Registry limits studies by restricting cases from the same population and same time period.

Tennessee: IRB Committee determines on a case-by-case basis to limit participation in studies depending on available resources.

West Virginia: Registry must limit the number of studies managed at one time due to limited staff available.

13. Involvement of cancer registry director or senior official in approval process

Not Involved in Approval Process (4)	Involved in Approval Process (49)
Connecticut, New Hampshire, Pennsylvania, Virginia	Alabama, Alaska, Arizona, Arkansas, California, Colorado, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Washington, West Virginia, Wisconsin, Wyoming