Obtaining Data from the California Cancer Registry

About California Cancer Registry (CCR)

- CCR is a program of the California Department of Public Health's Chronic Disease Surveillance and Research Branch (CDSRB).
- CCR is California's statewide population-based cancer surveillance system.
- CCR collects information about almost all cancers diagnosed in California. This information furthers our understanding of cancer and is used to develop strategies and policies for its prevention, treatment, and control.

About CCR

- Recognized as one of the leading cancer registries in the world, CCR has been the cornerstone of a substantial amount of research on cancer in the California population.
- To date, CCR has collected detailed information on over 3.4 million cases of cancer among Californians diagnosed from 1988 forward, and more than 162,000 new cases are added annually.

CDPH California Department of PublicHealth

Categories of Data Available from CCR

- Data and Statistics for the General Public
- Data for Approved Research Studies
- Access to Personal Information

CCR Data & Statistics for the General Public

- CCR provides information on the status of cancer in California, and responds to requests from the public for cancer data and statistics.
- Cancer rates by year, sex, and race/ethnicity for California as a whole and for individual counties are available through CCR's online query system, known as our Data and Mapping Tool.
- Questions that cannot be answered by the Data and Mapping Tool, may be answered by contacting staff at CCR.

CDPH California Department of PublicHealth

Data for Approved Research Studies

Types of Data Requests:

- Customized de-identified research datasets for analysis
- Case-listings for patient contact
- Data linkages to link a study's cohort or other database to CCR data using probabilistic matching software

CDPH California Department of PublicHealth

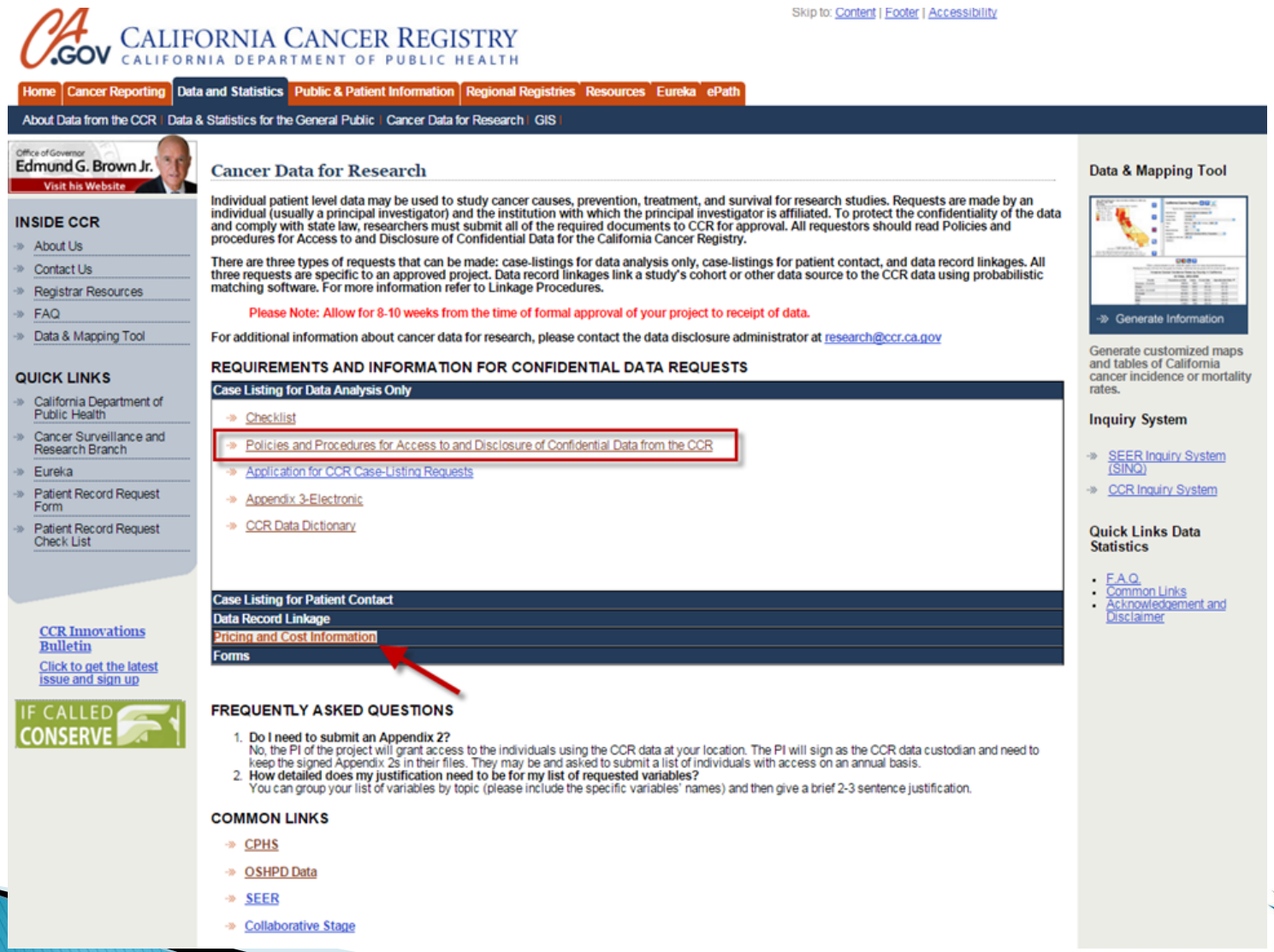
Data for Approved Studies

I need CCR data for my research project, where do I start?

Cancer Data for Research Page
of the CCR website

http://www.ccrcal.org/Data_and_Statistics/Cancer_Data_for_Research.shtml

Data for Approved Studies



CDPH California Department of PublicHealth

Data for Approved Studies

What is needed to obtain patient level data for a research study?

- Committee for the Protection of Human Subjects approval
- Institutional Review Board approval or exemption
- Application for Disclosure of Confidential Registry Data for Research
- Confidentiality Agreement for Disclosure of CCR Data
- List of requested variables, including justification

CDPH California Department of PublicHealth

Data for Approved Studies

Frequently Asked Questions

1. How long is the approval process?
   The approval process can take two-three months.
2. Are there any fees?
   Although there are no application fees, customized research datasets do incur fees. Please see the CCR Pricing Information sheet for charges related to preparing a dataset.

CDPH California Department of PublicHealth

Data for Approved Studies

3. Once approved, how does it take to receive the completed dataset?
   Most researchers receive the completed dataset four-six weeks after approval.
4. Are data released to allow a patient contact study?
   Researchers may receive patient identifiers for approved patient contact studies.
5. How complete are CCR data?
   California law requires most cancers diagnosed from 1988 onward among California residents to be reported to the CCR. It usually takes 18 to 21 months after the end of the year to reach 95% data completeness.

CDPH California Department of PublicHealth

Data for Approved Studies

Questions?

Contact California Cancer Registry
Email: research@ccr.ca.gov
Phone: (916) 731-2500

Access to Personal Information: Individual Record Request

Who can obtain individual CCR records?

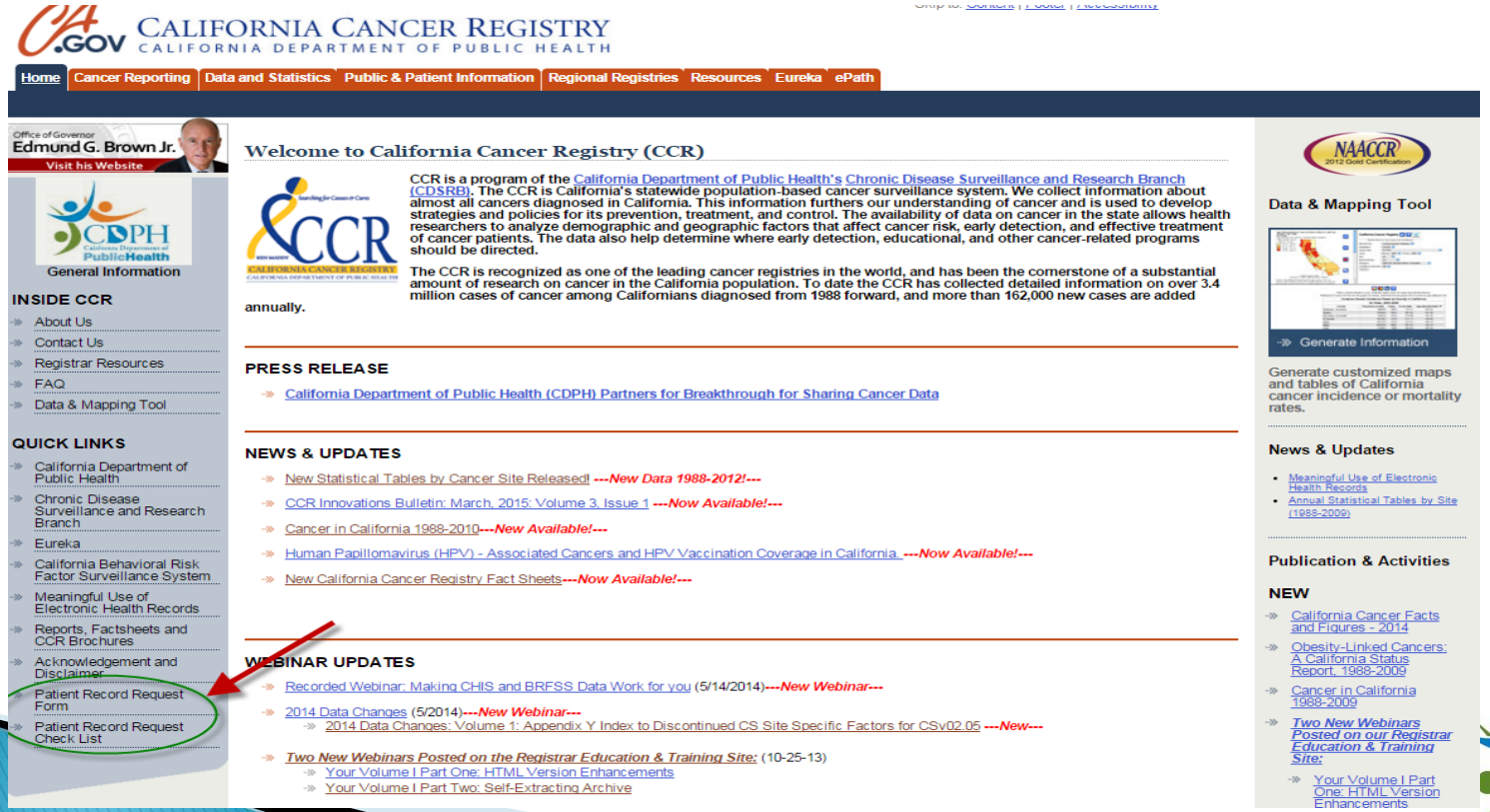
Legally authorized individuals such as:

- Self
- Surviving spouse
- Executor or Administrator of decedent's Will or Estate

Individual Record Request

How do I request an individual patient record?

Visit www.ccrcal.org



CDPH California Department of PublicHealth

Individual Record Request

CALIFORNIA CANCER REGISTRY PATIENT RECORD REQUEST FORM

Mail Requests to:

Chronic Disease Surveillance and Research Branch
California Cancer Registry
1631 Alhambra Blvd., Suite 200
Sacramento, CA 95816

INDIVIDUAL WHOSE INFORMATION YOU ARE REQUESTING
*Patient Name:
Patient Alias Name:
*Patient Social Security Number:
*Patient Date of Birth:
*Patient Date of Diagnosis:
*Type of Cancer:
*Patient Date of Death (if applicable): **CERTIFIED DEATH CERTIFICATE MUST BE ATTACHED (with raised seal)**
Patient Address at Diagnosis:
*Patient County of Diagnosis:
**required fields*

REPRESENTATIVE CONTACT INFORMATION		
Last Name:	First Name:	Middle Initial:
Physical Address:	City/State:	Zip Code:
Mailing Address (if different):	City/State:	Zip Code:
Daytime Phone Number:	Email Address:	Please return all certified copies: ☐ Yes ☐ No
WHAT LEGAL AUTHORITY DO YOU HAVE TO REQUEST HEALTH INFORMATION:		
☐ Self ☐ Parent	☐ Conservator ☐ Executor of Will	

☐ Guardian ☐ Medical Power of Attorney	☐ Other (Please specify – spouse, son, daughter, etc):
NOTE: You must attach all LEGAL documentation to verify that you have legal authority to access the patient's records (Please refer to the CCR Patient Record Request Check List).	

IDENTIFYING INFORMATION REQUIRED
☐ Copy of Identification Attached Type: _____ (Driver's License, Identification Card, Birth Certificate) ☐ Address Verification Attached TYPE: _____ (Utility Bill, Phone Bill, Driver's License, Etc.)
IF NO IDENTIFICATION IS ATTACHED, YOUR SIGNATURE MUST BE NOTARIZED. Notarized by _____ on _____ (Date) Notary Public Number _____ **UNOFFICIAL UNLESS STAMPED BY NOTARY PUBLIC**
I DECLARE UNDER PENALTY OF PERJURY THAT THE INFORMATION ON THIS FORM IS TRUE AND CORRECT. Representative Signature: Date:

CDPH California Department of PublicHealth

Individual Record Request

- Patient record requests are usually processed in two weeks.
- There is no charge to receive a copy of an individual patient record.

Questions?

Contact California Cancer Registry at (916) 731-2500.