Deploying KP Resources to Study Cancer Survivorship and Outcomes

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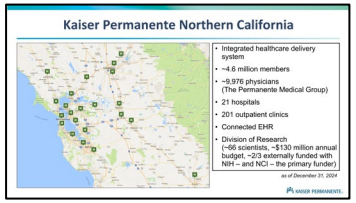
Conflicts and Disclosures

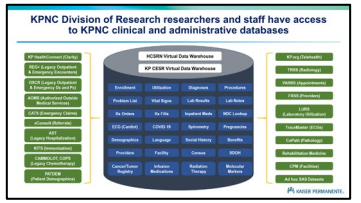
- No financial conflicts of interest to disclose.
- The research projects for which I am (Multiple) Principal Investigator are supported by the National Cancer Institute and the Department of Defense Breast Cancer Research Program.
- I generally do not accept funds from for-profit institutions.
- The views expressed in this presentation are my own and do not necessarily represent those of Kaiser Permanente or any other organization with which I may be affiliated.

What KPNC brings to research on cancer survivorship and outcomes

- The KPNC health system and member population



- Clinical and research health care data systems



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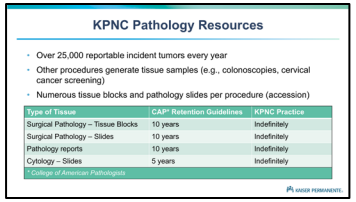
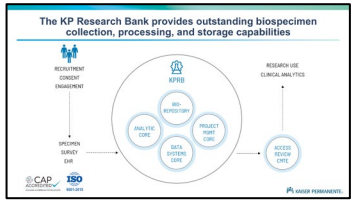


- Biospecimen (e.g., blood) collection resources



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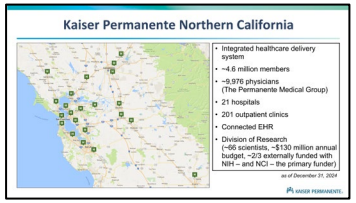

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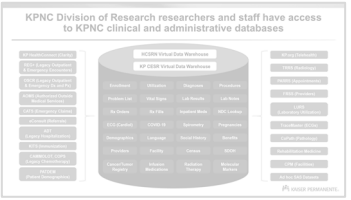

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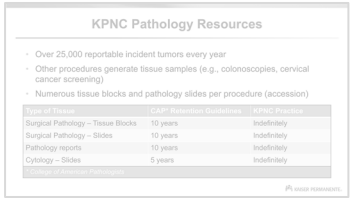

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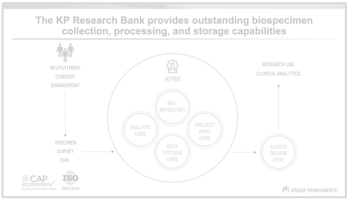

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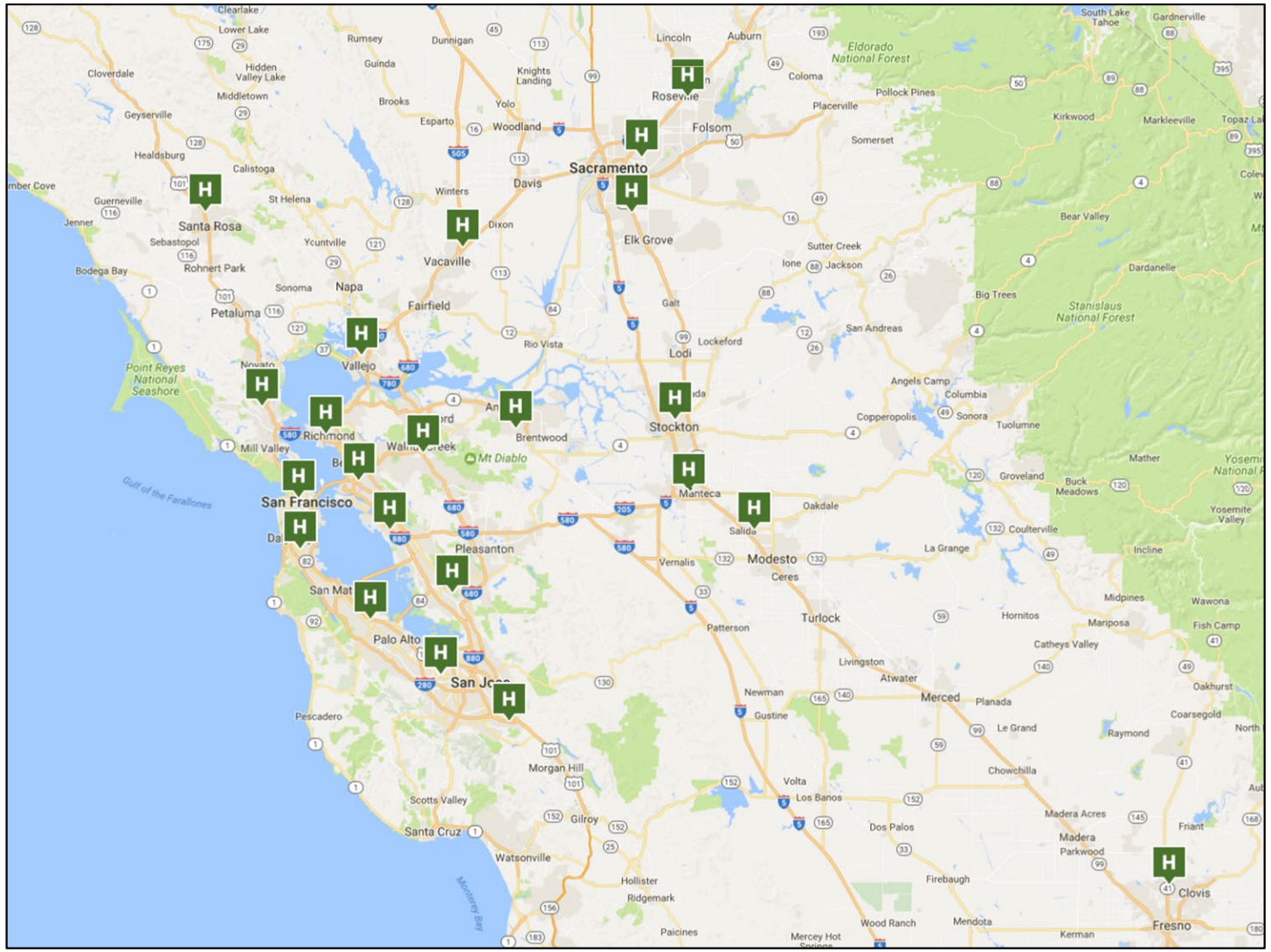
Kaiser Permanente Northern California



- Integrated healthcare delivery system
- ~4.6 million members
- ~9,976 physicians (The Permanente Medical Group)
- 21 hospitals
- 201 outpatient clinics
- Connected EHR
- Division of Research (~66 scientists, ~$130 million annual budget, ~2/3 externally funded with NIH – and NCI – the primary funder)

as of December 31, 2024

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Gomez et al. BMC Cancer (2015) 15:688
DOI 10.1186/s12885-015-1696-9

BMC Cancer

RESEARCH ARTICLE Open Access

Representativeness of breast cancer cases in an integrated health care delivery system

Scarlett Lin Gomez[1,3*], Salma Shariff-Marco[1,3], Julie Von Behren[2], Marilyn L. Kwan[4], Candyce H. Kroenke[4], Theresa H. M. Keegan[1,3], Peggy Reynolds[2,3] and Lawrence H. Kushi[4]

Abstract

Background: Integrated health care delivery systems, with their comprehensive and integrated electronic medical records (EMR), are well-poised to conduct research that leverages the detailed clinical data within the EMRs. However, information regarding the representativeness of these clinical populations is limited, and thus the generalizability of research findings is uncertain.

Methods: Using data from the population-based California Cancer Registry, we compared age-adjusted distributions of patient and neighborhood characteristics for three groups of breast cancer patients: 1) those diagnosed within Kaiser Permanente Northern California (KPNC), 2) non-KPNC patients from NCI-designated cancer centers, and 3) those from all other hospitals.

Breast cancer cases diagnosed and treated at KPNC are highly representative of its catchment area

(% of cases diagnosed 1996-2009; data from California Cancer Registry)

Characteristic	Category	Cancer Center (n=7,805)	KPNC (n=36,143)	Other Settings (n=68,330)	Total (n=112,278)
% of cases		7.0	32.2	60.9	100
Race/Ethnicity	Non-Hispanic White	70.2	70.8	74.6	73.0
	Non-Hispanic Black	6.4	8.0	5.0	6.0
	Asian/Pacific Islander	16.9	12.9	12.6	13.0
	Hispanic	5.5	7.4	7.0	7.0
	Other/Unknown	0.9	0.9	1.0	0.9
Age at diagnosis (y)	<50	31.1	20.8	23.9	23.4
	50-59	27.5	26.1	24.3	25.1
	60-69	20.4	25.3	20.6	22.1
	70-79	13.7	19.1	19.1	18.7
	80+	7.2	8.7	12.2	10.7

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Neighborhood SES	State quintile 1 (lowest)	3.4	4.2	6.5	5.5
	State quintile 2	7.1	11.2	11.1	10.8
	State quintile 3	13.7	19.1	18.1	18.1
	State quintile 4	22.4	29.1	25.4	26.4
	State quintile 5 (highest)	53.4	36.4	38.9	39.1
Urban/Rural	Rural or small towns	6.2	6.3	11.1	8.6
	Small, medium cities	7.8	29.2	29.4	27.8
	Suburban metropolitan	58.0	53.6	48.9	51.1
	Urban metropolitan	28.0	11.0	11.5	12.5

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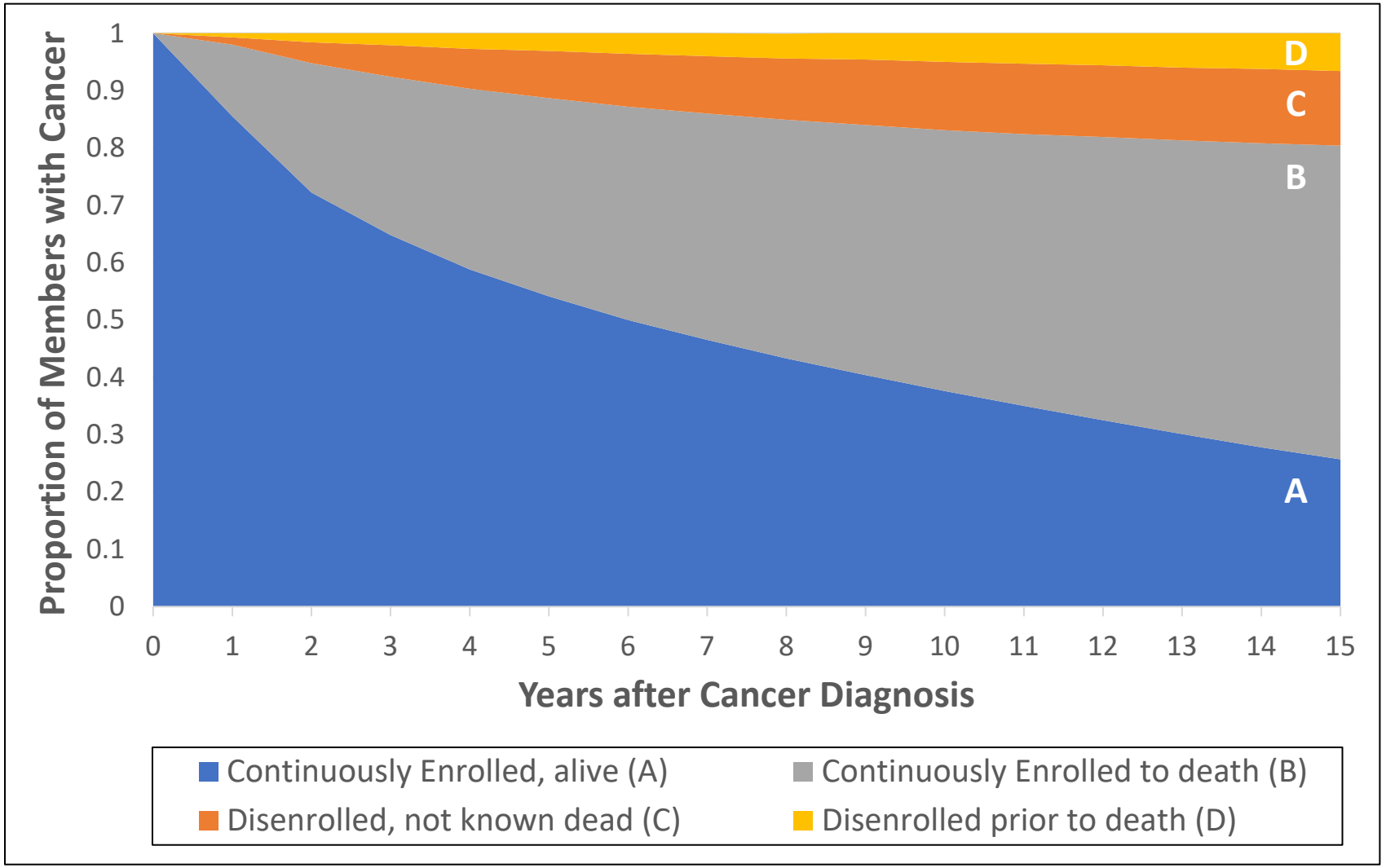

High Retention of KPNC Members AFTER Cancer Diagnosis

Years Post Cancer Dx	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Proportion in KPNC	1.00	0.98	0.95	0.92	0.90	**0.89**	0.87	0.86	0.85	0.84	**0.83**	0.82	0.82	0.81	0.81	**0.80**

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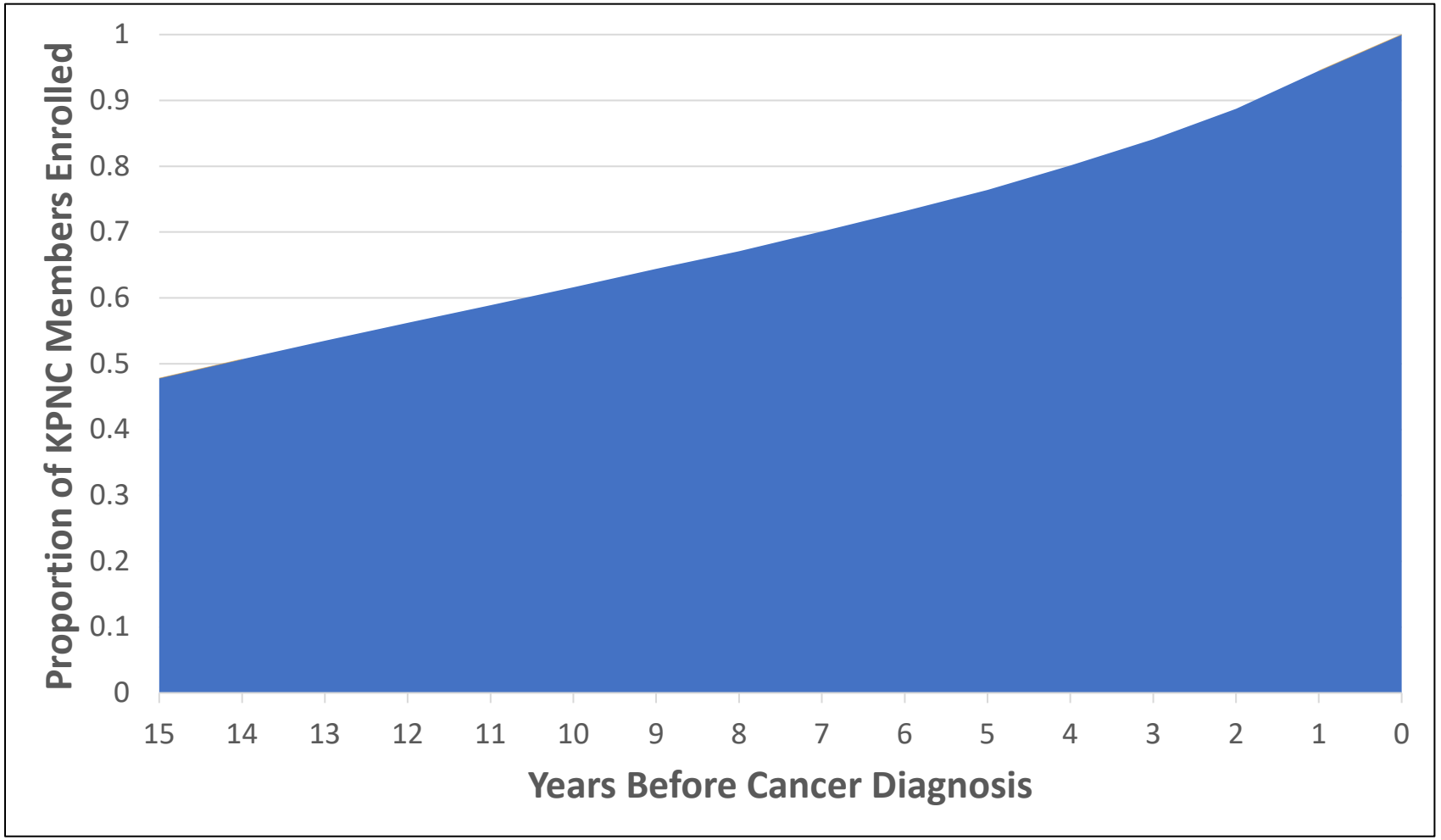

Continuous Enrollment of KPNC Members BEFORE Cancer Diagnosis

Years Pre Cancer Dx	15	14	13	12	11	10	9	8	7	6	5	4	3	2	1	0
Proportion in KPNC	**0.48**	0.51	0.54	0.56	0.59	**0.62**	0.64	0.67	0.70	0.73	**0.76**	0.80	0.84	0.89	0.95	1.00

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KP members participate in studies at a higher rate than elsewhere: The VOICE Study *(P01 CA233432)*

Status	Institution						Total	
	KPNC		KPSC		UNC Chapel Hill			
Survey participant	1,684	36.7	2,001	34.8	316	14.8	4,001	32.1
Non-respondent	2,837	61.7	3,615	62.9	1,754	81.9	8,206	65.7
Found not eligible	74	1.6	130	2.3	71	3.3	275	2.2
Total	4,595	100.0	5,746	100.0	2,141	100.0	12,482	100.0

	KPNC	KPSC	UNC Chapel Hill	
Overall Participation Rate	**37.2**	**35.6**	**15.3**	32.8

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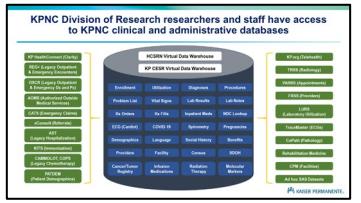
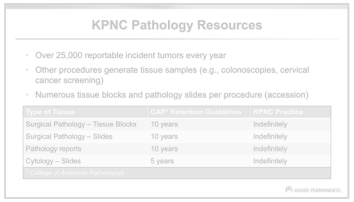
- Clinical and research health care data systems



- Pathology resources



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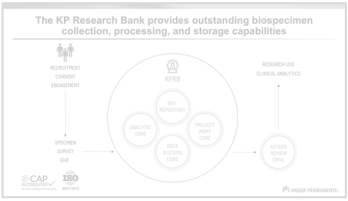

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The KPNC Cancer Registry is an outstanding resource that supports cancer research: reportable diagnoses, 2019–2023

Cancer Site	2019	2020	2021	2022	2023	KPNC 2019-2023	SF Bay Area*, 2018-2022
All Reportable	25,283	21,119	25,712	25,667	26,112	123,893	175,297
Breast	4,557	3,530	4,964	4,749	4,693	22,493	29,575
Melanoma	2,874	2,016	3,065	3,429	3,769	15,153	11,830
Prostate	2,541	2,107	3,064	3,300	3,142	14,154	22,539
Colorectal	1,884	1,675	1,897	1,835	1,889	9,180	14,168
Lung and Bronchus	1,899	1,731	1,758	1,732	1,834	8,954	15,484
Non-Hodgkin Lymphoma	1,006	902	1,069	992	1,019	4,988	8,761
Urinary bladder	953	855	891	890	901	4,490	6,994
Ovary	278	279	308	296	280	1,441	2,364

** From Greater Bay Area Cancer Registry, an NCI SEER Program Registry; includes counties of Alameda, Contra Costa, Marin, Monterey, San Benito, San Francisco, San Mateo, Santa Clara, Santa Cruz , https://cancerregistry.ucsf.edu/*

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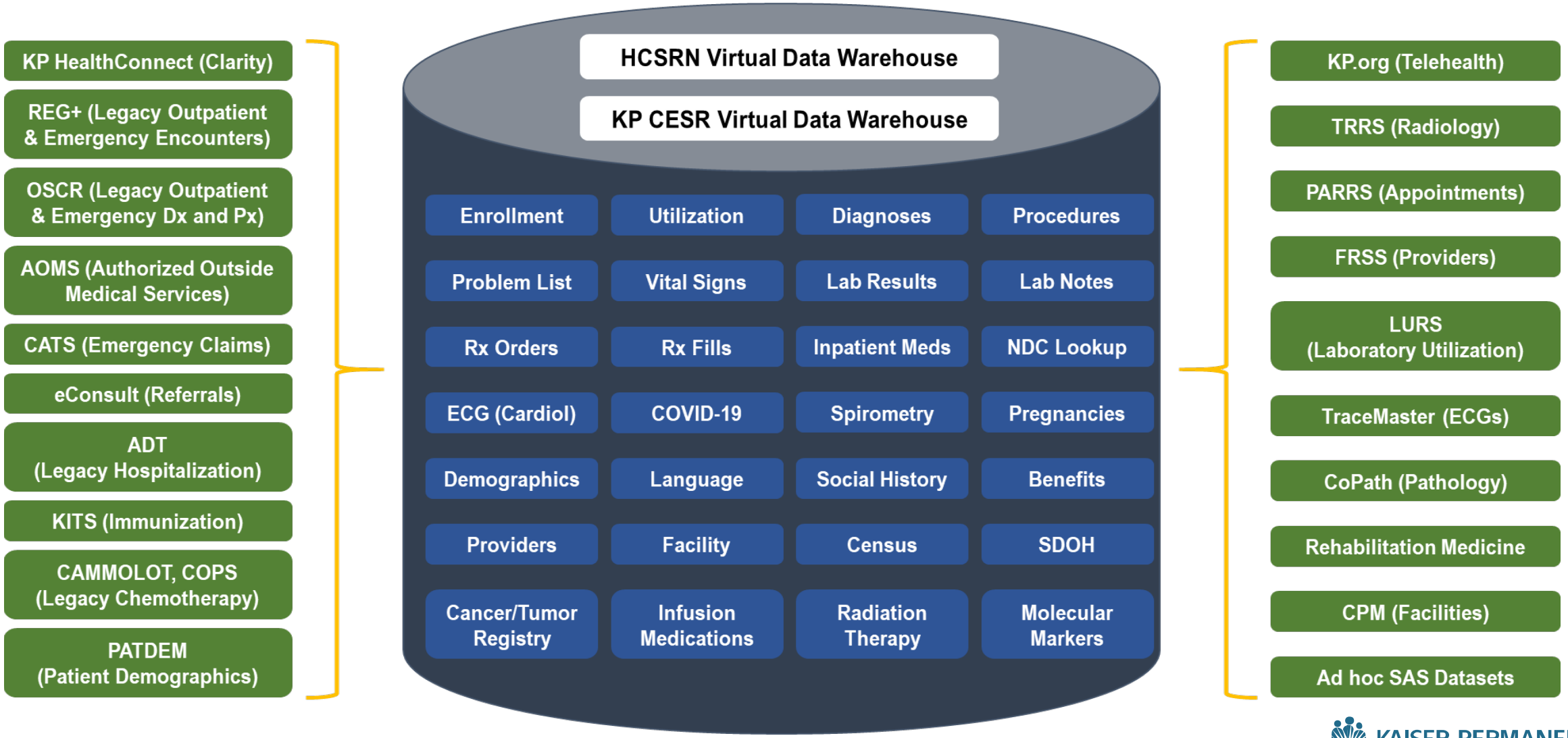
KPNC Division of Research researchers and staff have access to KPNC clinical and administrative databases



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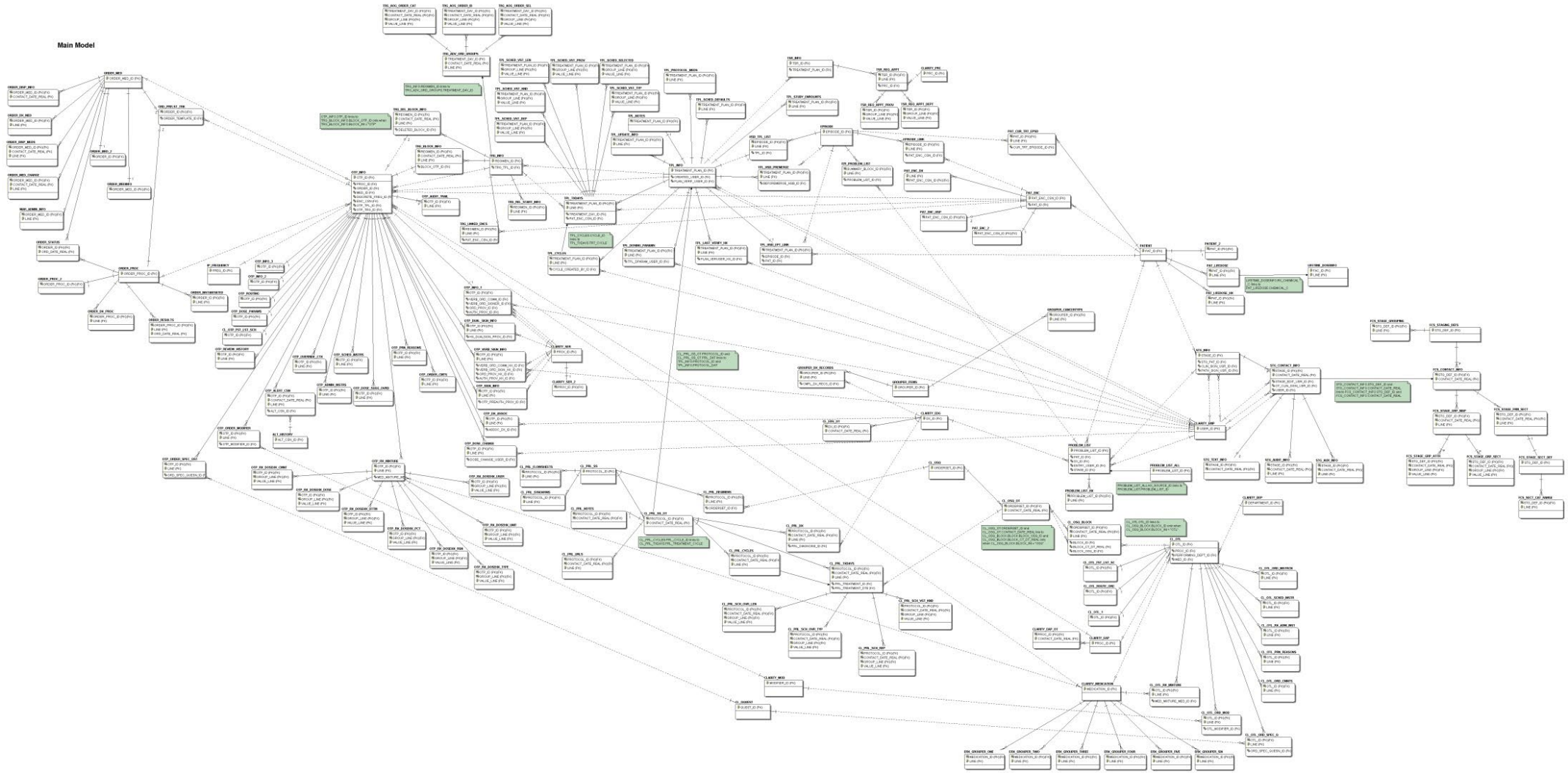
Example Data Domains available in KPNC Research Database and VDW; most data from 1996 *(N observations as of March 6, 2024)*

Table	Description	N Variables	N Observations	Update Frequency
Enrollment	Dates of Health Plan enrollment	32	93,731,332	Monthly
Demographics		34	18,228,751	Monthly
Utilization	All encounters: hospitalizations, emergency room, ambulatory, laboratory, telehealth, etc.	146	982,284,218	Daily
Diagnoses	ICD 9/10 codes	124	2,555,664,860	Daily
Procedures	CPT/HCPCS codes	129	1,919,007,296	Daily
Laboratory	LOINC codes	46	1,771,753,726	Daily
Pharmacy	NDCs	115	743,569,105	Daily
Vital Signs	Blood pressure, heart rate, etc.	85	970,528,124	Monthly
Tumor	ICD-O-3 codes, SEER variables	107	662,016	Quarterly
Death, Causes	Internal, State, and NDI linkage	25	6,889,501	Monthly / Yearly

Epic Beacon Infusion Data Model, ca. 2010



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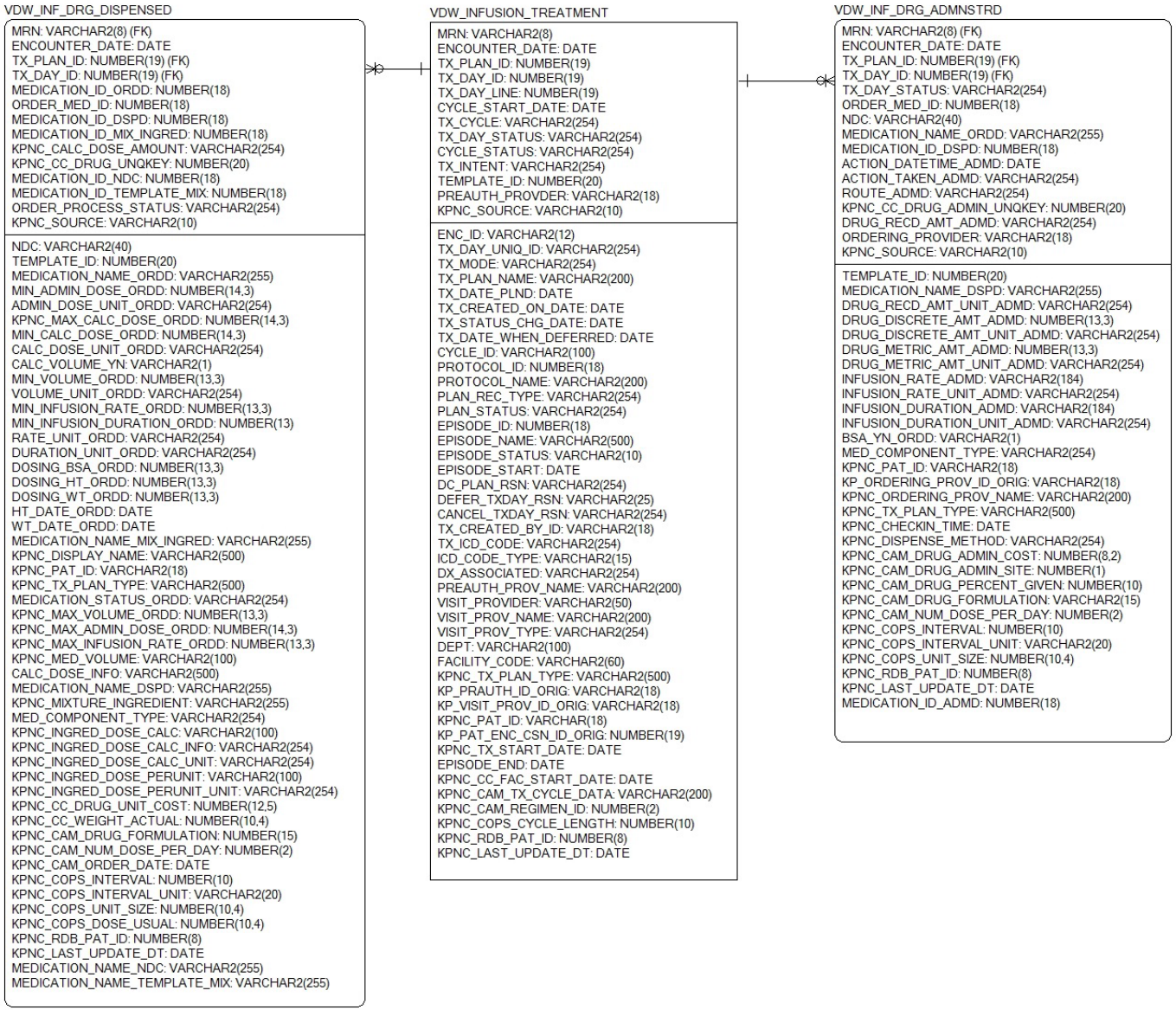

VDW Infusion Tables

- VDW_INFUSION_TREATMENT
  - Treatment plan, protocol name
  - Provider
  - Treatment intent
- VDW_INF_DRG_DISPENSED
  - Medications dispensed – anticancer, supportive
  - Dosing parameters
  - Calculated dosages
- VDW_INF_DRG_ADMINSTRD
  - Medications given
  - Dosages given
  - Start, end times and duration

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EDM Forum
EDM Forum Community

eGEMs (Generating Evidence & Methods to improve patient outcomes)

EDM Forum Products and Events

eGEMs: Vol. 2: Iss. 1, Article 2.
repository.academyhealth.org/egems/vol2/iss1/2/

3-24-2014

The HMO Research Network Virtual Data Warehouse: A Public Data Model to Support Collaboration

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Group Health Research Institute, Group Health Cooperative, Seattle, WA, ross.t@ghc.org

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HCSRN

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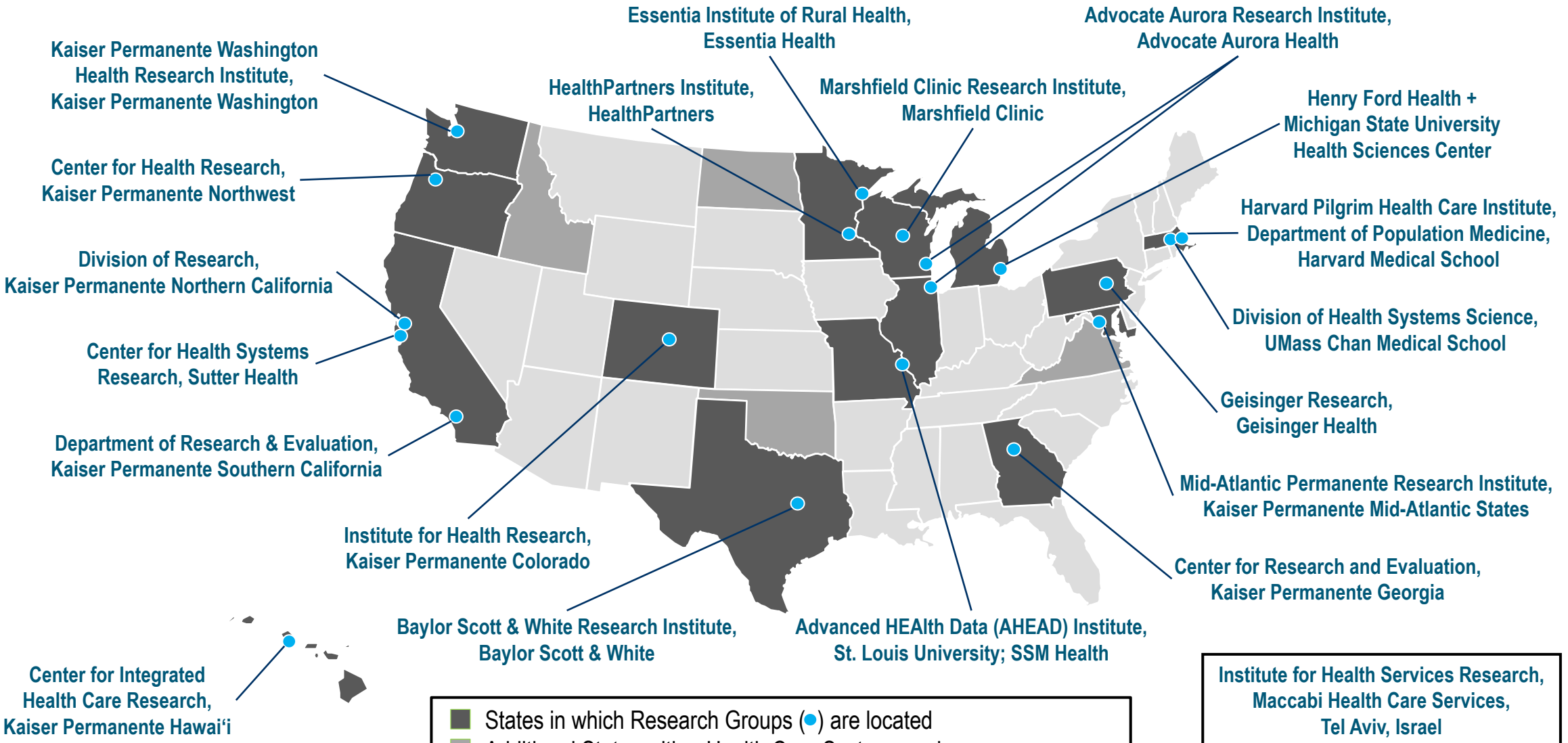
Health Care Systems Research Network



Institute for Health Services Research, Maccabi Health Care Services, Tel Aviv, Israel

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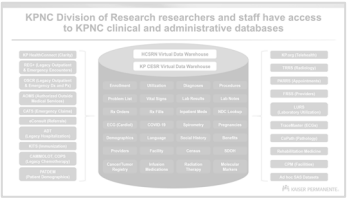

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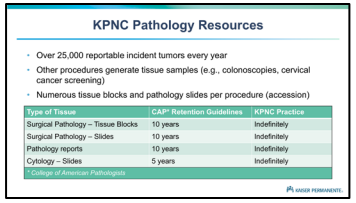

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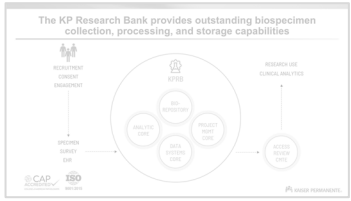

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KPNC Pathology Resources

- Over 25,000 reportable incident tumors every year
- Other procedures generate tissue samples (e.g., colonoscopies, cervical cancer screening)
- Numerous tissue blocks and pathology slides per procedure (accession)

Type of Tissue	CAP* Retention Guidelines	KPNC Practice
Surgical Pathology – Tissue Blocks	10 years	Indefinitely
Surgical Pathology – Slides	10 years	Indefinitely
Pathology reports	10 years	Indefinitely
Cytology – Slides	5 years	Indefinitely

** College of American Pathologists*

Obtaining tumor specimens and creating tissue microarrays in the Pathways Study (U01 CA195565)

Item	Status	Participants		Accessions	
		N	%	N	%
Pathology reports	Received	4,505	100		
	Reviewed	4,505	100		
Slides	Requested	4,438	100	5,183	100
	Received	4,206	94.8	4,764	91.9
	Scanned	4,280	96.4	4,507	87.0
FFPE Blocks	Requested	4,225	100	4,327	100
	Received	4,209	99.6	4,299	99.4
TMAs	Planned	3,680		3,682	
	Completed	3,680		3,682	

- Cases diagnosed 10/2005 to 5/2013
- Pathology work done 6/2001 to 10/2025

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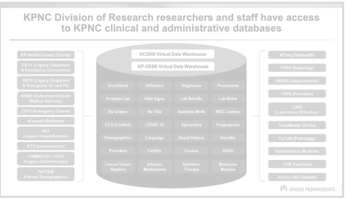

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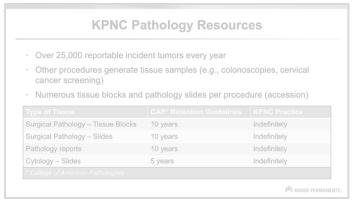

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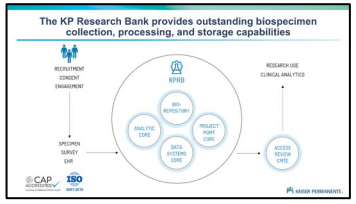

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KPNC Research Biospecimens Coordinating Committee oversees use of these specimens

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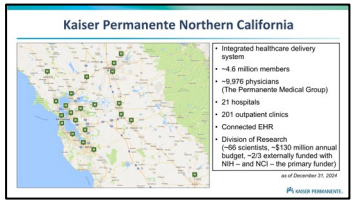
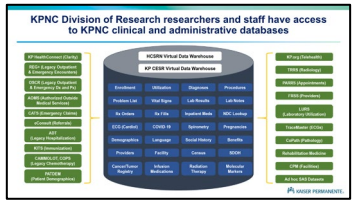
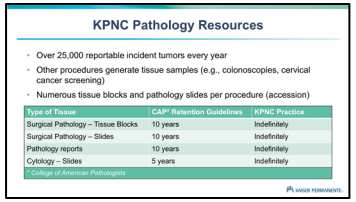


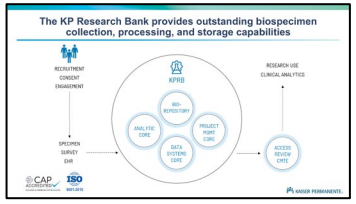
- Clinical and research health care data systems



- Pathology resources

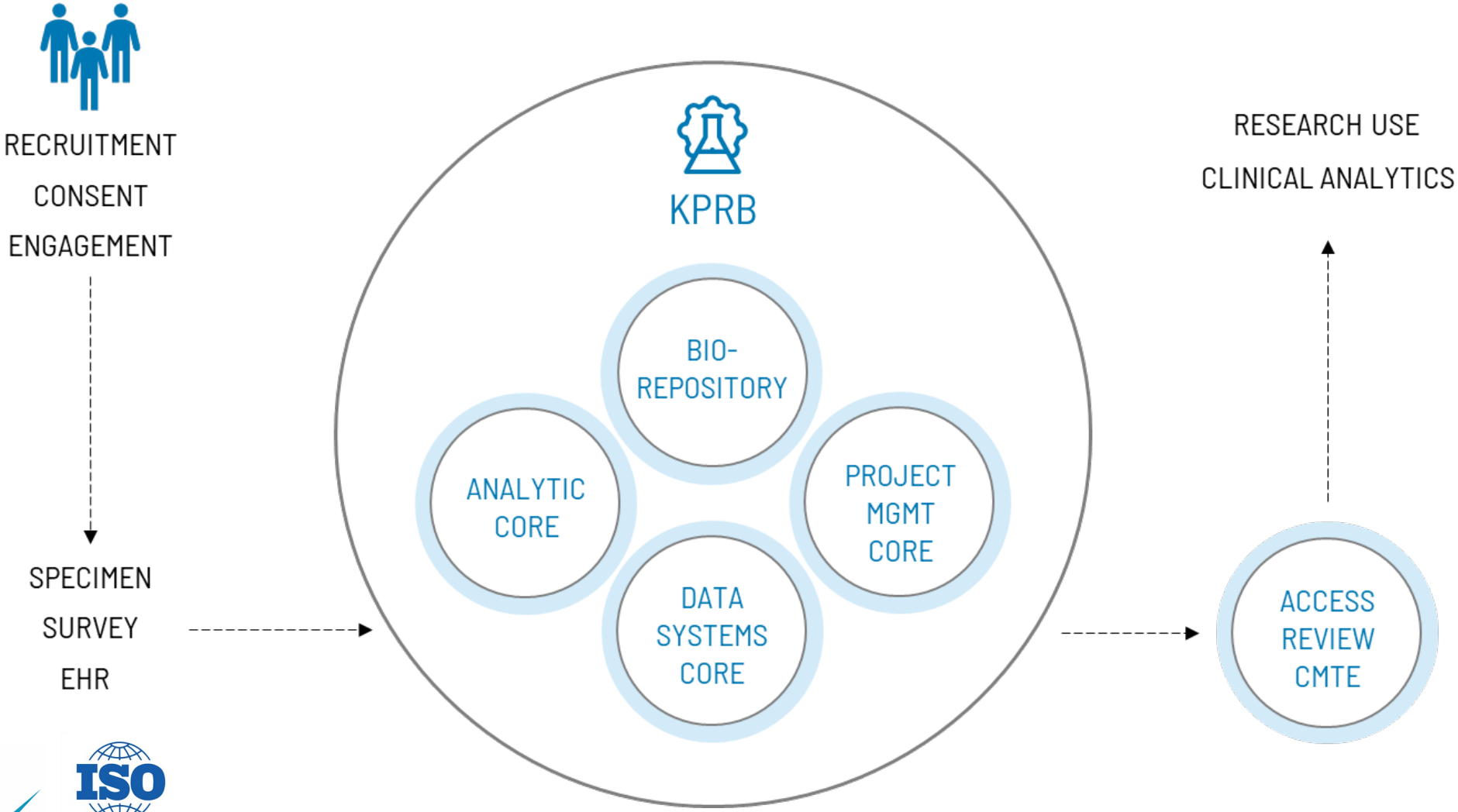


- Biospecimen (e.g., blood) collection resources



KAISER PERMANENTE®

The KP Research Bank provides outstanding biospecimen collection, processing, and storage capabilities



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KPRB – Example Workflow for Blood Collection

- Research Blood Draw has been established as an order that can be placed through the clinical laboratory system
- Standard research blood draw specifies types of readily-available vacutainers for collection
- Takes advantage of regional laboratory system with numerous locations for blood draw and several courier runs to central laboratory in Richmond
- When blood specimens are received in Richmond, bar codes indicate it should be routed to the KPRB biorepository in Berkeley
- After receipt at the KPRB biorepository, specimen processed according to study protocol

PAR-25-186 pre-submission meeting

Establishing the Preeminent Prospective Cohort Study and Research Resource on the Gut Microbome and Cancer Risk

MPIs: Lawrence H. Kushi, ScD, Jacek Skarbinski, MD, Kristi L. Hoffman, PhD

10 December 2024

KAISER PERMANENTE®

The KPRB has conducted several studies that demonstrate the feasibility of collecting, processing, and storing FIT specimens

- Informatics feed from KPNC Regional Laboratory Information System to the KPRB LIMS
  - Can identify which KP members have returned a FIT specimen
  - Includes relevant dates – date of collection, date of receipt by lab, date of testing
- Determined size and number of aliquots that can routinely be collected from FIT specimens
- Determined how to minimize cross-specimen contamination using automated liquid handlers
- Evaluated different methods for DNA extraction for one of the aliquots to minimize costs without compromising accuracy
- Working with outside laboratories, demonstrated ability to generate microbiome data from collected specimens
- Developed protocols with the KP Regional Lab to identify FIT specimens from individuals who have consented to research use of biospecimens, and to collect and process for long-term storage those FIT specimens prior to destruction

Status of FIT-based microbiome cohort study

- Proposal submitted to the NCI, but did not receive a fundable score
- PAR to which one can submit cohort applications is in limbo
- Next steps to obtain external funding unclear
- Meanwhile, we have continued to collect stool specimens from KPRB participants:

Total Cohort as of 10/15/2025	Fecal DNA extracted	Raw fecal specimens stored	People with repeat specimens
35,928	35,298	35,298	4,922

Summary

- KP in general and KPNC in particular provides outstanding resources for conducting studies in cancer survivorship and outcomes
- Drs. Siegel and Feliciano provide examples of areas in which we are doing pioneering work that is leading the field, clinically and as research areas
- There are numerous other benefits, including collaborations with clinical leaders and potential for cancer care delivery research and dissemination and implementation research to have a direct impact on improving the care and health of KPNC members
- There are many other examples of past, current, and future studies that have and can build upon the expertise and resources our environment provides
- This is an exciting time to be conducting research in the KP setting
- Many thanks to the many people who have made this research possible


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