

End-user recommendations for advancing registry-based cancer research

Jessica Chubak, PhD

Enabling 21st Century Applications for Cancer Registries and Beyond

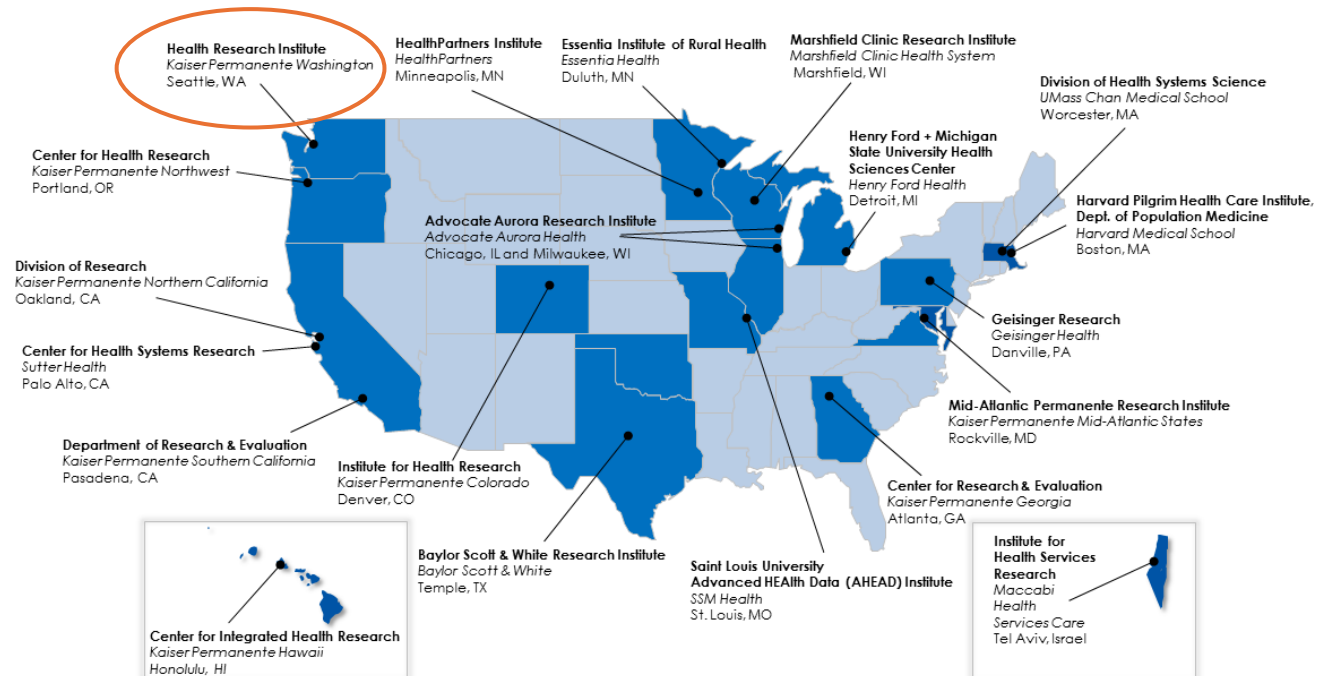
July 29, 2024

Disclosures

- I receive funding from the National Institutes of Health
- Opinions are my own and do not represent those of Kaiser Permanente

Perspective of a registry end-user

- Based at Kaiser Permanente Washington
- Part of Health Care Systems Research Network (HCSRN)



Linked data areas within the HCSRN

- Enrollment
- Demographics
- Pharmacy
- Encounters
- Procedures
- Diagnoses
- Vital signs
- **Tumor**
- Death
- Census
- And more!

Recommendations to advance registry-based cancer research

1. Ease data sharing restrictions
2. Require and fund inclusion of recurrence in cancer registries

1. Ease data sharing restrictions

- Linkages between registries and health care systems data are critical for cancer research
 - Health care systems have rich longitudinal data
- Challenges
 - Data Use Agreements are often for specific projects
 - Limits on further sharing (e.g., into data repositories)
- Solutions
 - Regulatory

2. Require and fund inclusion of recurrence in cancer registries

- Possible approaches
 - Medical records abstraction
 - Medical claims
 - Imaging and pathology feeds
 - Patient report
- Challenges
 - Distinguishing recurrence vs. progression (Thompson et al.)
 - Coverage
 - Accuracy
 - Cost
- Solutions
 - Multi-pronged data collection
 - Financial
 - Regulatory