FRED HUTCH
Hutchinson Institute for
Cancer Outcomes Research

Perspectives on Data Needs

Scott Ramsey, MD, PhD
Director
Hutchinson Institute for Cancer Outcomes Research

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Mission

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Eliminate cancer and related diseases as causes of human suffering and death.

HICOR
Hutchinson Institute for Cancer Outcomes Research

Improve the effectiveness of cancer prevention, early detection and treatment services in ways that reduce the economic and human burden of cancer.

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Community Engagement Program

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1. Cancer Care Northwest
2. CHI Franciscan Health
3. Compass Oncology
4. Confluence Health
5. The Everett Clinic
6. EvergreenHealth
7. Jefferson Healthcare
8. Kadlec
9. MultiCare Health System
10. Northwest Medical Specialties
11. Olympic Medical Center
12. Overlake Medical Center
13. Pacific Gynecology
14. Pacific Medical Centers
15. Partner Oncology
16. PeaceHealth
17. The Polyclinic
18. Providence Health & Services
19. Rockwood Clinic
20. Seattle Cancer Care Alliance
21. Skagit Regional Health
22. Southlake Clinic
23. Summit Cancer Centers
24. Swedish
25. Trios Health
26. Vancouver Clinic
27. Virginia Mason
28. Vista Oncology

Data Source: HICOR Data Repository

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Health Care Claims

Payer	Years
Premera Blue Cross	Jan 2011-Jun 2020
Regence BlueShield	Jan 2011-Jun 2020
Uniform Medical Plan	Jan 2011-Jun 2020
Medicaid	Jan 2011-Jun 2020
Medicare	Jan 2011-Dec 2019

Cancer Registries

Registry	Years
CSS-Puget Sound SEER	Jan 2011-Aug 2020
Washington State Cancer Registry	Jan 2011-Dec 2017

Clinical, Utilization, Cost and Survival Data of ~70% of cancer patients in Washington state

Over 119,932 patients at Diagnosis
Over 53,274 at time of Death

Community Cancer Care Report

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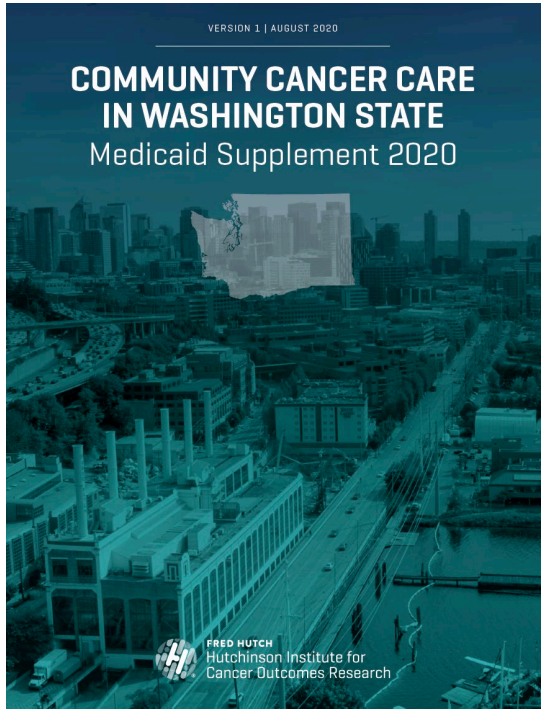
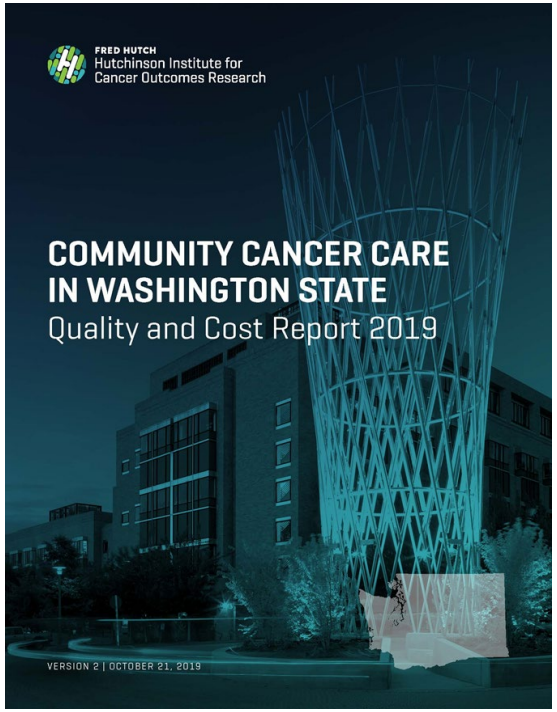
First in the nation to publicly report clinic-level quality measures linked to cost in oncology

Fred Hutch and Washington state are showing national leadership in data transparency in cancer care.

Unprecedented collaboration between health care stakeholders: payers, providers, patients, researchers





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How Can Databases Best Serve Patients?

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- Comprehensive capture of the patient experience
- Elements informed by patients and other stakeholders
- Relevant to decisions
- Ongoing mechanism for direct feedback on patient-identified priorities
- Information is relevant and accessible
- Timely

Are Patients Well-Served By Our Data Infrastructure?

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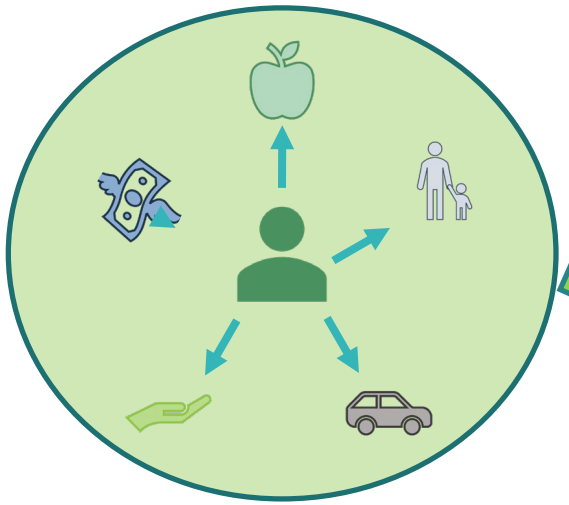
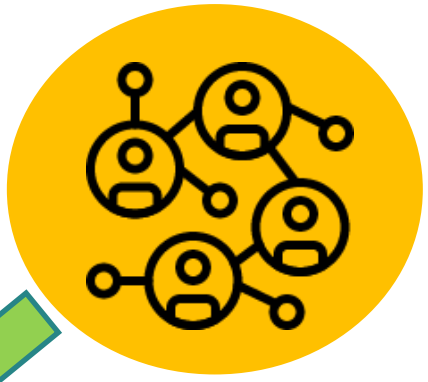
Social determinants
Medical conditions





Neighborhood and network effects

Understanding the Health System

Care plan and rationale

Ability to interrogate information

What factors influence patients' sense of well-being during cancer care?

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- Feeling that they are supported
- Dealing with uncertainty
- Perceived loss of autonomy
- Trust in the health system

What questions cannot be answered with the current PCOR data infrastructure?

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Existing data

Patient experience

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Role of social determinants of health

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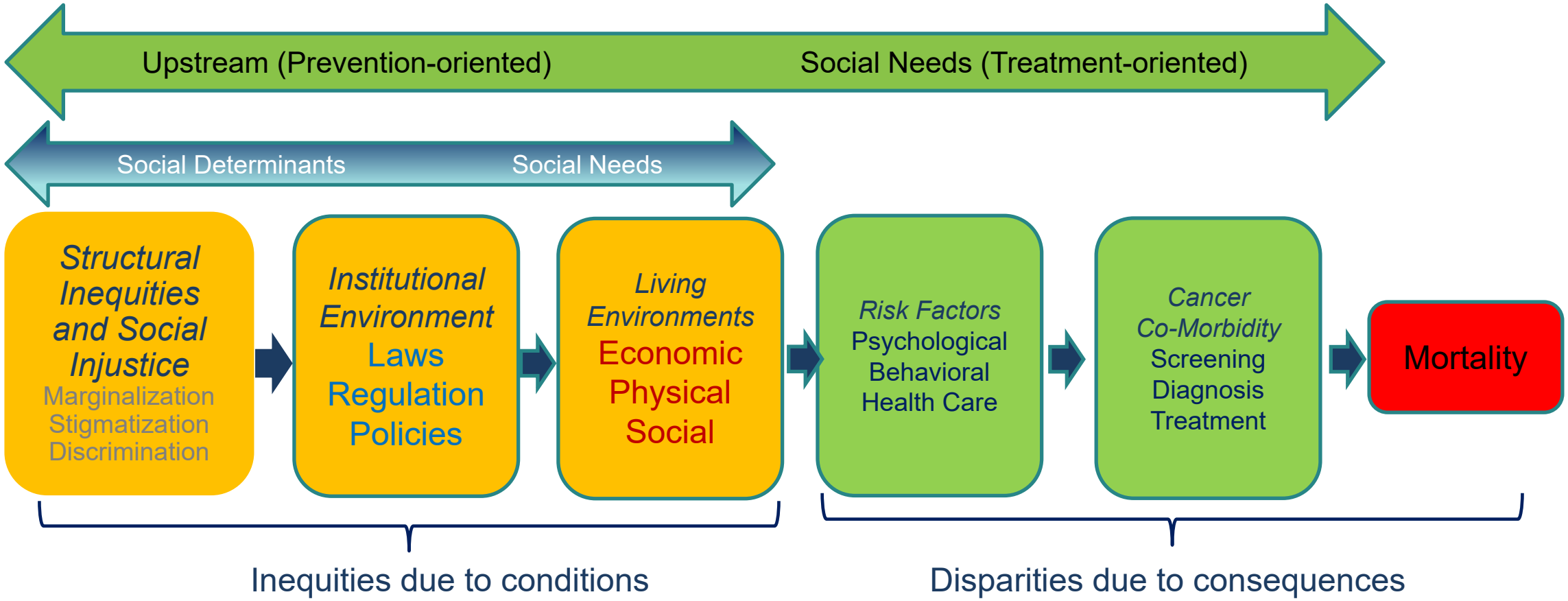

Adapted from: CA: A Cancer Journal for Clinicians, Volume: 70, Issue: 1, Pages: 31-46, First published: 29 October 2019, DOI: (10.3322/caac.21586)

Severe illness and adverse financial outcomes

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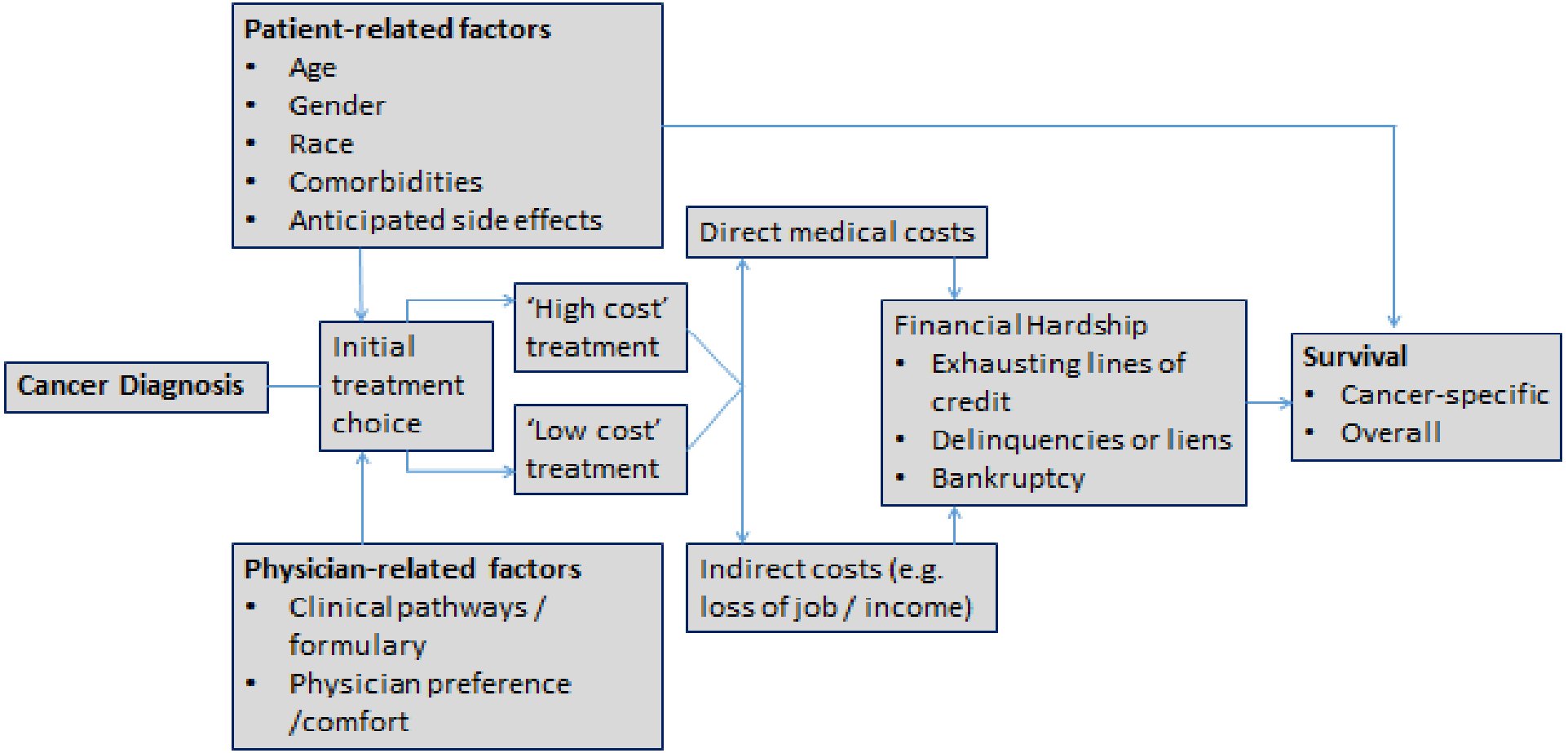

https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq

What data capacity challenges is HHS best positioned to address?

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- HHS doesn't need to create new data, it needs to facilitate access to existing data that currently lives in the private sector
- Create regulations that foster interoperability
- Establish privacy safeguards
- Improve timeliness of databases

THANK YOU

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