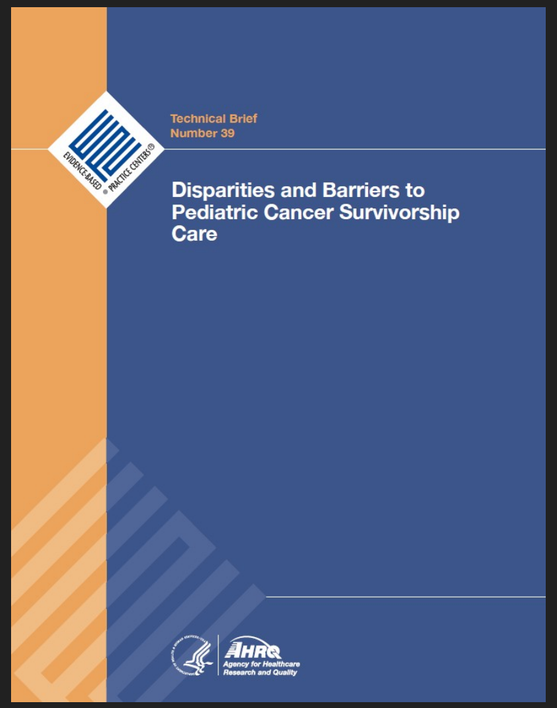
Disparities & Barriers to Pediatric Cancer Survivorship Care



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Presentation Outline

METHODS OF THE TECHNICAL BRIEF

FINDINGS BY GUIDING QUESTION

GUIDING QUESTIONS (GQ)

GQ1

What are the disparities in survivorship care for pediatric survivors?

GQ2

What are the barriers to survivorship care for pediatric cancer survivors?

GQ3

What are proposed strategies for addressing those barriers?

GQ4

What published and unpublished studies have assessed these strategies?

GQ5

What are the future directions for research in addressing barriers to survivorship care for pediatric cancer survivors?

Methods: Scoping Review

PROTOCOL
AHRQ Effective Healthcare website
Federal Register

AIM
Objective description of current science, framework for assessing interventions, identification of future research needs

DATA COLLECTION
1. Key informants
2. Grey literature
3. Published & ongoing research

INCLUSION CRITERIA
1. Childhood cancer survivors of all ages
2. Authors' definition or ≥50% of sample diagnosed prior to age 21
3. Received primary acute treatment for any cancer
4. Currently in remission
5. Currently receiving or eligible to receive survivorship care services, care plans, and/or models of follow-up care

KEY INFORMANTS

PATIENT, CAREGIVER, & FAMILY

- **Kaitlyn Ash, BS**
  Live For Today
- **Shelley Fuld Nasso, MPP**
  National Coalition for Cancer Survivorship

HSR & ACCESS TO CARE

- **Jennifer Tsui, PhD**
  University of Southern California
- **Robin Yabroff, PhD**
  American Cancer Society

CLINICAL & PATIENT CARE

- **Kira Bona, MD, MPH**
  Dana Farber Cancer Institute
- **Eric Chow, MD, MPH**
  Fred Hutchinson Cancer Research Center
- **Deborah Friedman, MD, MS**
  Vanderbilt University Medical Center
- **Melissa Hudson, MD**
  St. Jude Children's Research Hospital

ADMINISTRATIVE & PAYER

- **Jennifer Malin, MD, PhD**
  United Healthcare

SEARCHES & SOURCES

Search date:
10/08/2020

PubMed

CINAHL

PsycINFO

ClinicalTrials.gov

NIH RePORTER

PROSPERO

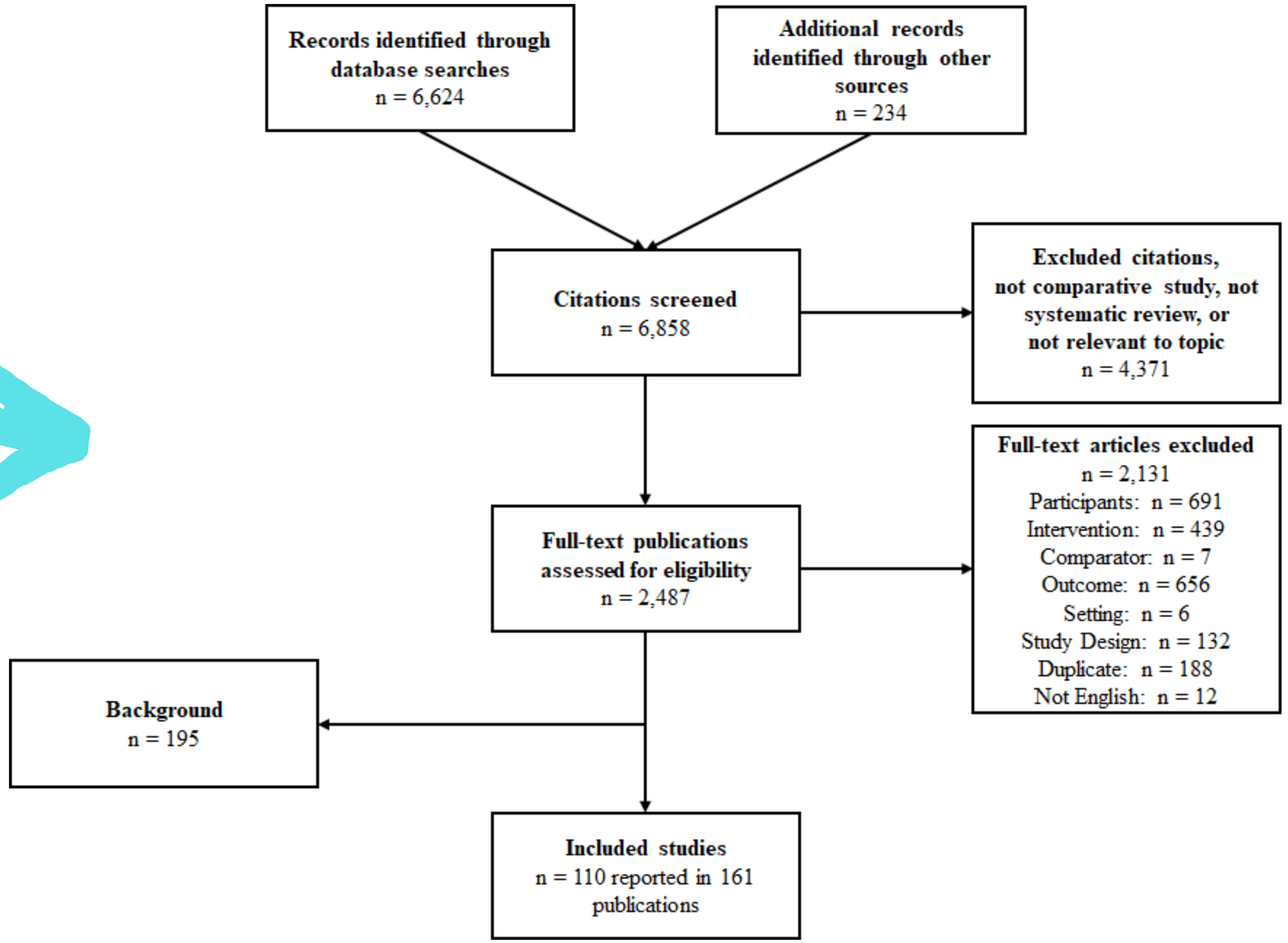
Open Science Framework

ECRI Guidelines Trust

Guidelines International Library (GIN)

Grey Literature Sources

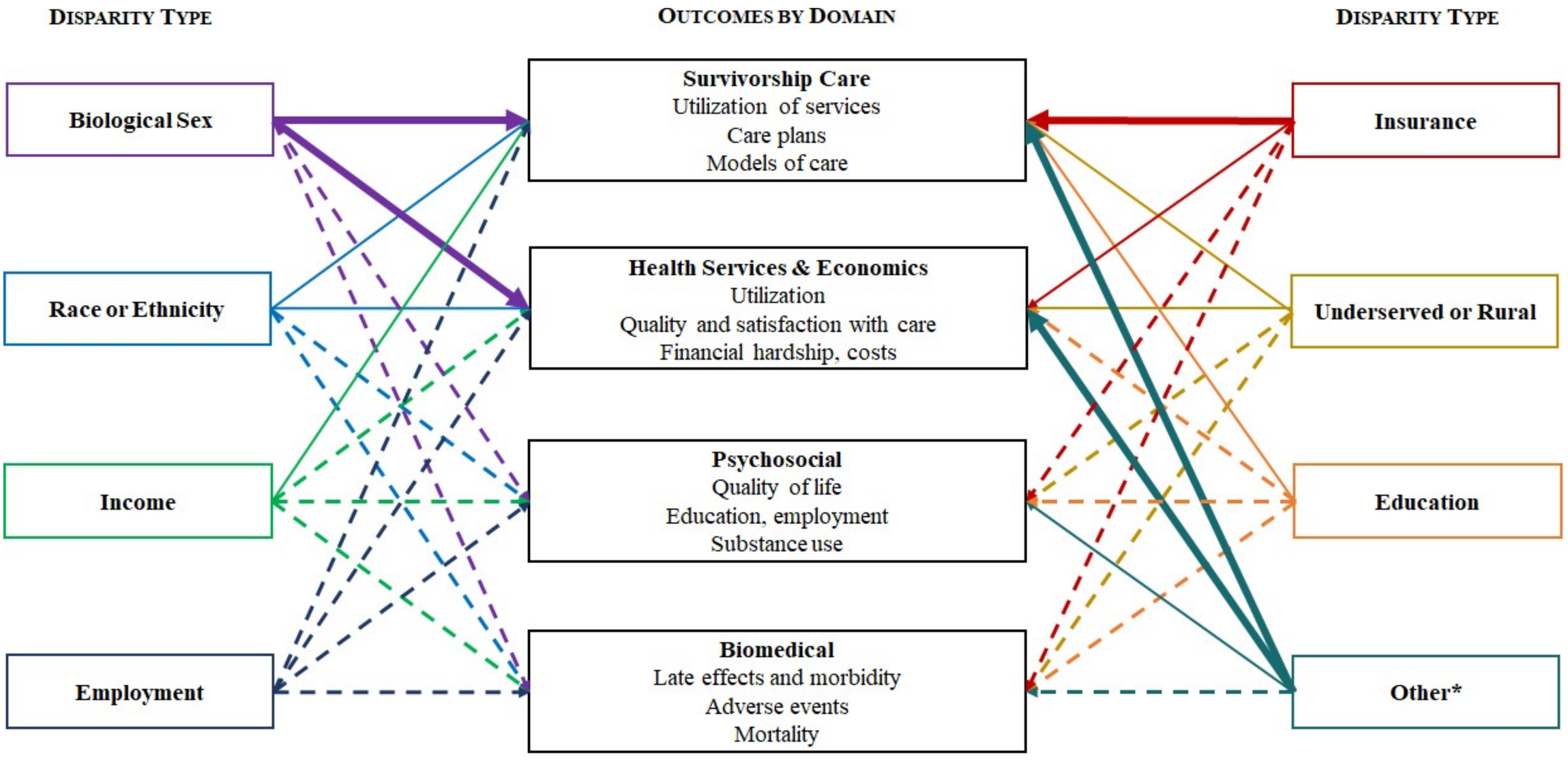
STUDY FLOW


Records identified through database searches
n = 6,624
Additional records identified through other sources
n = 234
Citations screened
n = 6,858
Excluded citations, not comparative study, not systematic review, or not relevant to topic
n = 4,371
Full-text publications assessed for eligibility
n = 2,487
Full-text articles excluded
n = 2,131
Participants: n = 691
Intervention: n = 439
Comparator: n = 7
Outcome: n = 656
Setting: n = 6
Study Design: n = 132
Duplicate: n = 188
Not English: n = 12
Background
n = 195
Included studies
n = 110 reported in 161 publications

GUIDING QUESTION 1

DISPARITIES

What are the disparities in survivorship care for pediatric cancer survivors?



**Other* frequently includes age and year at diagnosis, age and marital status at study, diagnosis, and type of treatment received and intensity.

DISPARITIES

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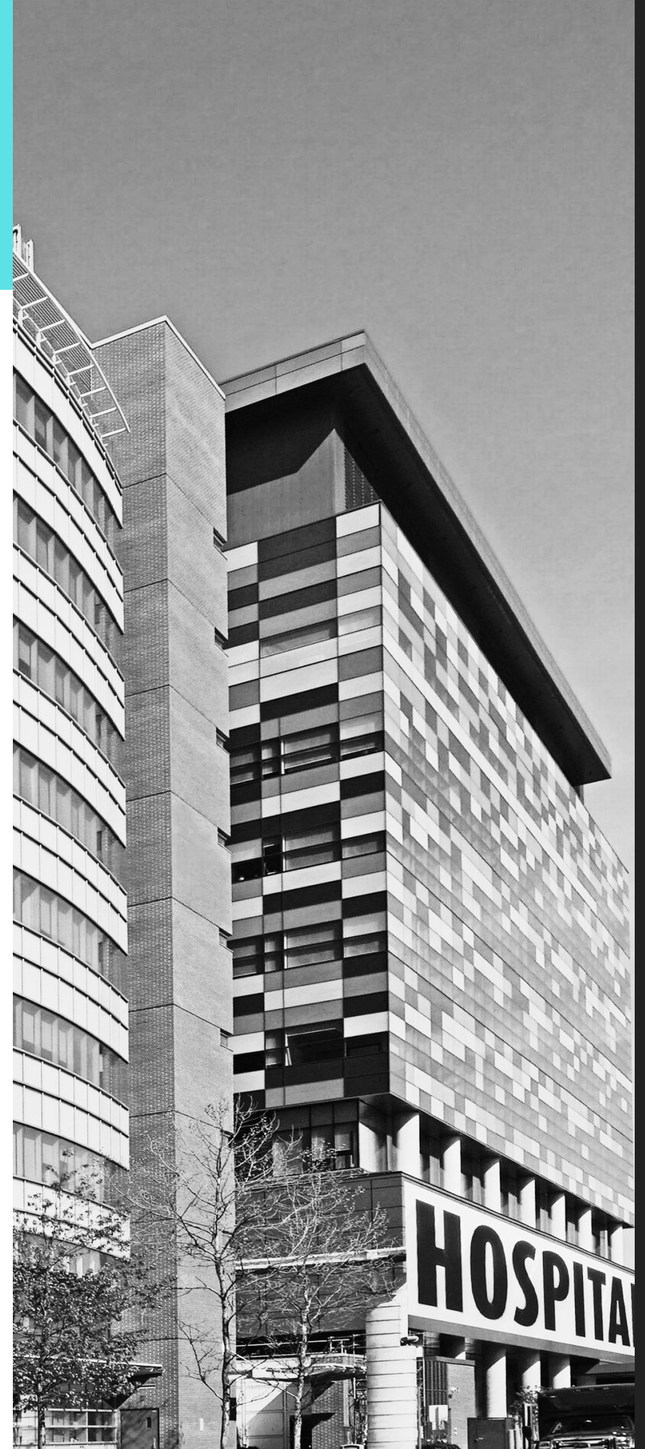
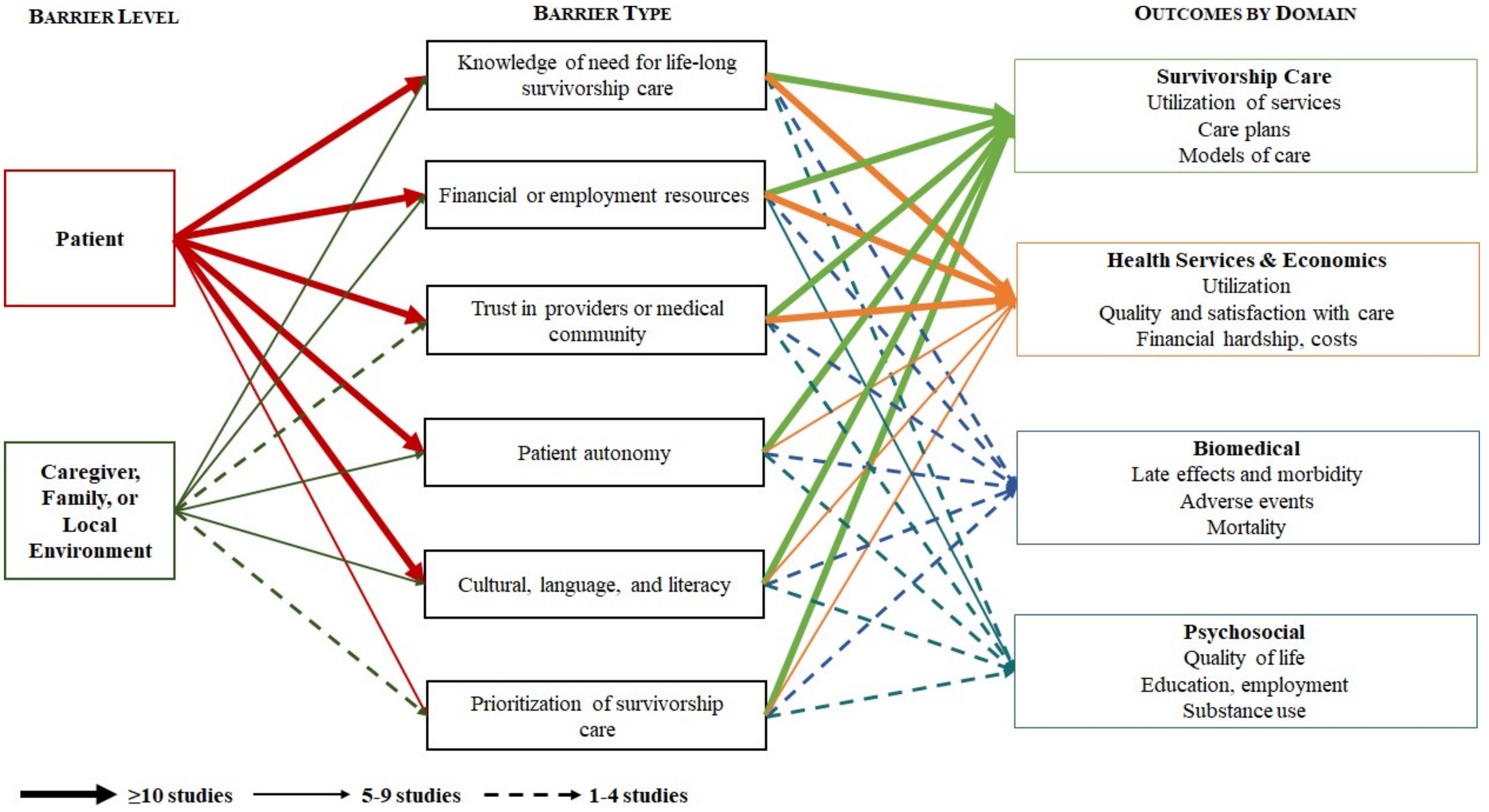
STUDIES INVESTIGATED DISPARITIES IN SURVIVORSHIP CARE FOR PEDIATRIC CANCER SURVIVORS

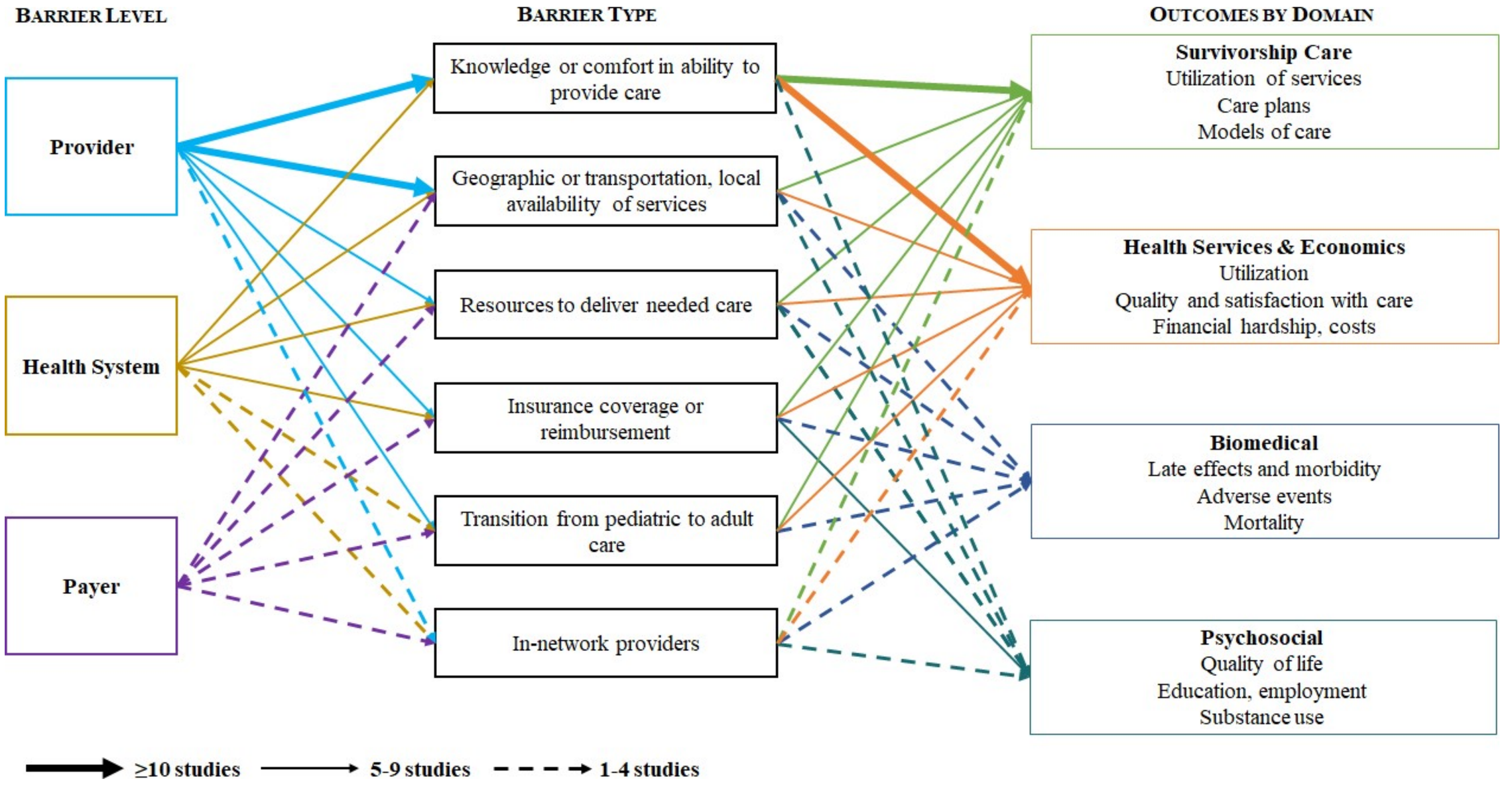


GUIDING QUESTION 2

B A R R I E R S

What are the barriers to survivorship care for pediatric cancer survivors who experience disparities?


BARRIER LEVEL
BARRIER TYPE
OUTCOMES BY DOMAIN
Patient
Caregiver, Family, or Local Environment
Knowledge of need for life-long survivorship care
Financial or employment resources
Trust in providers or medical community
Patient autonomy
Cultural, language, and literacy
Prioritization of survivorship care
Survivorship Care
Utilization of services
Care plans
Models of care
Health Services & Economics
Utilization
Quality and satisfaction with care
Financial hardship, costs
Biomedical
Late effects and morbidity
Adverse events
Mortality
Psychosocial
Quality of life
Education, employment
Substance use
≥10 studies
5-9 studies
1-4 studies


BARRIER LEVEL
BARRIER TYPE
OUTCOMES BY DOMAIN
Provider
Health System
Payer
Knowledge or comfort in ability to provide care
Geographic or transportation, local availability of services
Resources to deliver needed care
Insurance coverage or reimbursement
Transition from pediatric to adult care
In-network providers
Survivorship Care
Utilization of services
Care plans
Models of care
Health Services & Economics
Utilization
Quality and satisfaction with care
Financial hardship, costs
Biomedical
Late effects and morbidity
Adverse events
Mortality
Psychosocial
Quality of life
Education, employment
Substance use
≥10 studies
5-9 studies
1-4 studies

BARRIERS

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STUDIES ASSESSED BARRIERS TO SURVIVORSHIP CARE

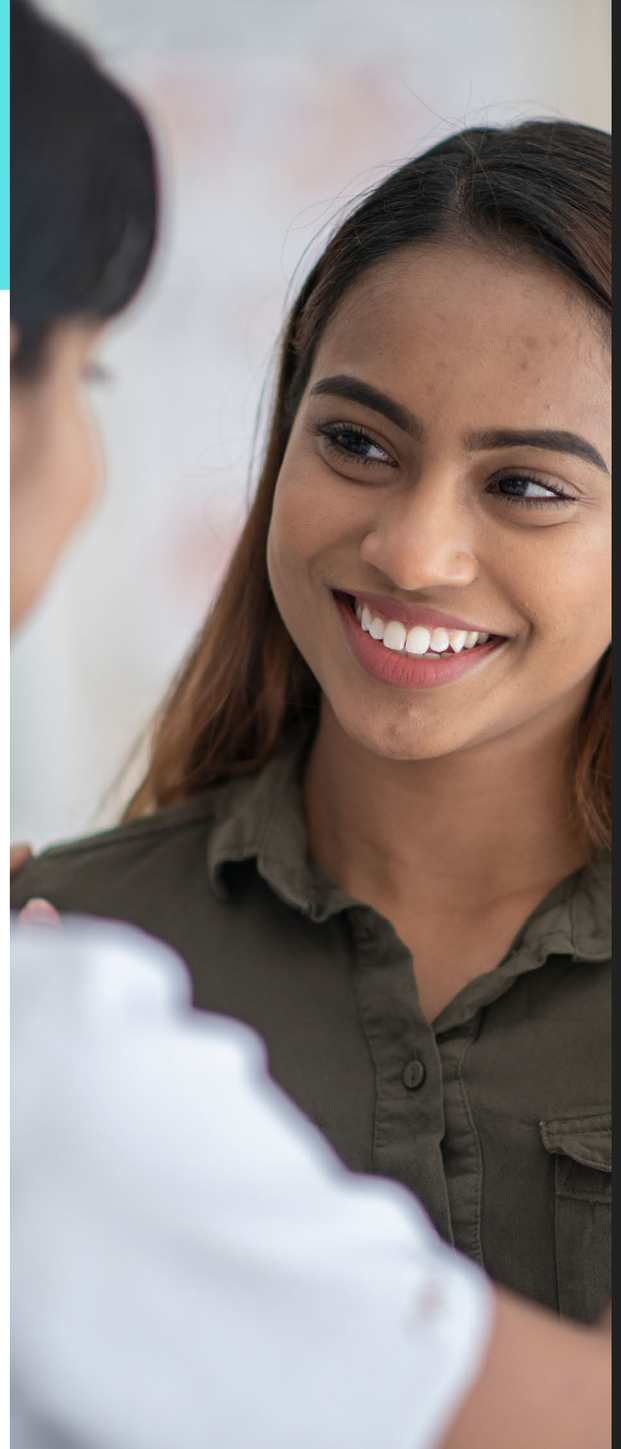
Patient

Caregiver, family member, or community

Provider

Health system

Payer



GUIDING QUESTION 3

PROPOSED STRATEGIES

What are proposed strategies for addressing those barriers?

Organization (Year)	Country	Type
International Society of Paediatric Oncology (1996)	Multiple countries	Clinical Practice Guideline
National Academies of Sciences, Engineering, and Medicine (2003)	USA	Policy Statement
International Society of Paediatric Oncology (2004)	Multiple countries	Meeting Summaries and Recommendations
United Kingdom Children's Cancer Study Group: Late Effects Subcommittee (2005)	UK	Clinical Practice Guideline
UK Children's Cancer Study Group (UKCCSG) Late Effects Group (LEG) (2006)	UK	Clinical Practice Guideline
Children's Oncology Group Nursing Discipline (2007)	USA	Meeting Summaries and Recommendations
American Academy of Pediatrics (2009)	USA	Clinical Practice Guideline
Late Effects Taskforce of the Dutch Childhood Oncology Group (2010)	Netherlands	Clinical Practice Guideline
Scottish Intercollegiate Guidelines Network (2013)	UK	Clinical Practice Guideline
American Academy of Pediatrics (2014)	USA	Policy Statement
Working Group on Adolescents, Young Adults, and Transition (2017)	Germany	Meeting Summaries and Recommendations
Children's Oncology Group (2018)	USA	Clinical Practice Guideline
Cancer Leadership Council (2019)	USA	Policy Statement
National Comprehensive Cancer Network (2020)	USA	Clinical Practice Guideline
International Guideline Harmonization Group (2020)	Multiple countries	Clinical Practice Guideline
Children's Cancer Cause (2020)	USA	Policy Statement

PROPOSED STRATEGIES

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ORGANIZATIONS
ACKNOWLEDGED DISPARITIES

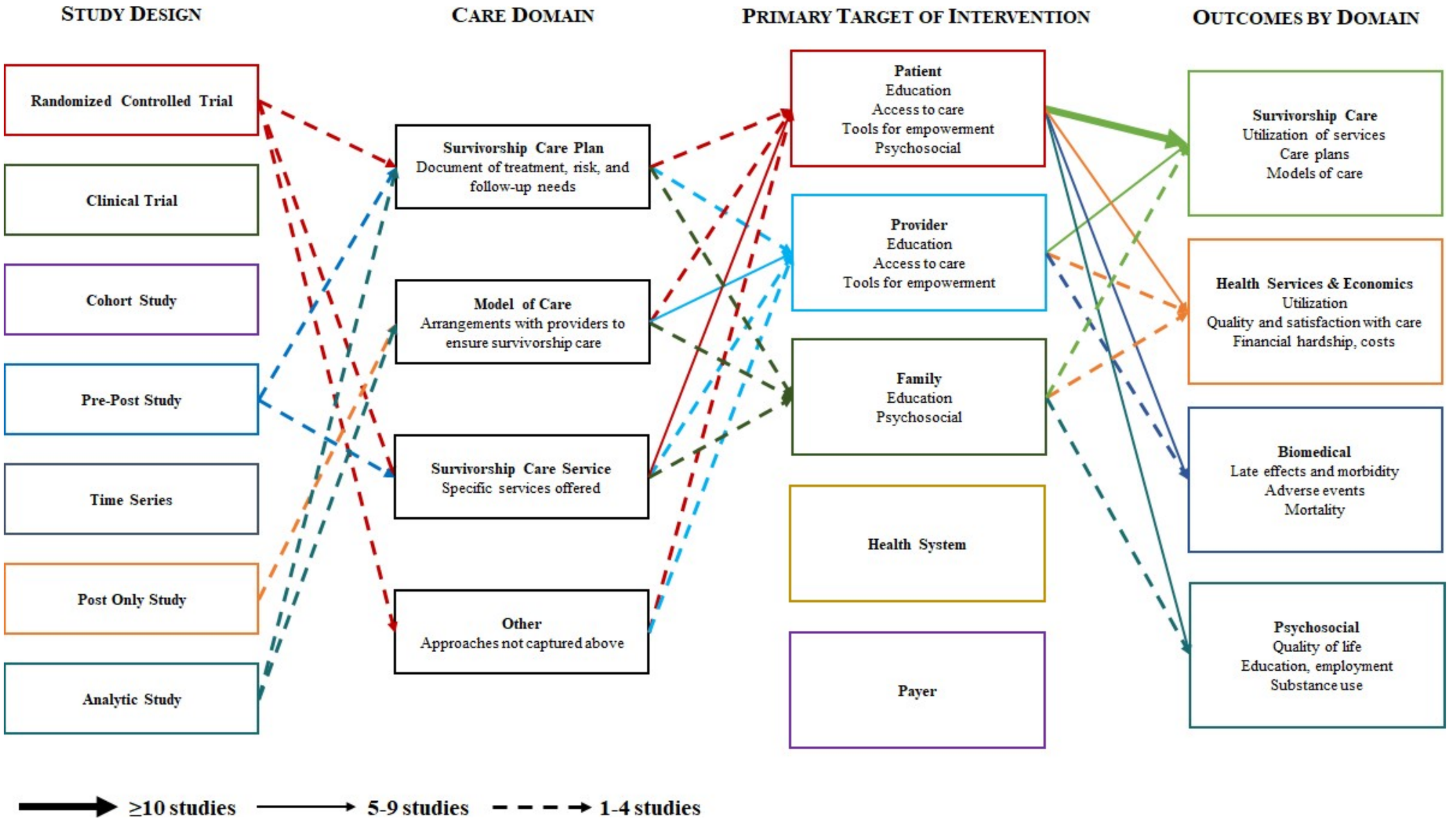
LIMITED

INFORMATION ABOUT BARRIERS

GUIDING QUESTION 4

EVALUATED STRATEGIES

What published and unpublished studies have assessed these strategies?


STUDY DESIGN
CARE DOMAIN
PRIMARY TARGET OF INTERVENTION
OUTCOMES BY DOMAIN
Randomized Controlled Trial
Clinical Trial
Cohort Study
Pre-Post Study
Time Series
Post Only Study
Analytic Study
Survivorship Care Plan
Document of treatment, risk, and follow-up needs
Model of Care
Arrangements with providers to ensure survivorship care
Survivorship Care Service
Specific services offered
Other
Approaches not captured above
Patient
Education
Access to care
Tools for empowerment
Psychosocial
Provider
Education
Access to care
Tools for empowerment
Family
Education
Psychosocial
Health System
Payer
Survivorship Care
Utilization of services
Care plans
Models of care
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Quality and satisfaction with care
Financial hardship, costs
Biomedical
Late effects and morbidity
Adverse events
Mortality
Psychosocial
Quality of life
Education, employment
Substance use
≥10 studies
5-9 studies
1-4 studies

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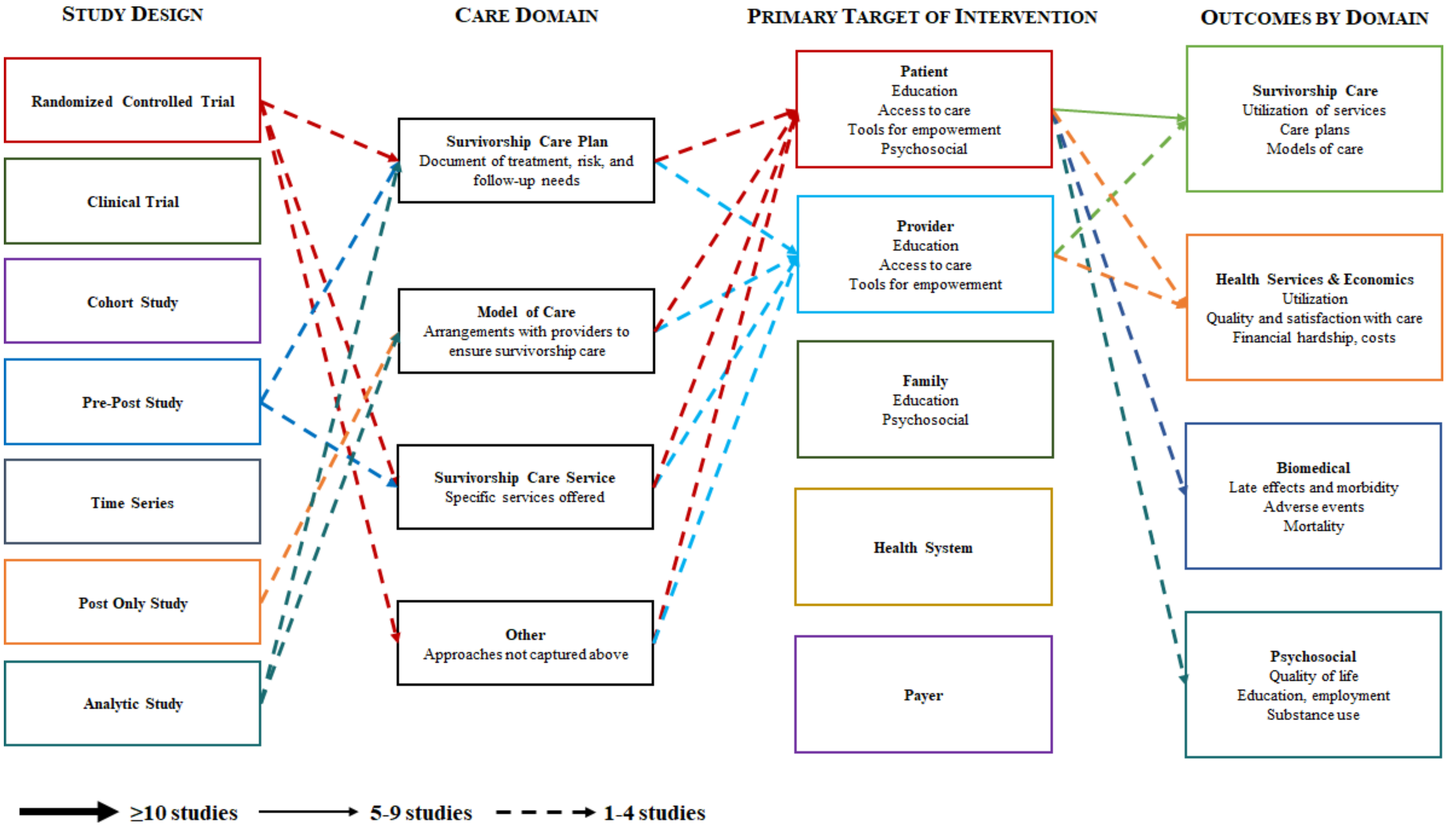
EVALUATED STRATEGIES

Studies evaluated the effectiveness of strategies to reduce disparities and barriers to pediatric cancer survivorship care.

GUIDING QUESTION 5

FUTURE DIRECTIONS

What are future directions for research in addressing barriers to survivorship care for pediatric cancer survivors?


STUDY DESIGN
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PRIMARY TARGET OF INTERVENTION
OUTCOMES BY DOMAIN
Randomized Controlled Trial
Clinical Trial
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Mortality
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Quality of life
Education, employment
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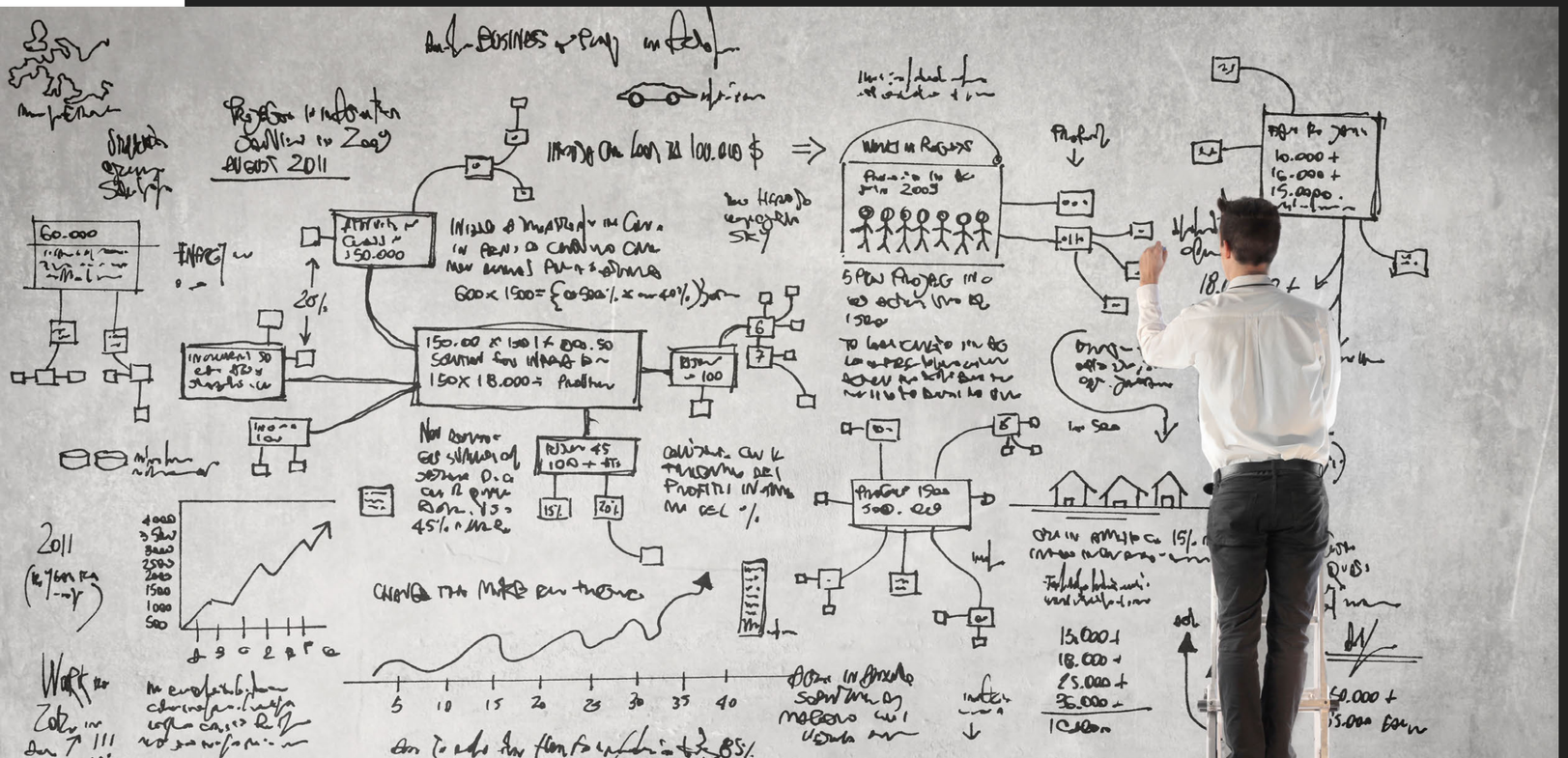
FUTURE DIRECTIONS

8 Ongoing studies included directions for future research on disparities and barriers to pediatric cancer survivorship care.



1 Ongoing study explicitly designed to address disparities and barriers.

Next Steps

Population

Social determinants of health
Engagement in health system

Interventions

Technology
Risk stratification
Individually-tailored at multiple levels

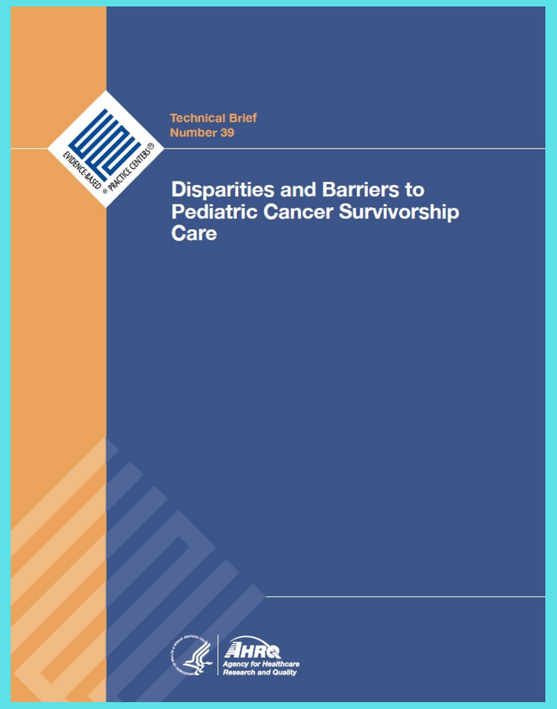
Outcomes

Under/over surveillance
Facilitators of desired outcomes

Study Design

Multi-site, longitudinal studies
Economics-based studies

Thank You!



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