

# Health Care Transition and Gaps in AYA Survivorship Care

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We Treat Kids Better



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# Outline

1. AYA Survivors—Who Are They?
2. Needs of AYA Survivors
3. The Central Challenge in AYA Survivorship
4. Health Care Transition in Survivorship
5. Barriers to Survivorship Transition
6. Addressing the Barriers

# AYA Survivors—Who Are They?

- Age
  - NCI definition for AYA Oncology = 15-39 years
  - Applies to survivorship because age continues to drive many survivorship issues
    - Developmental biology-physiology of host
      - Characteristic types of late effects (e.g., AVN)
      - Some late effects emerge only or principally during this age interval (e.g., infertility, SMNs)
    - Psychosocial challenges
      - Backdrop of normal maturation into young adulthood
      - Access to care
      - Adherence to medical recommendations

# AYA Survivors—Who Are They?

- AYA Survivors vs. Survivors of AYA Cancer
- Population
  - Survivors of **childhood cancer**  
(treated < 15 years old)
  - Survivors of **adolescent cancer**  
(treated 15-19 years old)
  - Survivors of **young adult cancer**  
(treated 20-39 years old)
- Potential implications for service models

# Key Issues for Young Adult Survivors

- Detection and management of late effects
  - Continued management if present
  - Continued risk-based surveillance and preventive practices
- Psychosocial functioning
  - Interpersonal relationships (including sexuality)
  - Chronic anxiety, depression
- Health-related education
  - Previous diagnosis and cancer therapy
  - Current state of health and health risks
  - Disease prevention and wellness practices
- Financial challenges
  - Health insurance—obtaining and maintaining
  - Employment—relative to disabilities

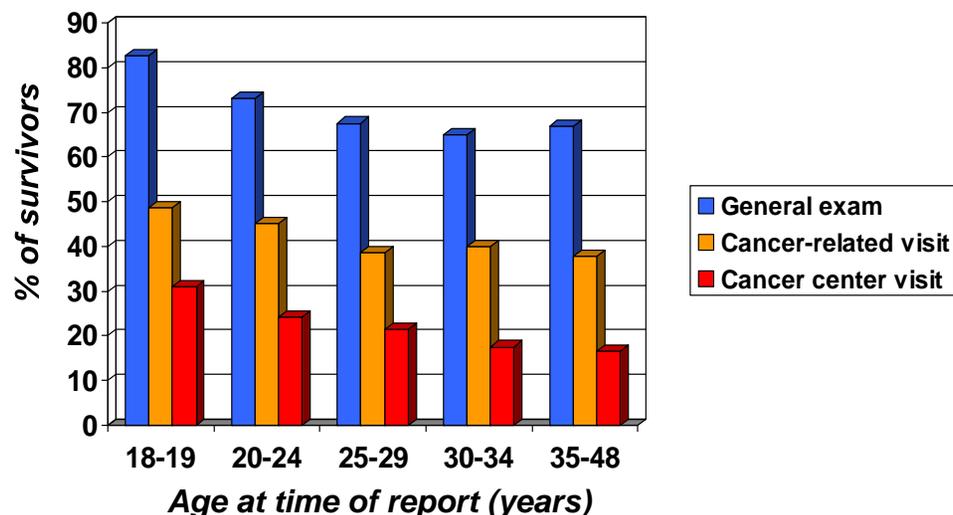
# The Central Challenge in AYA Survivorship

## Suboptimal Longitudinal Follow-up

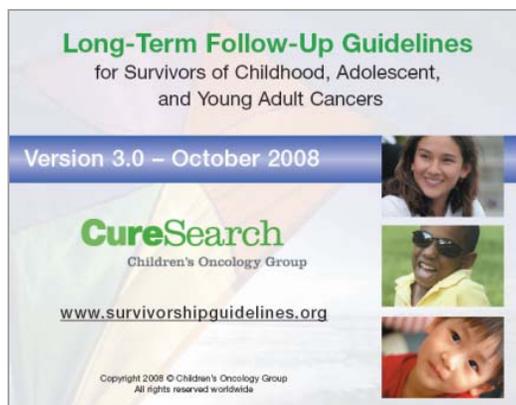
- Endpoints
  - Clinical assessments with providers
  - Risk-based monitoring for late effects
- Implications
  - Late diagnosis of late effects
  - Missed opportunities for risk modification and secondary prevention
  - Incomplete anticipatory guidance
  - Inability to conduct longitudinal research

# Suboptimal Medical Follow-up for Young Adult Survivors

## Fewer Medical Assessments with Age



Oeffinger et al. *Ann Fam Med* 2:61-70;2004



[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

## Low Proportion of Medical Assessments

Type	%
None	11.2
General	57.3
General survivorship	13.7
Risk-based	17.8

## Low Proportion of Screening Tests

	Received (at risk)	%
Echocardiogram	511 (1810)	28.2
Mammogram	169 (414)	40.4

Nathan et al. *J Clin Oncol* 2008; 26:4401-9

# Health Care Transition for AYA Survivors

- **What**—*The planned movement of older adolescents and young adults from a child-centered to an adult-focused health care provider and environment\**
- **Why**—*To continue age-appropriate risk-adapted monitoring, psychosocial support, and health-related education relevant to cancer survivorship*
- **Potential Impact**
  - Earlier diagnosis, reduction or prevention of late effects
  - Improved health-related quality of life
  - Enhanced self-efficacy and general quality of life

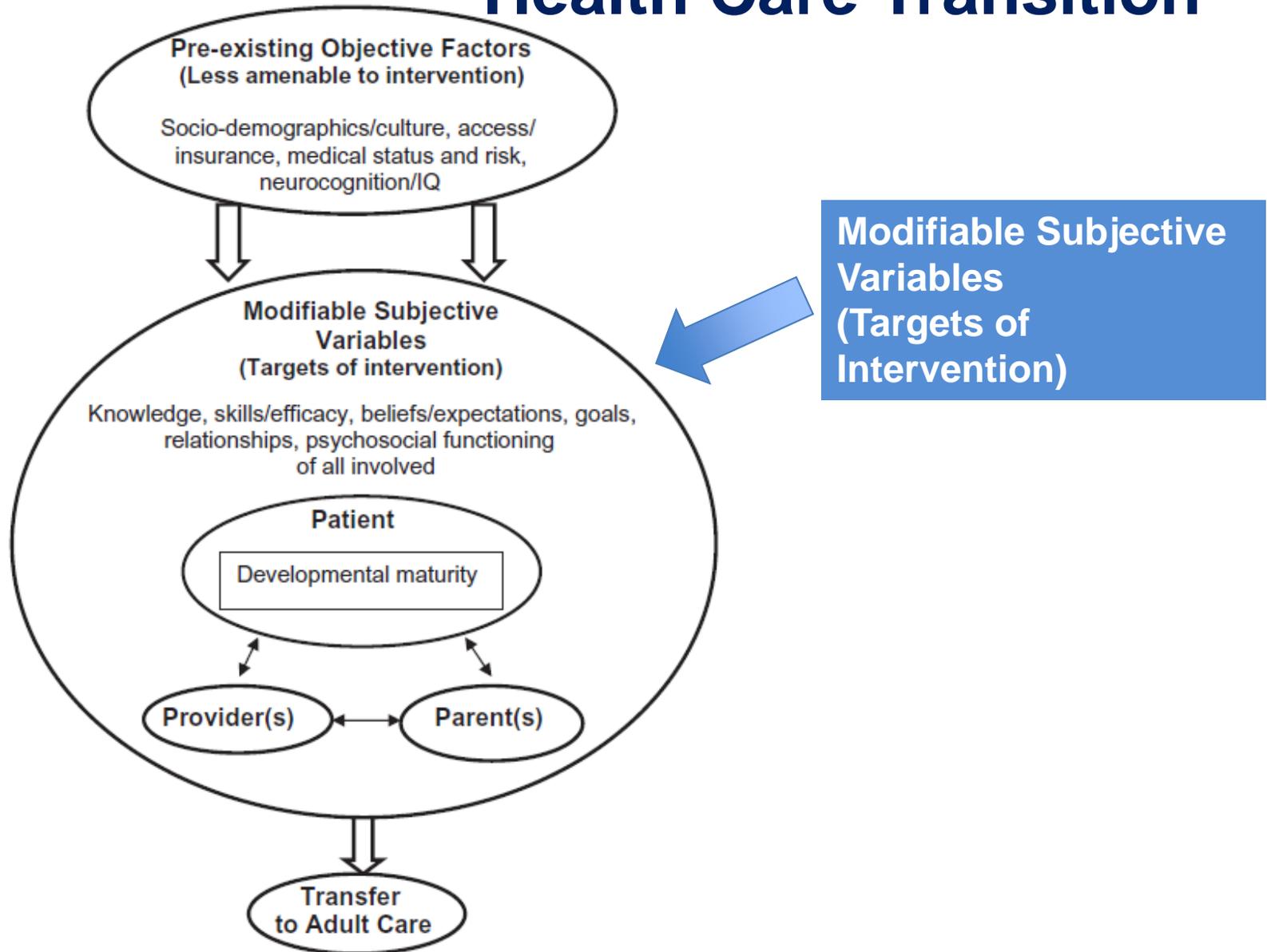
# Health Care Transition in Pediatric Oncology

- Several published reviews
  - Case statement and conceptual framework
  - General models of care
- Some data
  - Prevalence and types of adult-focused services
  - Current transitional care practices
  - Patient-level barriers and perceptions
  - Provider-level perceptions
- Little or no empiric data (yet)
  - Outcomes with specific care models
  - Determinants of transition-readiness or interventions
  - Predictors of successful transition or interventions

# Potential Barriers to Transition for Young Adults

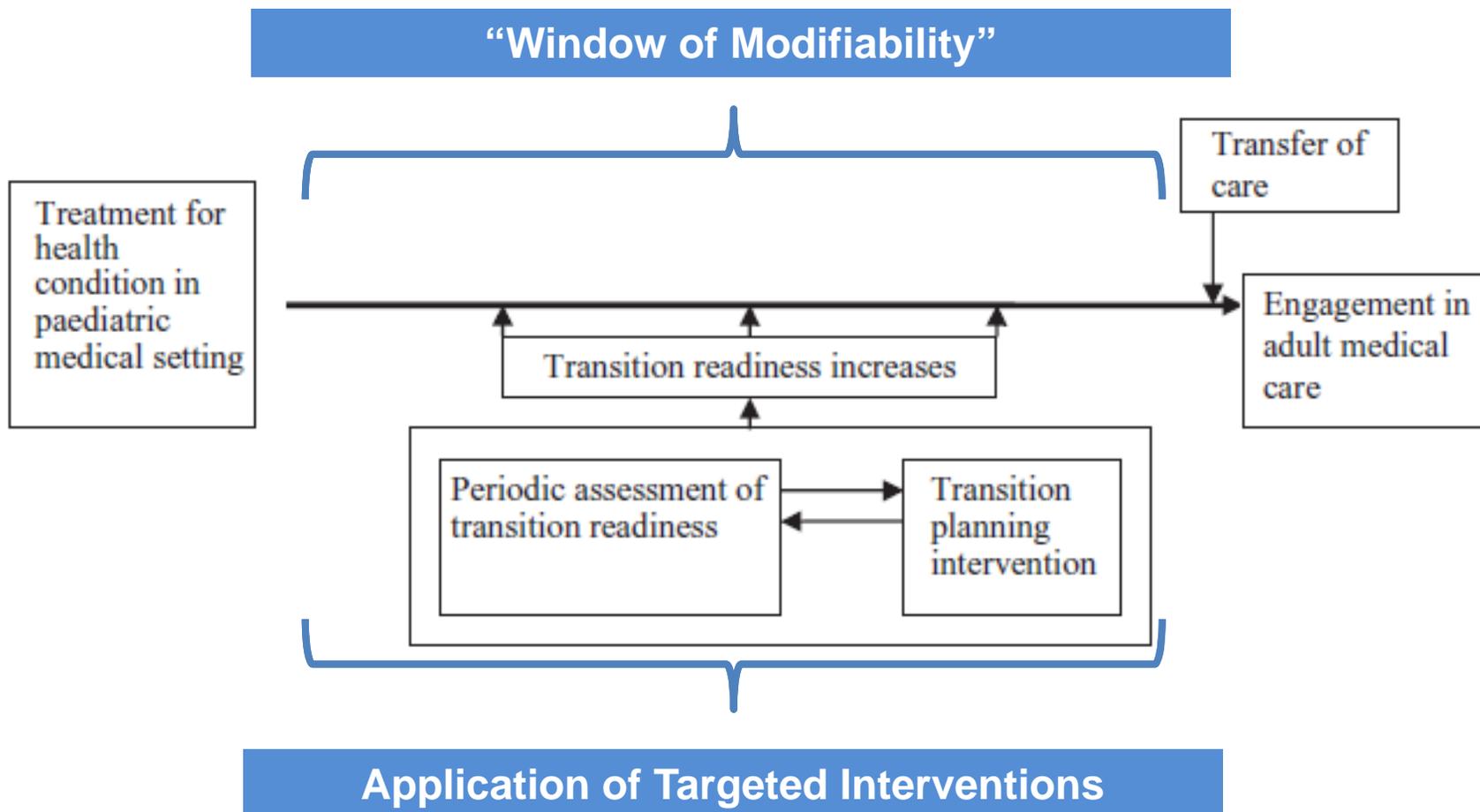
Level	Selected Barriers
Patient	<ul style="list-style-type: none"> <li>• Complex medical history, multiple risks</li> <li>• Low personal priority for young adult (awareness)</li> <li>• No prior relationship with new provider</li> </ul>
Family	<ul style="list-style-type: none"> <li>• Over-protectiveness, loss of control</li> <li>• Emotional dependency on survivor</li> <li>• No prior relationship with new provider</li> </ul>
Provider	<ul style="list-style-type: none"> <li>• Lack of relevant knowledge, experience and comfort</li> <li>• Burden of care for medically complex patient</li> <li>• No prior relationship with new patient</li> </ul>
Health Care System	<ul style="list-style-type: none"> <li>• Loss of health insurance coverage</li> <li>• Lack of seamless referral networks linking providers</li> <li>• Lack of inclusion of survivorship in medical training</li> </ul>

# Social-Ecological Model of Health Care Transition



# Addressing the Barriers

## Patient and Family Levels



## Provider Level

- Medical Training
  - Undergraduate (concept)
  - Graduate (practice)
    - Pediatric and Medical Oncology Fellowship
    - Primary Care Residencies (FM, IM, MP, Ped)

### CHLA-USC

- Required rotation in 2<sup>nd</sup>-3<sup>rd</sup> yrs pediatric hem-onc fellowship
- Elective available to pediatric residents
- Next: primary care residencies at USC

- Continuing Education

- Journals

Late Effects in Adult Survivors of Pediatric Cancer: A Guide for the Primary Care Physician

Am J Med 2012; 125:636-41

Lisa M. Kopp, DO, Puja Gupta, MD, Luz Pelayo-Katsanis, CPNP, Brenda Wittman, MD, MPH, Emmanuel Katsanis, MD  
Department of Pediatrics, University of Arizona, Tucson.

- Continuing medical education conferences

- Support Systems for Clinical Guidance

- Web-based

Family doctor-driven follow-up for adult childhood cancer survivors supported by a web-based survivor care plan

J Cancer Surviv 2012:163-71

- Family Physicians
    - Passport for Care

R. Blaauwbroek · H. A. Barf · K. H. Groenier ·  
L. C. Kremer · K. van der Meer · W. J. E. Tissing ·  
A. Postma



[www.passportforcare.org](http://www.passportforcare.org)

## Health Care System Level-1

- Models of Transitional Care
  - Three basic models recognized
    1. Continued care within cancer treatment center
    2. Transfer of care to community-based provider (primary care)
    3. Hybrid: transfer of care with continued support from center
  - Needed
    - Innovation with specific models
    - Comparison of resource intensity and outcomes
  - Success influenced by attitudes and preferences
    - Patient—levels of awareness and activation<sup>1</sup>
    - Providers—trust and acceptance of responsibility<sup>2</sup>

<sup>1</sup>Hudson SV et al. Transl Behav Med 2012; 2:322-31

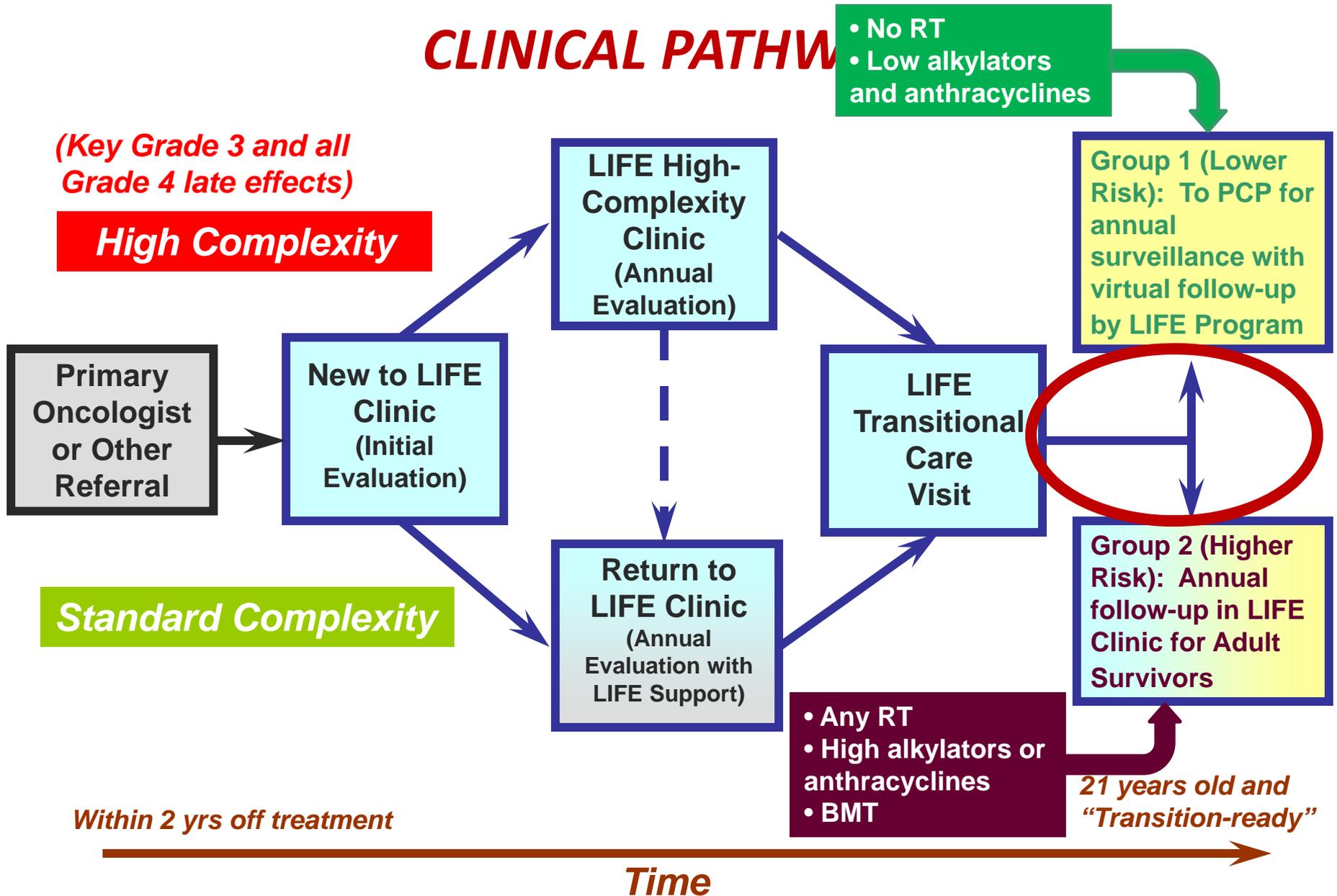
<sup>2</sup>Cheung WY et al. J Cancer Surviv 2013 Mar 24, epub

## Health Care System Level-2

- Tiered Transitional Care
  - Concept
    - Survivors can be differentiated according to long-term risk
    - Type and intensity of required follow-up differs by group
    - Implicit in risk-adapted monitoring guidelines (e.g., COG)
  - United Kingdom
    - Three risk levels based on treatment exposures<sup>1</sup>
    - Followed by specialized center, PCP or by mail
  - CHLA (LIFE Clinic for Adult Survivors)
    - Transition at 21 years of age
    - Two risk levels based on treatment exposures

# LIFE Cancer Survivorship & Transition Program

## CLINICAL PATHWAY



# Planned Approach

## Unified Adult Cancer Survivorship Program

*Three Streams of Survivors*

*One Adult Survivorship Program*

CHLA

AYA@USC

USC Norris CCC

“Adult Survivors of Childhood Cancer”

“Adult Survivors of AYA Cancer”

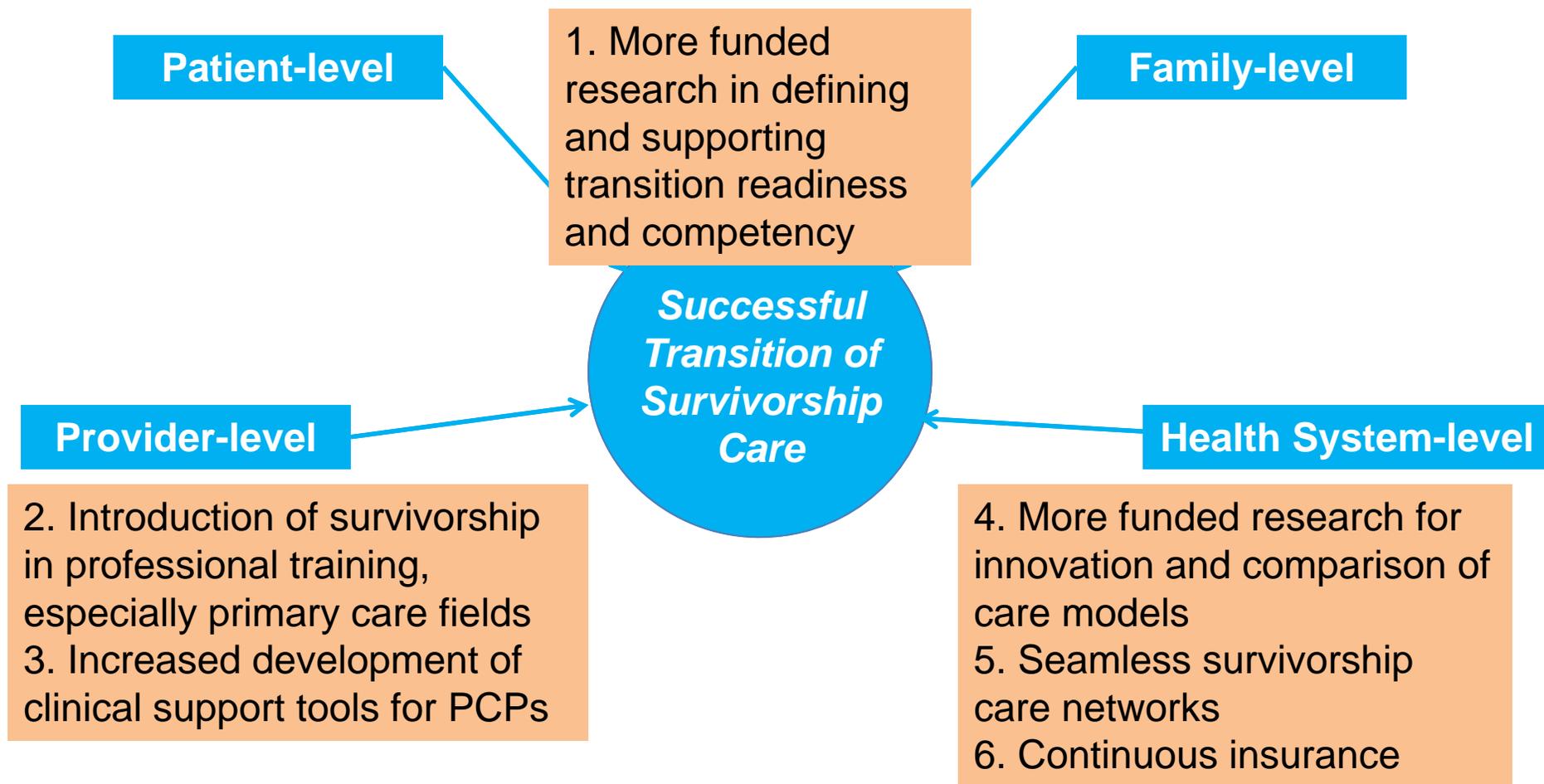
“Adult Survivors of Adult Cancer”

- Common population: adult survivors
- More alike by current age than different by age at treatment
- Opportunities for clinical efficiency, resource sharing, and research
- Modeled on successful CHLA-PSJMC pilot experience

## Health Care System Level-3

- Opportunities afforded by health care reform
  - Problems
    - ~ 30% of Americans 18-24 yrs old uninsured
    - AYA survivorship care currently fragmented
  - How the PPACA may help AYA survivors
    - National high-risk pool created for adults with pre-existing conditions
    - Dependents covered by parent policies until 26 yrs old
    - No lifetime limits on coverage
    - No exclusions for children with pre-existing conditions
    - Coming 2014
      - No exclusions for adults with pre-existing conditions
      - Premiums not driven primarily by health status
      - Expanded patient-centered care coordination (e.g., ACOs)

# Summary Observations and Recommendations



**Follow-Up Gap**

- Increased utilization of PCPs for care delivery
- Effective methods to “push” key health education to survivors

