

Adolescent and Young Adult Survivorship: Knowledge Gaps and Challenges for the Future

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What age range defines AYA Oncology?



A Surveillance,
Epidemiology and End
Results current data
analyses (**15-29→39**)



NCI's AYA Oncology
Progress Review Group
defined as individuals
diagnosed with cancer
from ages **15-39. (2006)**

Literature: 12 to 20's to 30's

**CHILDREN'S
ONCOLOGY
GROUP**

COG's AYA
committee defines the
group as ages **15-29**

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C O R R E S P O N D E N C E

VOLUME 29 NUMBER 16 JUNE 1 2011 | Ann M. Geiger and Sharon M. Castellino

Delineating the Age Ranges Used to Define Adolescents and Young Adults

"...Substantial variability in the age ranges used by authors to define this group. Failing to clearly delineate age ranges could be barrier to advancing care and research."

Variability in Cancer Diagnoses in AYA Age Spectrum

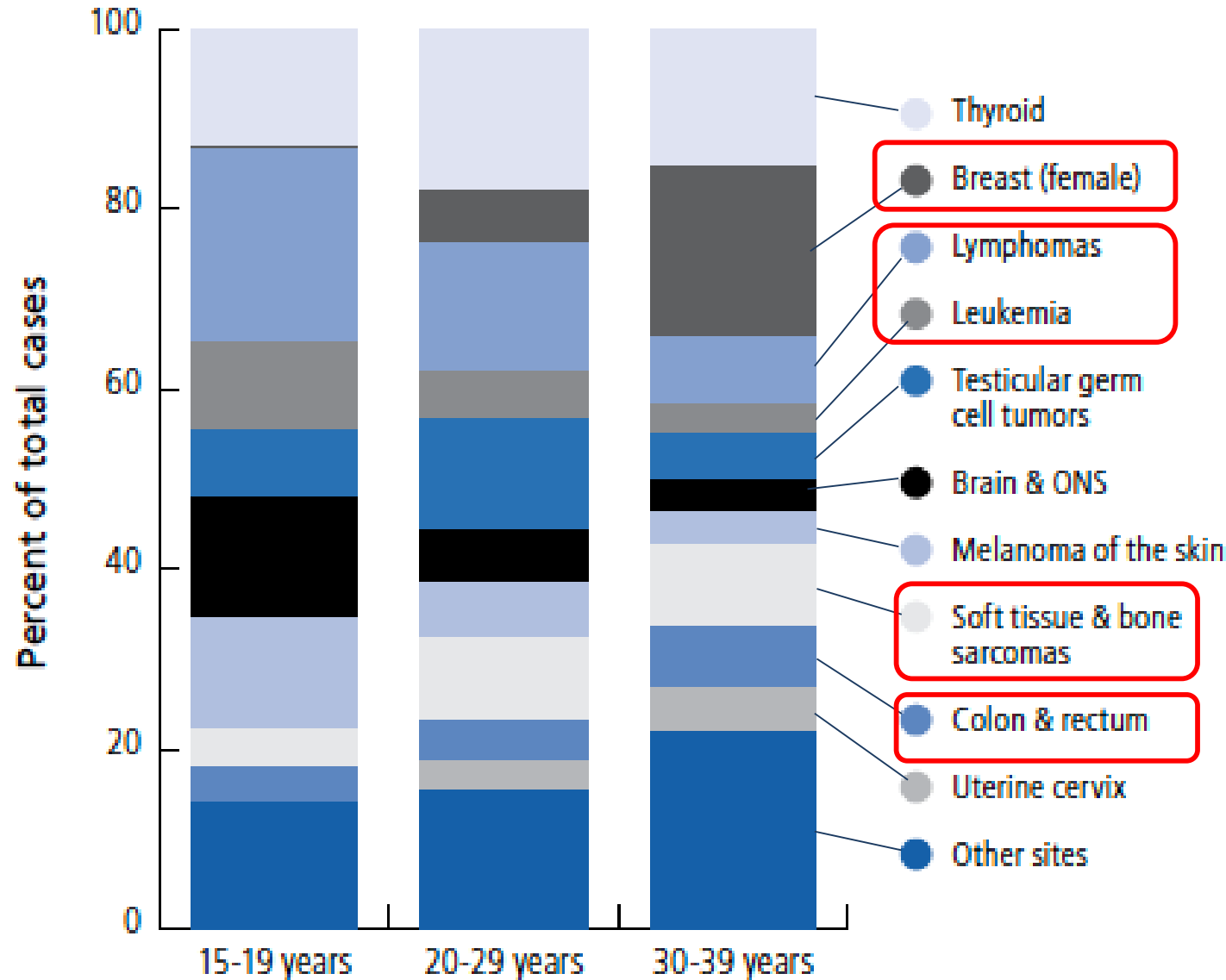


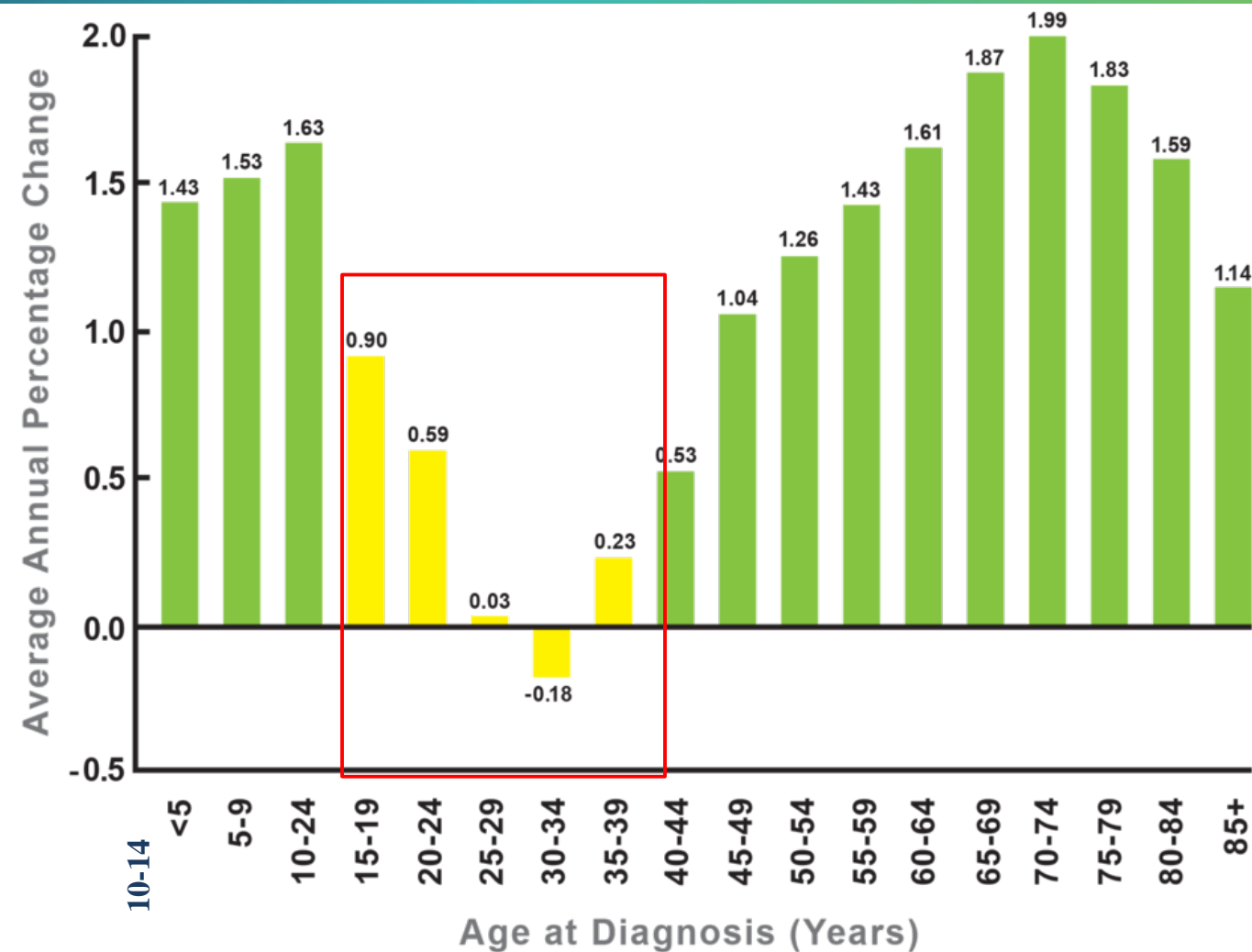
Table S1. Estimated Cancer Cases and Deaths in AYAs by Age, US, 2020

Age	Estimated cases	Estimated deaths
15-19 years	5,800	540
20-29 years	24,900	2,210
30-39 years	58,800	6,520
Total	89,500	9,270



AYA Cancer Survivors: A Diverse Group With Disparities in Outcomes

Average Annual %
Change in 5-Year
Survival



Why are outcomes worse for cancer in AYA

- Differences in biology and response to treatment
- Insurance barriers & delay in diagnosis
- Poor AYA enrollment in clinical trials
- Unique psychosocial challenges at diagnosis, during treatment and as survivors

AYA Survivors are at risk for adverse long-term outcomes

- Cardiomyopathy
- Cardiometabolic
- Endocrine/hormonal
- Osteonecrosis
- Subsequent malignancy

- School
- Work
- Financial burdens
- Insurance issues

Health Related

Behaviors Emotions

Disrupted Life Goals

Social Relationships

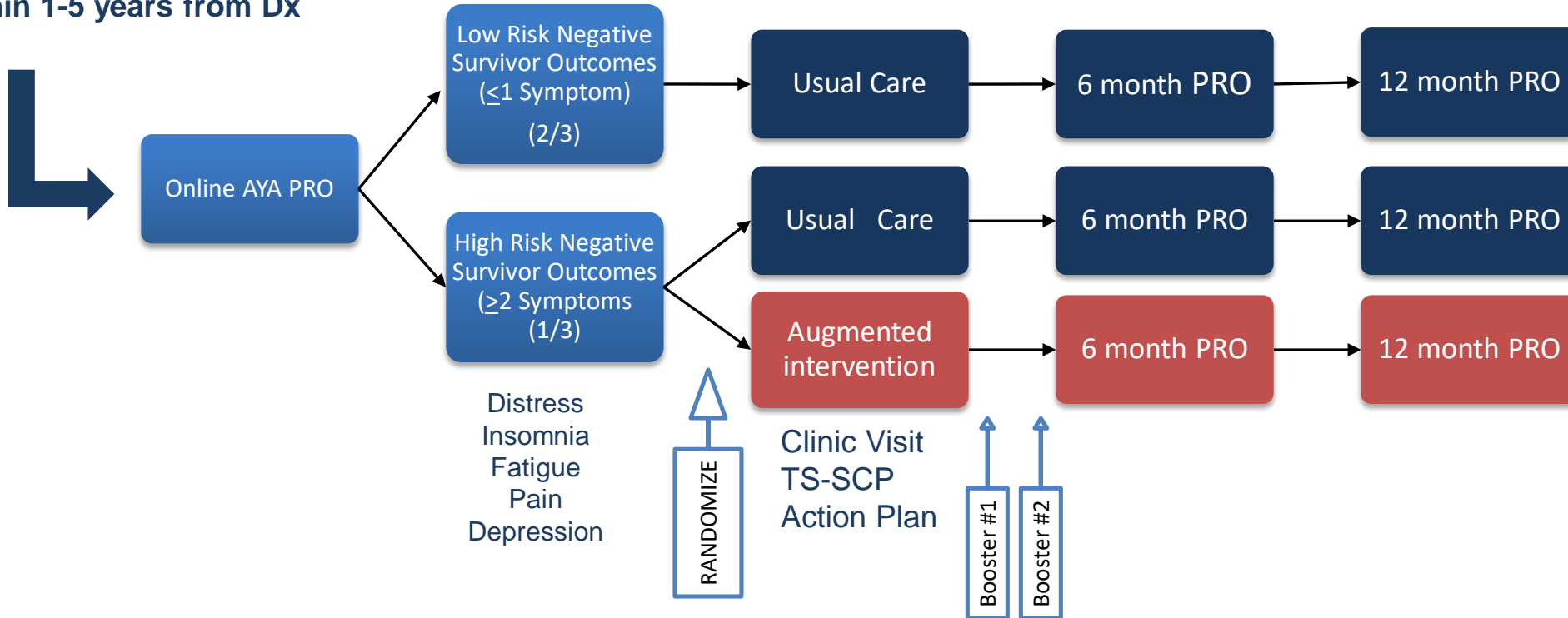
- Smoking, alcohol, recreational drugs
- Body image, sexuality, infertility
- Anxiety, depression
- Fear of Recurrence

- Family dynamics
- Peers
- Dating
- Intimacy
- Social isolation

Challenges for Survivorship Research in AYA's

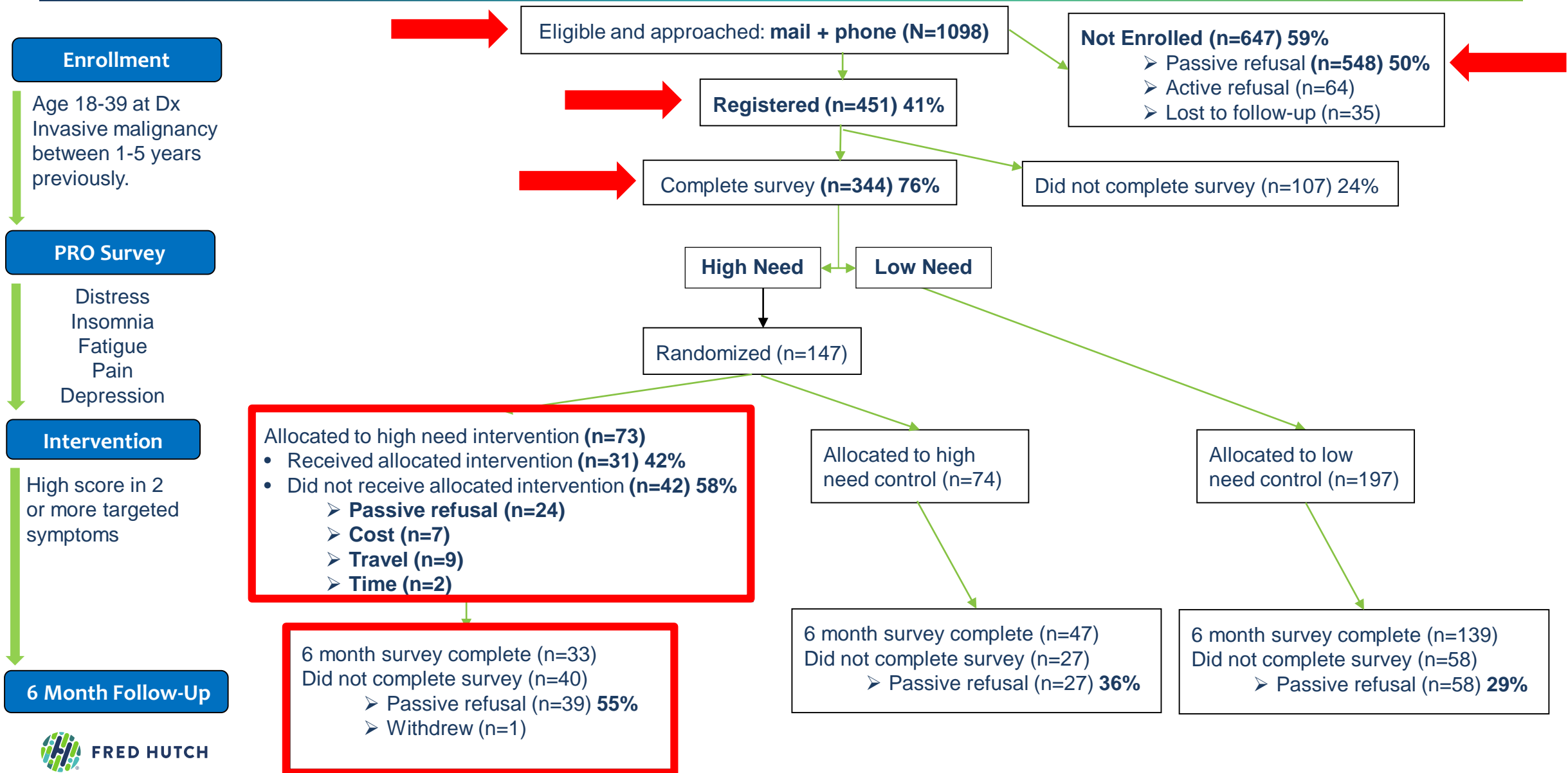
Survivorship Care for AYA Survivors, A Multicenter RCT to Improve Symptom Outcomes: Study Design

- Age 18-39 at Dx Invasive malignancy
- Within 1-5 years from Dx

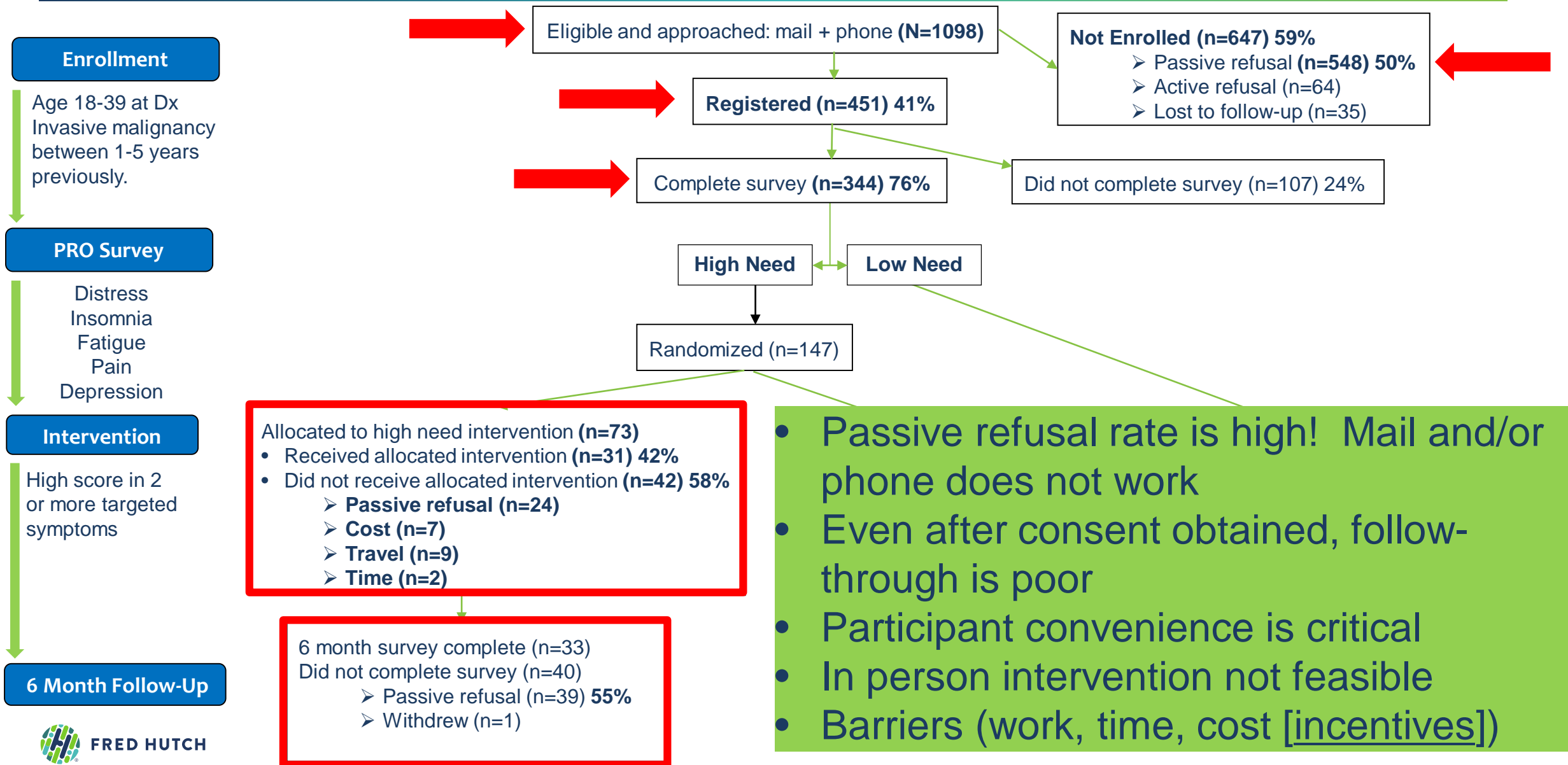


Booster #1: 4-6 weeks after Survivorship Clinic visit
Booster #2: 12-14 weeks after Survivorship Clinic visit

Survivorship Care for AYA Survivors: A Multicenter RCT to Improve Symptom Outcomes: Enrollment



Survivorship Care for AYA Survivors, A Multicenter RCT to Improve Symptom Outcomes: Enrollment



AYA Survivorship research requires a new paradigm

AYA feedback/ involvement in early phases of study design

- Use of focus groups or patient panels
- Methodology concerns/logistics
- Design of study materials
- Useability testing PRO, Apps, etc

Electronic recruitment/ enrollment methodology

- Text or email links to on-line consent forms, surveys, etc.

Remote based study methods

- Video telehealth
- home based assessments (\$)
- DBS, Oragene DNA

Incorporation of age appropriate social media

- Recruitment
- Engagement
- Retention

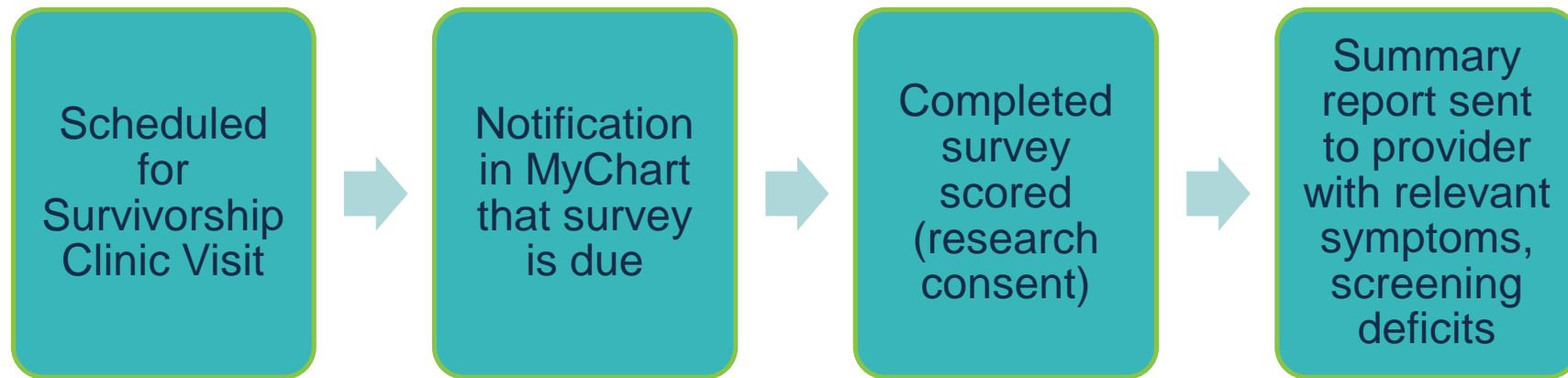
Peer Involvement

- “Buddy” for participants of exercise intervention
- Peer based private virtual support group (FB group)



Using technology to support AYA clinical care and research

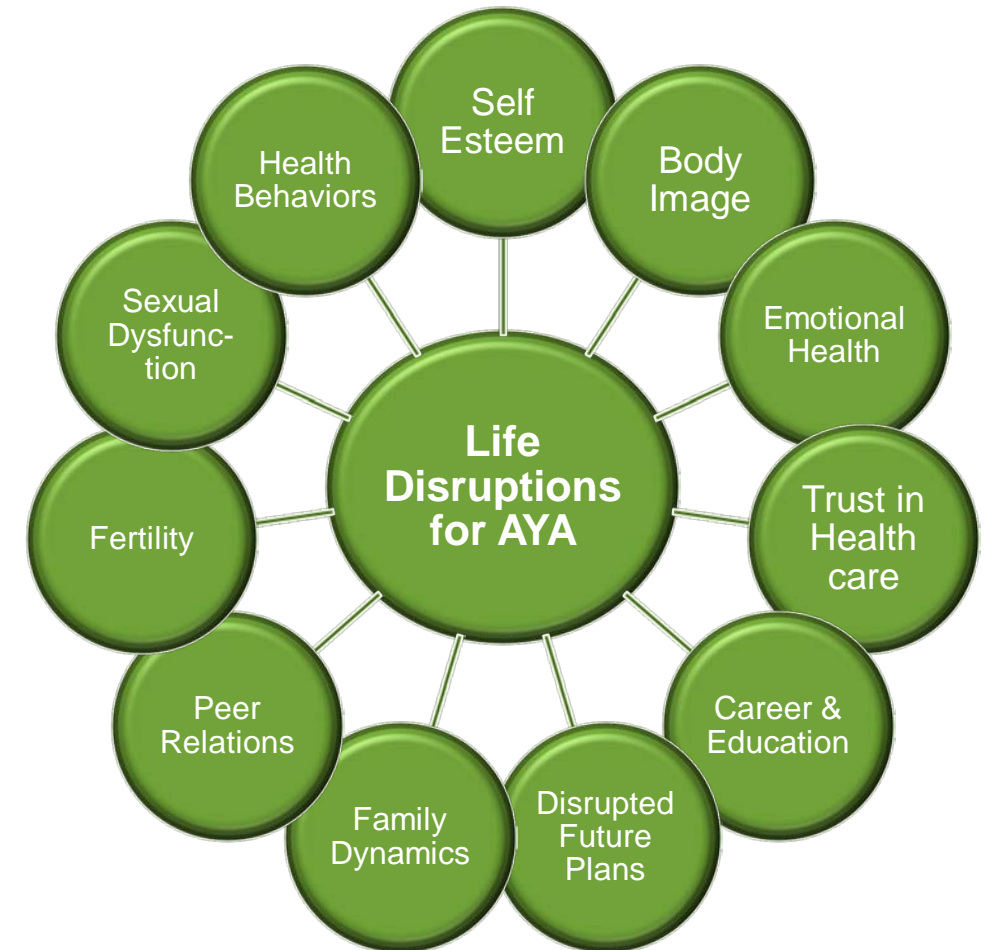
- Use of EMR based tools for research and/or clinical needs
 - Comprehensive Survivorship PRO built into Epic (symptoms [pain, fatigue, sleep, distress, anxiety, depression, etc]; cancer screening, CV risk assessment, etc)



- PRO data can be exported for research
 - Use of PRO data for identification/recruitment of cases
- Treatment summary and survivorship care plan
 - Cumulative dose tracking of relevant agents (anthracyclines)
- Use of telehealth in clinical care and research

Summary and Future Directions

- AYA survivorship is complex and issues are very different compared to childhood or older adult survivors
 - Need for dedicated AYA cancer programs, including survivorship
 - Need for AYA specific survivorship guidelines
- Research methods need to be continuously adapted (modernized) to maximize participation of AYA survivors
 - HIPAA regulatory issues regarding approach restrictions needs to be addressed



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