

<http://hcri.org/programs/change-it-back/>

Change it Back's Centers of Excellence Program was established to directly respond to contributing factors and cancer-care needs of Adolescents and Young Adults (AYAs – ages 15-39) diagnosed with cancer through the implementation of a focused and structured approach to improving cancer prevention, cancer-care, and the duration and quality of life for this vital segment of our society.

During our Pilot phase **Change it Back** encourages leaders in the field of AYA oncology and cancer services to apply for our *Center of Excellence* designation and join efforts in building a national movement to improve outcomes and elevate the quality of services available to the AYA population. Participating institutions support **formal implementation of readily identified services** known to mitigate structural challenges faced by the AYA cancer community. Although institutions may vary how and when such services are appropriately delivered along the continuum of care, experts agree such interventions are central to jump starting stagnating survival rates.

Nearly 72,000 AYAs are diagnosed with cancer each year. It is widely known that compared with younger and older age groups, survival rates for AYAs diagnosed with cancer have seen little or no improvement in more than two decades. In 2005, the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG), supported by the National Cancer Institute (NCI) and the Lance Armstrong Foundation (LAF), issued a report identifying the factors that may contribute to poorer outcomes for many AYA cancer patients. The factors identified include: restricted or delayed access to care; delays in diagnosis; inconsistency in cancer treatment; lack of follow-up care; lack of participation in clinical trials; and lack of psychosocial and support services available, even though AYA's needs for such services may be more extensive than among younger and older patients.

Change it Back is dedicated to facilitating the expansion of needed services to the AYA cancer population and increasing awareness about available services to patients and their families.

ELIGIBILITY CRITERIA FOR PROVIDERS

To receive a Center of Excellence designation, a cancer center, hospital or clinic must directly provide and/or facilitate the following:

1. Fertility Counseling

- Provide a clear explanation of patient's reproductive risks and options for preserving fertility as early in treatment planning as possible.
- Give referrals to appropriate specialists, internally or externally, for fertility preservation and/or information on parenthood after cancer.
- Establish a formal internal policy or description of planned procedural change to implement this standard.

2. Health Insurance and Financial Counseling

- Provide insurance education and advocacy services and/or referrals that empower AYA patients to understand and manage their own care by:
- Assisting in cross-referencing patients' health insurance coverage with their treatment plans;
- Explaining insurance related issues such as co-pays, co-insurance, COBRA and HIPAA;
- Assistance in enrollment in a health plan where necessary.
- Supply information and advocacy regarding rights of cancer patients when health insurance claims are denied and how to appeal those denials.

3. Clinical Trial Education and Facilitation

- Promote awareness and education for clinical providers (oncologists, nurse managers) to counsel AYAs about available clinical trials and how to participate in them.
- Establish a formal internal policy or procedure to operationalize disclosure of clinical trial information to AYA patients.

4. Psychosocial Support

- Consult or refer to a health professional with education, training, and experience necessary to provide AYA-specific psychosocial support services.
- Establish a formal internal policy or procedure to ensure access to psychosocial support services that address how cancer may impact:
 - Employment and career or higher education;
 - Social functioning;
 - Sexual health;
 - Mental health status including psychiatric symptoms, cognitive functioning, and spiritual perspectives;
 - Financial and legal issues.
- Provide resources that support parents, siblings, and spouses of AYAs.
- For facilities that cannot provide direct access to AYA-specific psychosocial support services, facilitate access to AYA-specific psychosocial support services within the community at-large with identified partners.

5. Transition to Surveillance and Survivorship

- Implementation of procedures for post-treatment transition and long term follow up with AYA patients. These services cut across settings and may be provided in the context of health insurance advocacy, psychosocial support, clinical case management or stand-alone transition and survivorship resources.
- Services should include:

- Documented transition checklists from treatment to surveillance and surveillance to survivorship. (Including resources for managing lingering treatment side effects, issues related to treatment and ongoing late-term treatment effects.)
 - Identification of a primary care physician for every AYA patient. If the patient does not have a primary care physician, help them locate one.
- Transition and survivorship care documentation to patients and appropriate health providers such as:
 - Surveillance “cheat sheet” – Written, distributed schedule of tests and scans required for effective
 - follow up (which tests and scans, at what intervals, for what duration after treatment ends);
 - Email alerts and push notifications based on provided follow-up care schedule;
 - Access to portable treatment records (to support continued follow-up services if insurance changes or a patient moves away).