

From the Ground Up: Assessing Institutional Readiness and Toolkit

Susan T. Vadaparampil, PhD, Moffitt Cancer Center

Gwendolyn Quinn, PhD, New York University

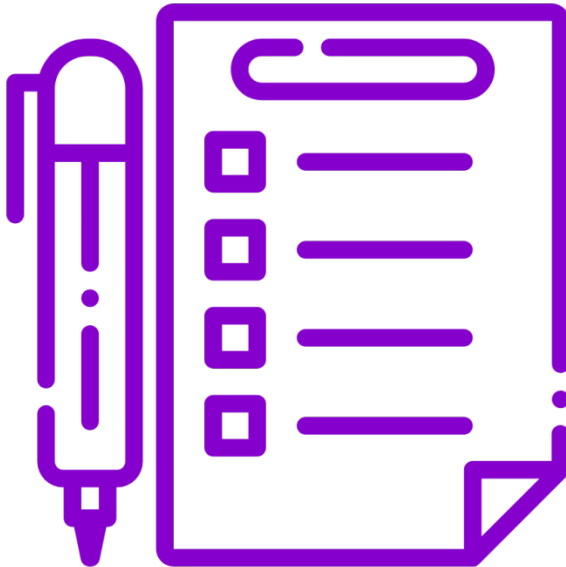


Objectives

- Identify current professional guidelines that create the foundation for best practices in Oncofertility
- Identify components of an Oncofertility program
- List tools in Oncofertility Toolkit



Current Guidelines



ASCO

Key Recommendations

- Discuss fertility preservation with all patients of reproductive age (and with parents or guardians of children and adolescents) if infertility is a potential risk of therapy
- Refer patients who express an interest in fertility preservation (and patients who are ambivalent) to reproductive specialists
- Address fertility preservation as early as possible, before treatment starts
- Document fertility preservation discussions in the medical record
- Answer basic questions about whether fertility preservation may have an impact on successful cancer treatment
- Refer patients to psychosocial providers if they experience distress about potential infertility
- Encourage patients to participate in registries and clinical studies

Adult Males

- Present sperm cryopreservation (sperm banking) as the only established fertility preservation method
- Do not recommend hormonal therapy in men; it is not successful in preserving fertility
- Inform patients that other methods (eg, testicular tissue cryopreservation, which does not require sexual maturity, for the purpose of future reimplantation or grafting of human testicular tissue) are experimental
- Advise men of a potentially higher risk of genetic damage in sperm collected after initiation of chemotherapy

Adult Females

- Present both embryo and oocyte cryopreservation as established fertility preservation methods
- Discuss the option of ovarian transposition (oophoropexy) when pelvic radiation therapy is performed as cancer treatment
- Inform patients of conservative gynecologic surgery and radiation therapy options
- Inform patients that there is insufficient evidence regarding the effectiveness of ovarian suppression (gonadotropin-releasing hormone analogs) as a fertility preservation method, and these agents should not be relied on to preserve fertility
- Inform patients that other methods (eg, ovarian tissue cryopreservation, which does not require sexual maturity, for the purpose of future transplantation) are still experimental

Children

- Use established methods of fertility preservation (semen cryopreservation and oocyte cryopreservation) for postpubertal minor children, with patient assent, if appropriate, and parent or guardian consent
- Present information on additional methods that are available for children but are still investigational
- Refer for experimental protocols when available



NCCN



National
Comprehensive
Cancer
Network®

NCCN Guidelines Version 1.2018 Adolescent and Young Adult Oncology

[NCCN Guidelines Index](#)
[Table of Contents](#)
[Discussion](#)

FERTILITY/ENDOCRINE CONSIDERATIONS

- Fertility preservation as well as sexual health and function should be an essential part in the management of AYAs with cancer who are at any risk for infertility due to cancer treatmentsⁱ
- Discuss risks for infertility due to cancer and its therapy (especially for high-risk therapies such as alkylating agents or gonadal irradiation), fertility preservation, and contraception prior to the start of therapy^j
 - Men are at risk for azoospermia following therapy, which may or may not resolve over time
 - Women are at risk for premature ovarian failure following therapy

- Initiate referral for fertility preservation clinics within 24 hours for all patients who choose the option of fertility preservation
- Refer to a mental health professional to assist with complex decision making if needed.
[See Psychosocial/Behavioral Considerations \(AYAO-7 and AYAO-8\)](#)

Males

- Discuss the option of sperm banking
- Suggest a local sperm bank, or available online sperm banking kit
- Consider follow-up with fertility specialist post-treatment

Females

- Discuss the option of embryo or oocyte cryopreservation or ovarian tissue cryopreservation (if available)
 - Initiate if provider deems that therapy can be delayed long enough for a cycle of oocyte stimulation (for low- and intermediate-risk Hodgkin's lymphoma, low-grade sarcomas, and breast cancer)
- Consider follow-up with fertility specialist post-treatment
- Oophoropexy
 - Ovaries may be surgically moved away from the planned radiation field, either during cancer surgery or in a separate procedure
- Menstrual suppression
 - Medroxyprogesterone, oral contraceptives, or gonadotropin-releasing hormone (GnRH) agonists may be used in protocols that are predicted to cause prolonged thrombocytopenia and present a risk for menorrhagia
 - It is controversial whether menstrual suppression would protect the ovaries, but some data suggest that menstrual suppression with GnRH agonists may protect ovaries in young women with breast cancer before the initiation of chemotherapy.^k



Best Practices Summary

Discuss

- Risk of infertility
- Fertility preservation options

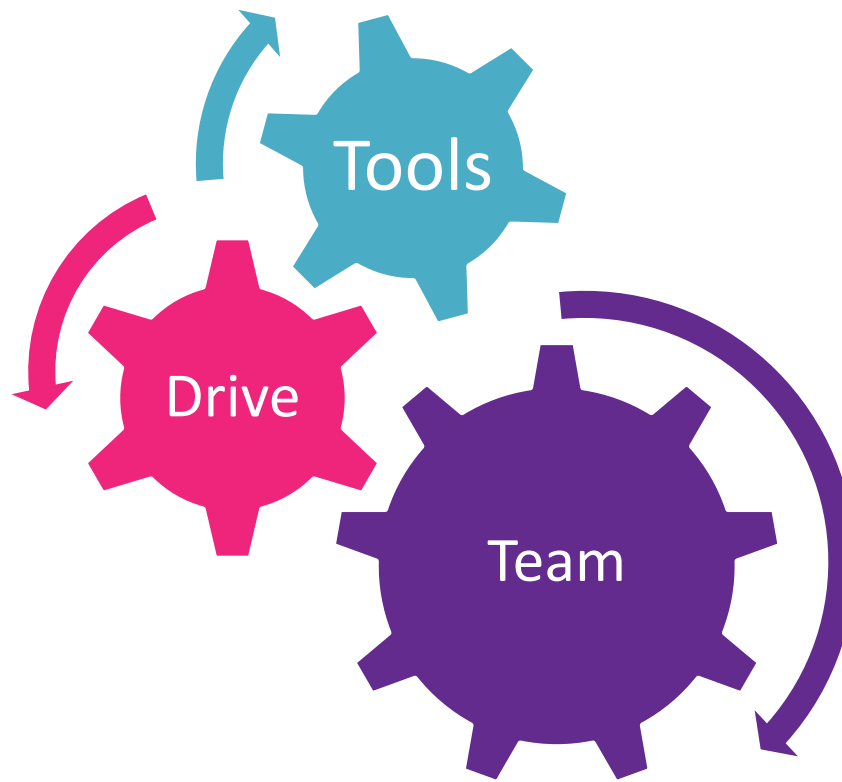
Refer

- Reproductive specialist
- Mental health professional

Document

- Discussions
- Referrals

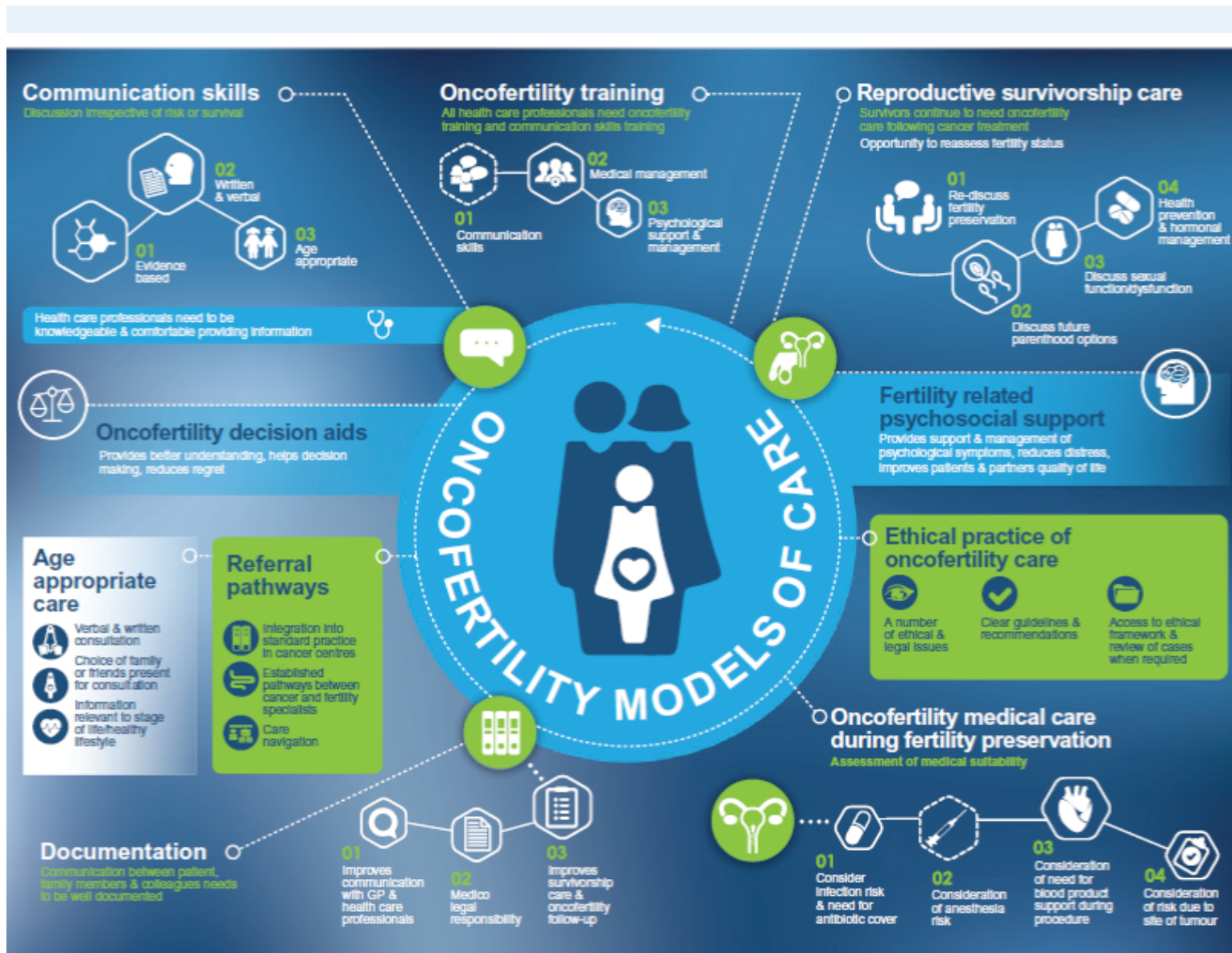




Components of an Oncofertility Program



What Makes an Oncofertility Program?





Communication

- Ideally conversation begins before treatment begins
- Should occur regardless of risk or prognosis
- Age appropriate
- Evidence based
- Between:
 - Patient and providers
 - Medical team



Oncofertility Decision Aids

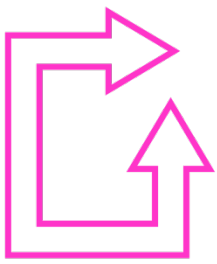
- Important for understanding and facilitating decision making
- Types of decision aids:
 - Decision trees
 - Electronic educational tools
 - Brochures/booklets
- Materials should be:
 - Age appropriate
 - Inclusive (race, ethnicity, sexual orientation, gender identity)



Provision of Care

- Age-appropriate
- Tailored for an individualized experience based on:
 - Age
 - Patient vs survivor
 - Relationships
 - Concerns
- Includes patients' preferred support systems
- Clinician comfort and scope of practice, quality of verbal and written information and institutional factors





Referral Pathways

- Integrate into standard of care
- Ideal pathways:
 - Have an established and clear pathway between cancer center and fertility specialist
 - Specialists commit to consulting with patients in a timely manner (e.g., 48 hours)





Documentation

- Discussions of fertility preservation between:
 - Patient and provider
 - Team members
- Patient decision
- Procedures performed





Training

- Oncofertility training domains:
 - Communications skills
 - Clinical content
 - Risk of infertility
 - Fertility preservation options
 - Psychosocial support
 - Navigation
- Audience:
 - Oncologists
 - APPs
 - Social workers
 - Nurses
 - Psychologists
- Venue:
 - Web-based
 - In-person





Medical Supportive Care

- Considerations:
 - Infection risk
 - Anesthesia risk
 - Need for blood product
 - Risk dependent on tumor site
- Consult with entire medical team to ensure risks are addressed



Reproductive Care in Survivorship

- Revisit:
 - Fertility preservation
 - Alternative family building options
 - Sexual functioning
 - Relationships (romantic, peer, family)
 - Manage hormones as needed





Psychosocial Support

- Refer to mental health professionals to manage and assist with reproductive health:
 - Fertility preservation decision making
 - Anxiety and distress (FP, body image)
 - Relationships





Ethical Practice

- Number of ethical issues to consider
- Use existing professional guidelines and recommendations
- Ensure access to ethical framework or cases



**Implementation of an evidence-based
intervention will
not necessarily lead to changes in
outcomes.**

**Outcomes may vary depending on the
quality of implementation.**



Toolkit



Institutional Readiness Checklist



Referral pathways to reproductive specialist and mental health professionals

Documentation system

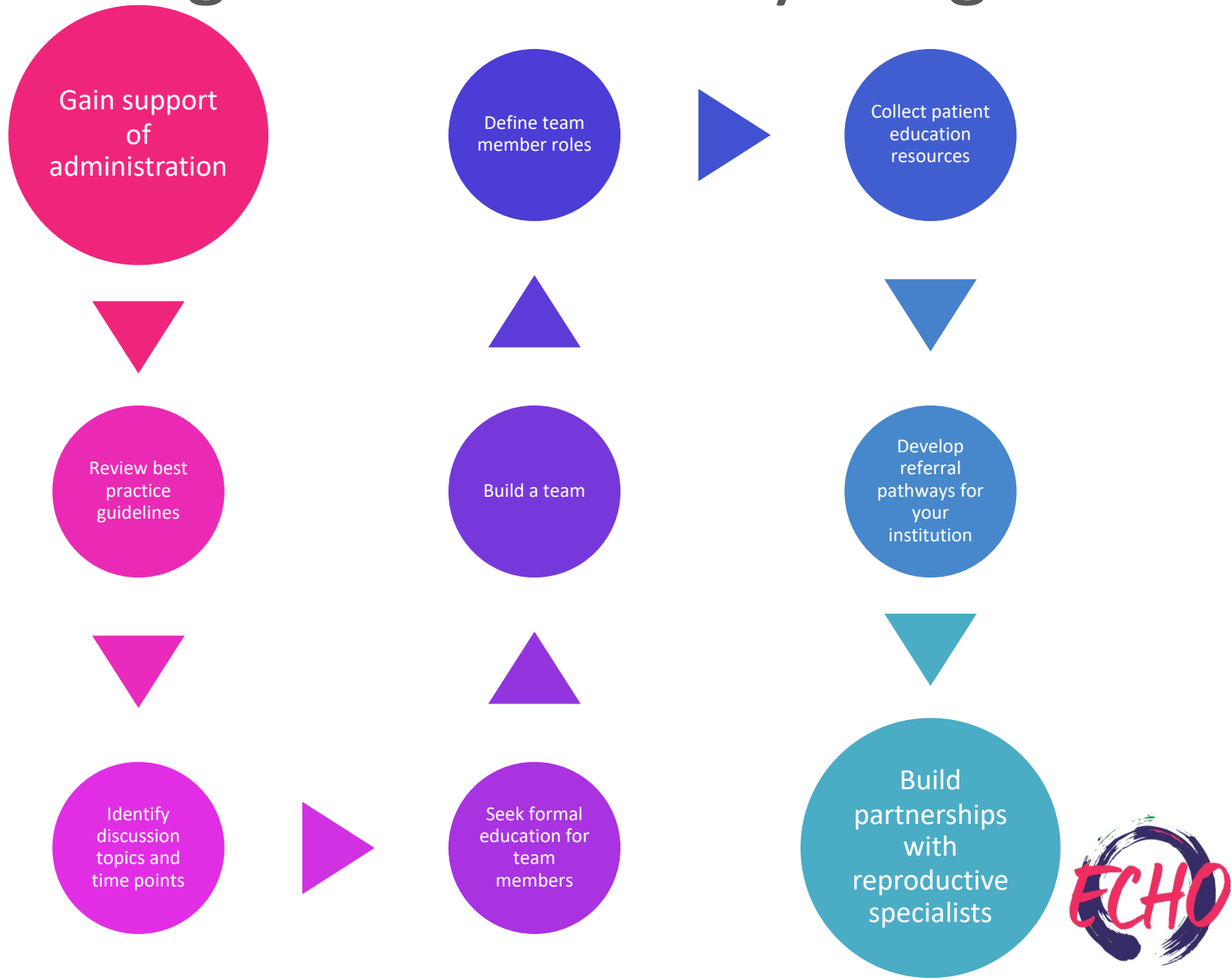
Communication training for providers

Support during FP

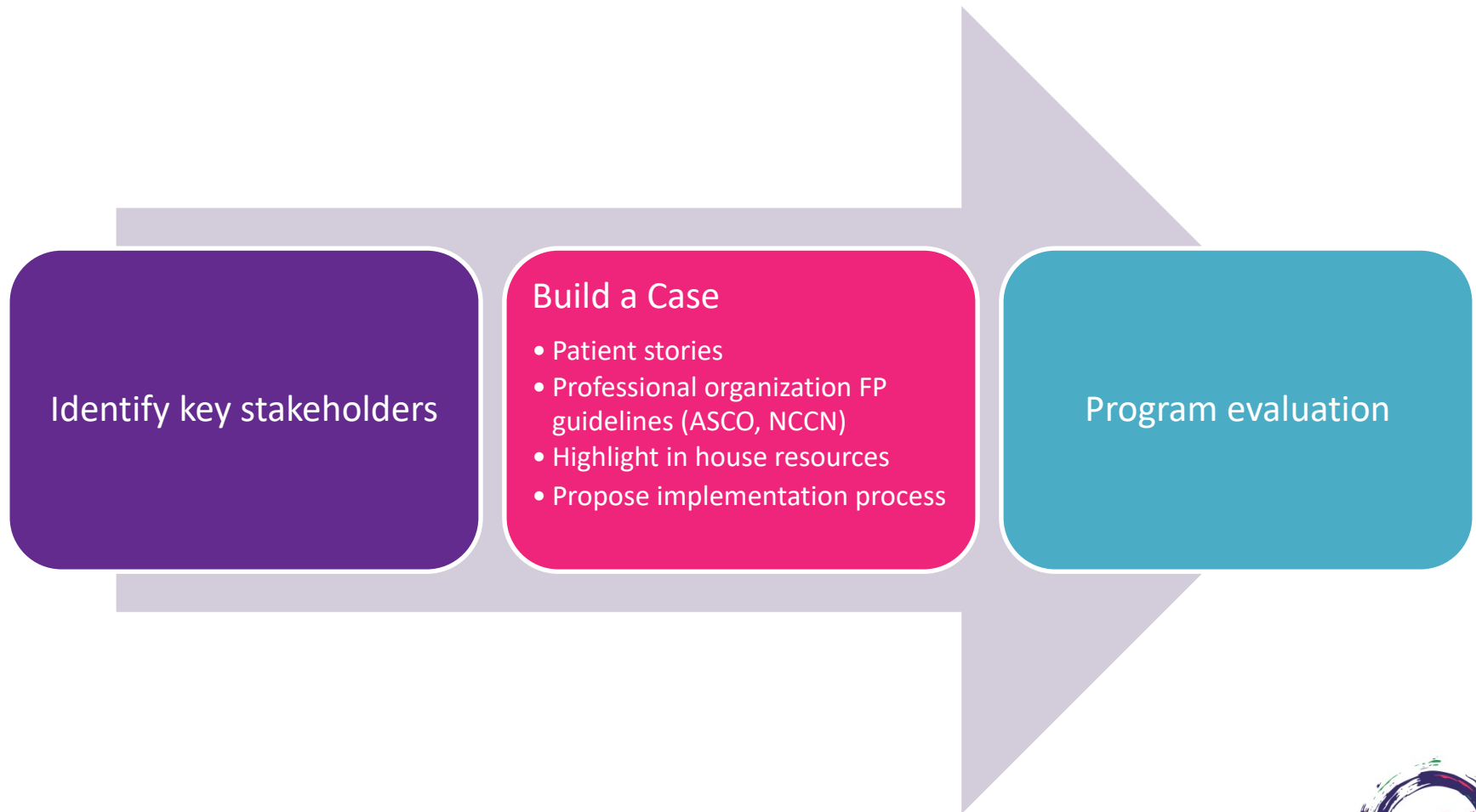
Psychosocial support services

Patient education, aids, and tools

Building an Oncofertility Program



Gain Support of Administration



Review Best Practices



National
Comprehensive
Cancer
Network®

NCCN Guidelines Version 1.2018 Adolescent and Young Adult Oncology

[NCCN Guidelines Index](#)
[Table of Contents](#)
[Discussion](#)

FERTILITY/ENDOCRINE CONSIDERATIONS

- Fertility preservation as well as sexual health and function should be an essential part in the management of AYAs with cancer who are at any risk for infertility due to cancer treatmentsⁱ
- Discuss risks for infertility due to cancer and its therapy (especially for high-risk therapies such as alkylating agents or gonadal irradiation), fertility preservation, and contraception prior to the start of therapy^j
 - ▶ Men are at risk for azoospermia following therapy, which may or may not resolve over time
 - ▶ Women are at risk for premature ovarian failure following therapy

- Initiate referral for fertility preservation clinics within 24 hours for all patients who choose the option of fertility preservation
- Refer to a mental health professional to assist with complex decision making if needed.
[See Psychosocial/Behavioral Considerations \(AYAO-7 and AYAO-8\)](#)

Males

- Discuss the option of sperm banking
- Suggest a local sperm bank, or available online sperm banking kit
- Consider follow-up with fertility specialist post-treatment

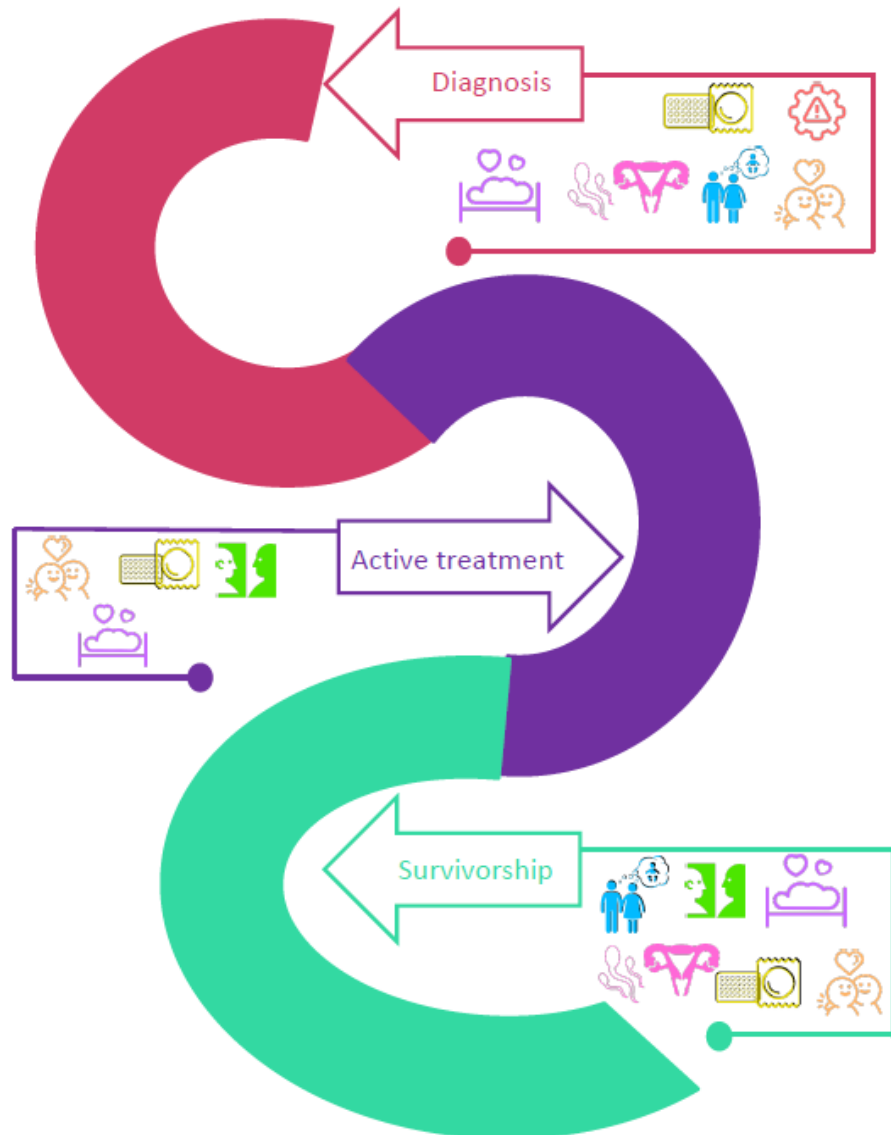
Females

- Discuss the option of embryo or oocyte cryopreservation or ovarian tissue cryopreservation (if available)
 - ▶ Initiate if provider deems that therapy can be delayed long enough for a cycle of oocyte stimulation (for low- and intermediate-risk Hodgkin's lymphoma, low-grade sarcomas, and breast cancer)
- Consider follow-up with fertility specialist post-treatment
- Oophoropexy
 - ▶ Ovaries may be surgically moved away from the planned radiation field, either during cancer surgery or in a separate procedure
- Menstrual suppression
 - ▶ Medroxyprogesterone, oral contraceptives, or gonadotropin-releasing hormone (GnRH) agonists may be used in protocols that are predicted to cause prolonged thrombocytopenia and present a risk for menorrhagia
 - ▶ It is controversial whether menstrual suppression would protect the ovaries, but some data suggest that menstrual suppression with GnRH agonists may protect ovaries in young women with breast cancer before the initiation of chemotherapy.^k



Discussion Topics and Time Points

Reproductive Health Discussions Along the Cancer Care Continuum



Map Icon Key

** Please note that reproductive health conversations can/should occur across the cancer continuum. These are suggestions about key time points to discuss, but individual patient treatment plan should be considered.



Risk of infertility: Cancer treatment with chemotherapy, radiation, or surgery can affect the reproductive system in a variety of ways. It is important to communicate risk before cancer treatment begins.



Fertility preservation: Freezing of sperm, eggs, and embryos may preserve the ability of survivors to have a biologic child in the future. Additionally, there are options for minimizing reproductive damage (ovarian transposition, ovarian suppression, fertility sparing surgeries, testicular shielding, and nerve sparing surgeries). Refer interested patients to reproductive specialists. It is ideal to discuss these options before cancer treatment begins.



Sexual functioning: Stress, fatigue, and treatment side effects can affect sexual functioning and desire. Providers should check-in with their patients on this topic at diagnosis and, throughout treatment, and into survivorship. Make appropriate referrals if a patient reports sexual dysfunction.



Contraception: Promote safe sex by educating patients on the need to use contraception to prevent pregnancy and barriers (condoms) to prevent sexually transmitted infections. It is important to note the danger of an unplanned pregnancy and the effect that the cancer treatment could have on a developing fetus.



Romantic partnerships: Cancer can disrupt romantic partnerships through stress of diagnosis, change in roles, and treatment side effects. Consultations with mental health professionals can support both patient and partner during this challenging time.



Body image: Physical changes due to cancer treatment (hair loss, surgical scars, weight changes) can lead to emotional distress and poor self esteem. Checking in with patients about their adjustment to these changes and referring to mental health professionals is important to address from diagnosis and into survivorship.



Alternative family building options: For those who are unable to have a biologic child or carry a pregnancy, other options for building a family are available, such as adoption; donor eggs, sperm, or embryos; and surrogacy. Bringing up these options at diagnosis and at survivorship is important to ensure family building goals are being met.

Education

In-service

- Grand rounds
- Lunch and Learn series

Short Term Course

- ASCO
- ASRM

Long Term Course

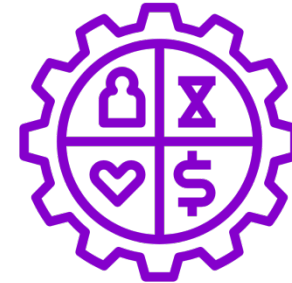
- ECHO



Building an Oncofertility Team



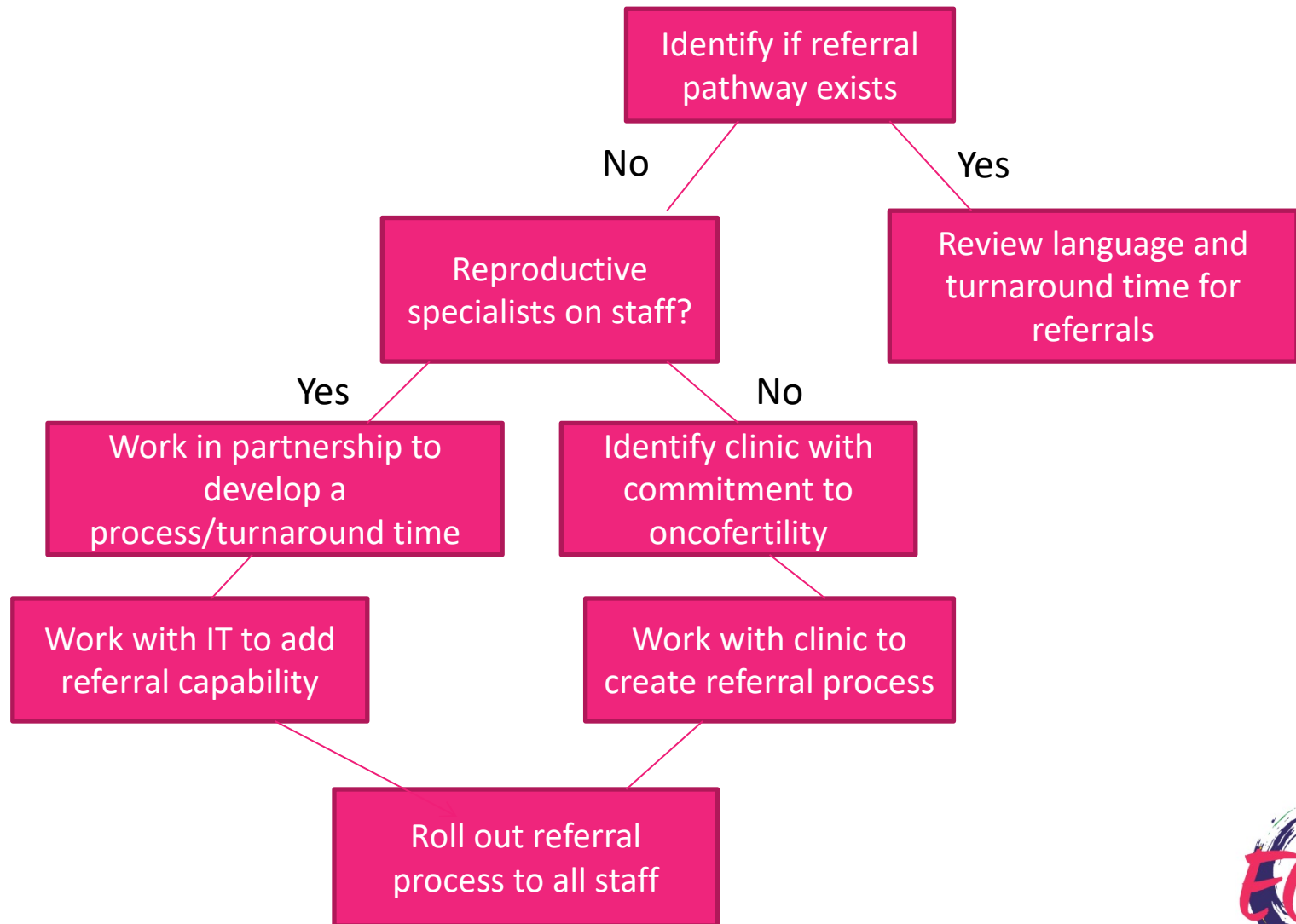
Collect Patient Education Resources



- Identify Materials:
 - Decision aids
 - Fertility preservation options
 - Financial assistance programs
 - Patient support
 - Insurance issues
- Ensure all materials are population/age appropriate (i.e., males vs. females, pediatrics vs adults)



Referral Pathway Development



Build Partnerships with Reproductive Specialists

Fertility Scout™

This tool allows cancer patients and oncology professionals to search for fertility preservation services in their area, and to submit referrals or request appointments through our secure online system.

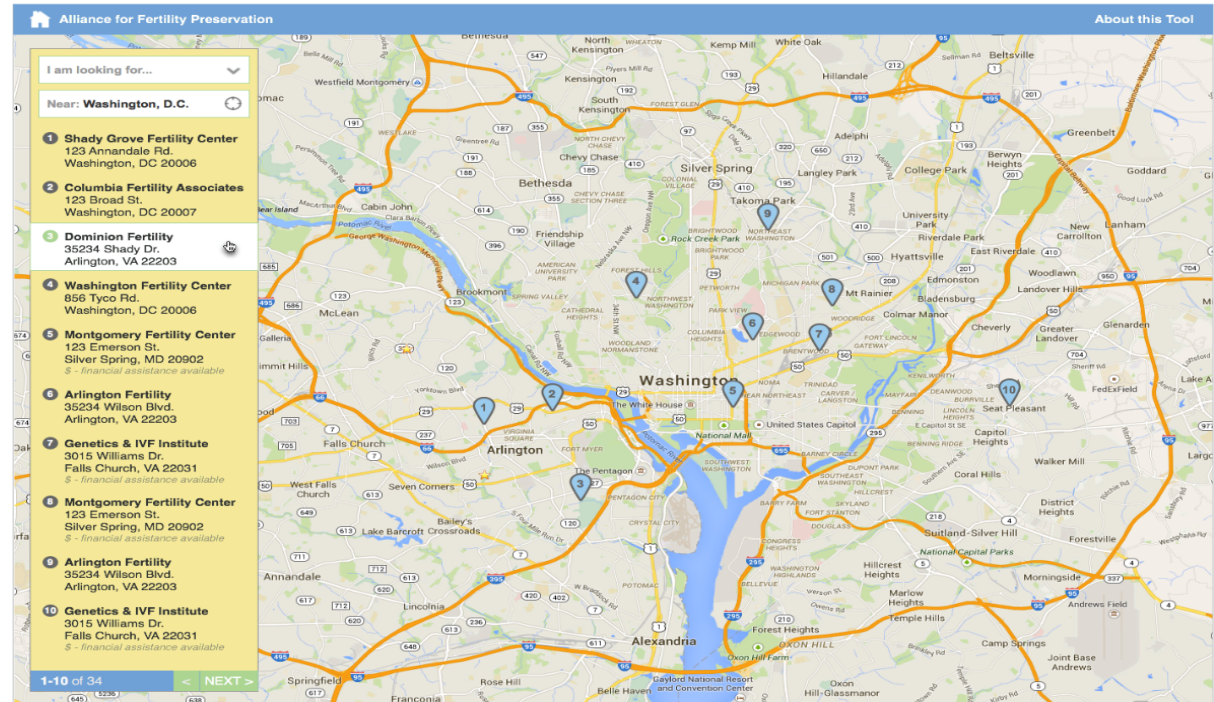
[Learn More](#)

[Find A Location](#)



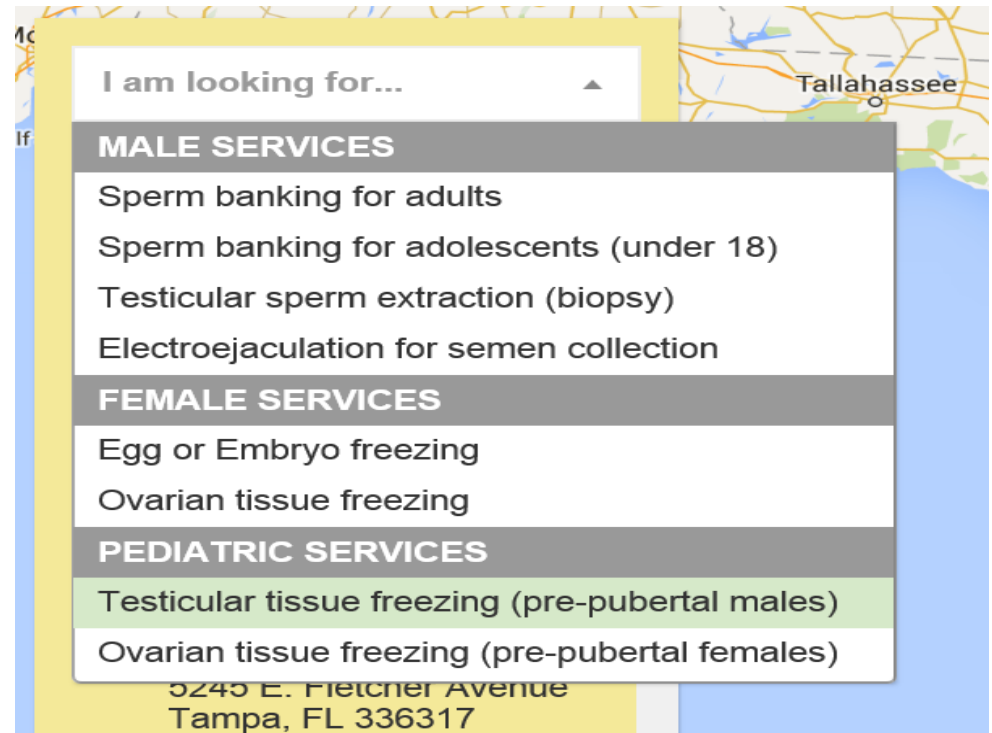
1. Home page

- Go to:
fertilityscout.org
- Phone, tablet,
computer
- Allow geo-location
OR
- Enter another
location/zip code
- Map shows pins
- List shows 10
closest facilities
- Can expand map or
go to “next” on list



2. Search for services

- Use drop-down menu to select service
- Male, Female & Pediatric services
- Map and list will update to reflect selection



Financial Aspects

- Show the cost benefit to your institution
 - Physician time vs AHP time
 - Legal issues
 - Good PR
 - Role of REI group
 - AFP and other national organizations
 - See Joyce's presentation on state legislation
- Stakeholder Support
 - MDs want to please patients
 - Document patient interest
 - Document MD need for assistance
 - Avoid negative PR
 - Avoid REI vs ONC issues



Summary

- Create a program that meets the unique needs of your patients and your institution
- Develop a team who are passionate about the success of a fertility preservation program and clearly define each members roles
- Don't get hung up on barriers – even a small program, educational information, and informal counsel are better than nothing
- Work to first change practice and policy within your institution, then look further to your community and local legislation
- Continue to build your program and set new goals throughout the process

