

## NIH Needs Survey - Adolescents (13-17 years old)

<b>Age:</b> _____	<b>Race (please check):</b> <div style="display: flex; justify-content: space-between;"> <div style="width: 30%;">           White            Black or African American            Asian            Unknown         </div> <div style="width: 30%;">           American Indian or Alaska Native            Native Hawaiian or Other Pacific Islander            Multi-Race            Other please specify: _____         </div> </div>	
<b>Sex (please check):</b> Male      Female		
<b>Medical Diagnosis:</b> _____	<b>Ethnicity (please check):</b> <div style="display: flex; justify-content: space-between;"> <div style="width: 30%;">           Hispanic or Latino         </div> <div style="width: 30%;">           Not Hispanic or Latino         </div> <div style="width: 30%;">           Unknown         </div> </div>	

***Below are areas that adolescents with a health condition may have questions about or need help with. Please check “yes” to any items below that you or others your age would like information about or help with. This information will guide us in planning services to fit the needs of teenagers at the NIH.***

### HEALTH AND WELLNESS

YES

- My health condition
- Medical treatments and side effects
- Nutrition and/or healthy eating
- Physical activity and exercise
- Complementary healthcare (e.g., yoga, meditation)
- My ability to have children in the future

### LEARNING, SCHOOL, AND WORK

YES

- Learning difficulties
- Attention problems
- Returning to school after treatment
- Transitioning to college
- Jobs/careers that fits my skills/abilities
- Impact of my medical condition at school or work

### MANAGING PHYSICAL SYMPTOMS

YES

- Pain
- Sleep difficulties
- Eating and/or weight (loss or gain)
- Appearance (how I look)
- Physical limitations (e.g., difficulties walking, poor vision, problems hearing)

### ADJUSTMENT DURING AND AFTER TREATMENT

YES

- Adjusting to my diagnosis and treatment at NIH
- Communicating with my healthcare providers throughout treatment (e.g., learning to speak up about my needs or ask questions about treatment)
- Adjusting to life after treatment (e.g., fitting back in with friends, moving on with my life)
- Having difficult conversations (e.g., talking about my diagnosis, prognosis, or concerns related to death and dying)

### SOCIAL-EMOTIONAL WELLBEING

YES

- Symptoms and treatment of anxiety or depression
- Coping better with my medical condition and treatment
- Relaxation/stress management tools
- Getting support from my family or friends
- Talking to others about my medical condition
- Keeping and making friends
- Dating, relationships, sexual identity
- Uncertainty about the future

### HEALTHCARE AND PRACTICAL NEEDS

YES

- Transitioning from pediatric care to adult care
- Medical insurance (Medicaid/private)
- Legal and practical services (e.g., living will, power of attorney)

## NIH Needs Survey - Adolescents (13-17 years old)

***Below are services, events, or programs that may be helpful for adolescents at the NIH. Please check “yes” to any items below that you or others your age would be interested in to guide us in planning services for teens at the NIH:***

### COUNSELING SERVICES THROUGH NIH

YES

- Supportive counseling for myself while I am at NIH
- Supportive counseling for my family while at NIH
- One-on-one video chat sessions at home to check in with a NIH therapist in between visits
- Attending in-person support groups for teens with my health condition at NIH
- Participating in an online support group or chat room for teens with my health condition

### RECREATIONAL SERVICES THROUGH NIH

YES

- A hang-out space at NIH for teenagers
- Recreational weekend programs with other teens with the same/similar health condition
- Scheduled recreational activities during the day for teens (e.g., games, bowling)

### NIH GROUPS AND EVENTS

YES

- A NIH electronic newsletter that provides information related to my health condition
- A NIH website that provides information related to my health condition
- Connecting with others who have a similar health condition through social media (e.g., Facebook, Twitter)
- A NIH event where experts would address issues that teens face related to my health condition
- Would you be willing to make an extra visit to NIH to attend an event for patients or families?

***Please write in your comments to give us additional information and your ideas:***

#### WHAT ARE THE TOP 3 THINGS THAT WOULD IMPROVE YOUR EXPERIENCE AT THE NIH?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

#### PLEASE SHARE OTHER IDEAS OR COMMENTS YOU HAVE TO HELP US MAKE NIH BETTER FOR TEENS!

---

---

---

---

---