

Workshops to Support Transition-Age Patients Co-designed and Developed with Adolescent and Young Adult Advisory Council

Rachel Cuevas, BS, BA, Martha Mendoza Orozco, MPH, Emozino Ayetuoma, MPH, Brianna Capers, AA, Jesus Covarrubias, Soha Ghavami, Danissa Maroquin, MS, Monica Mejia, Adan Santiago, Asma Sodager, BS Dalen Thomas, BA, Daron Wong, Courtney Porter, MPH, CPHQ

Background

- To have a successful transition, adolescent and young adult (AYA) patients with chronic health conditions need to develop skills to manage their condition(s) and transfer to comprehensive health care services in adulthood
- Health care team members and caregivers play an essential role in introducing skills and education needed for pediatric patients to begin exploring healthcare independence
 - Patients can also benefit from learning from other AYAs
- Engagement of individuals with lived experience in the co-design of interventions on transition skills has been demonstrated to bring unique knowledge and experience and well received by AYA participants

Aim

- Within the context of an institution-wide approach to transition support, the Center for Healthy Adolescent Transition (CHAT) and hospital AYA Advisory Council aimed to co-design and implement a virtual workshop series to provide:
 - Support to patients aged 15-21
 - Education, tools, and resources to help patients feel confident about their transition to adulthood and adult care

Methods

- Fifteen AYA Advisory Council members used their lived experience to narrow the list of transition topics previously identified through patient focus groups
- Ten council members formed a workgroup to co-design and develop a workshop series focused on the top three topics identified by the larger council
 - Workshop #1: Healthcare transition and independence
 - Workshop #2: Insurance
 - Workshop #3: Self-care and support
- Advisory Council members were compensated at an hourly rate for their time, expertise, and experience
- Varied opportunities for workgroup to engage in the co-design process in ways that best fit their schedules (Table 1)
- Introduced the hospital's Patient & Family Education (PFE) Health Literacy and Marketing guidelines and updated workgroup on approval process of submitted material
- Incorporated feedback within the parameters of marketing visual and health literacy standards and presented to workgroup members for final edits

Table 1. Co-Design Opportunities

Engagement Opportunities	Maximum # of Hours
Content Review: Suggestions and Feedback	
Bi-weekly, virtual meetings	12
Electronic survey or email feedback	2
Content Development & Implementation	
Developing AYA-friendly supplemental resources	5
Preparing for and facilitating breakout rooms	2
Implementation Feedback	
Attending workshops and providing feedback	6
Debrief meetings to inform future implementation	3

Figure 1. AYA Workshop Flyer: Ready, Set, Adult

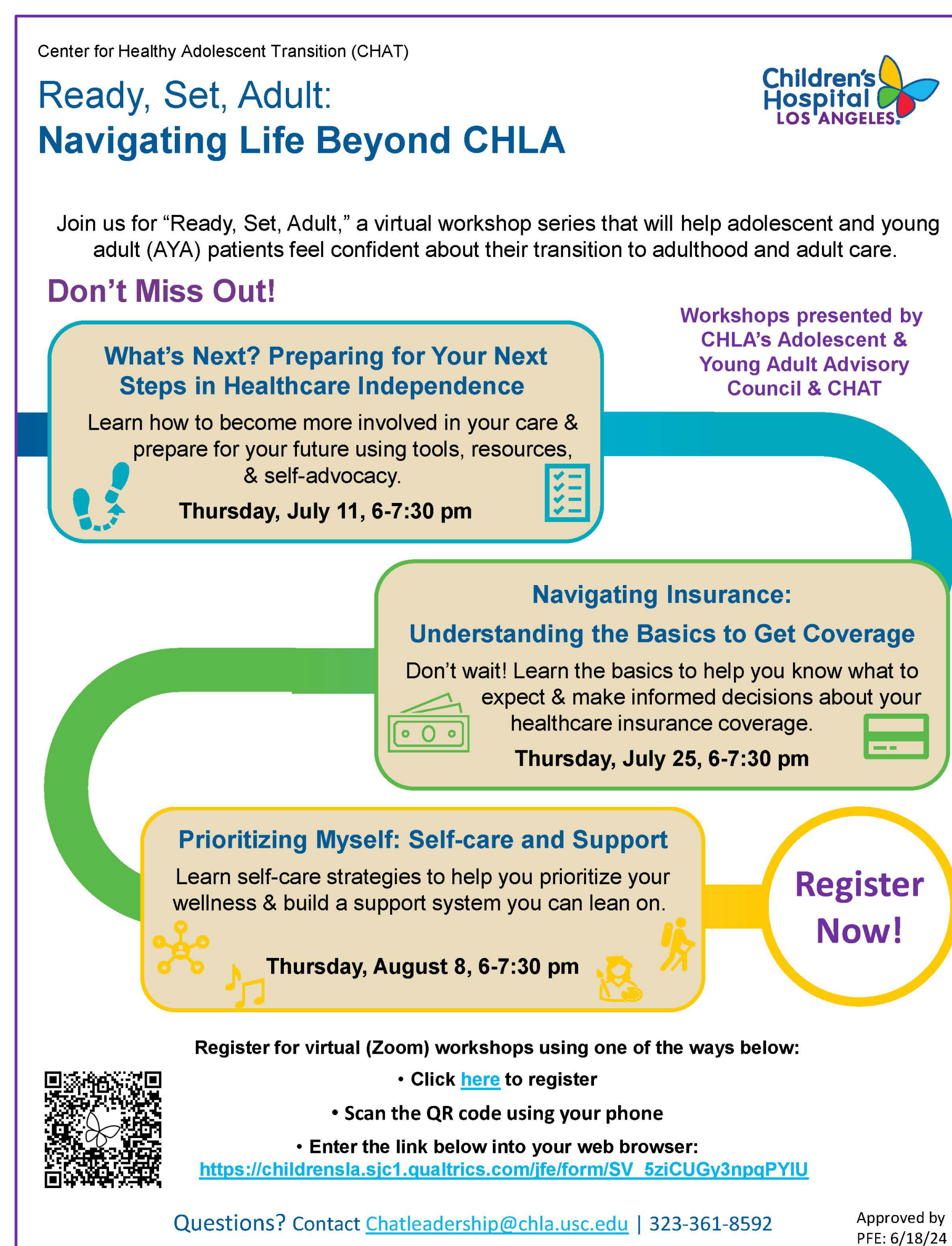


Figure 2. AYA Co-design Involvement Tailored Approach

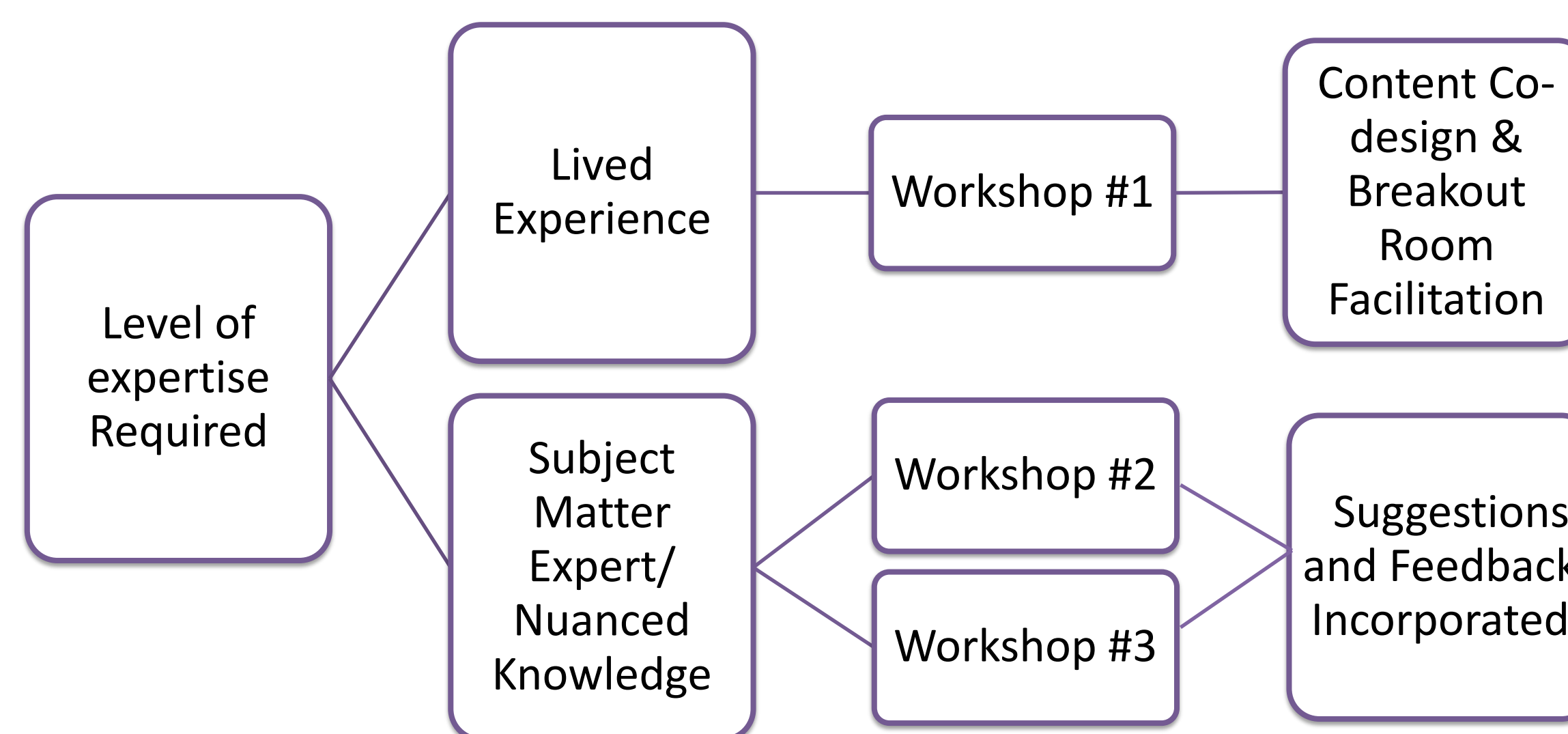


Figure 3. Supplemental Resources Created

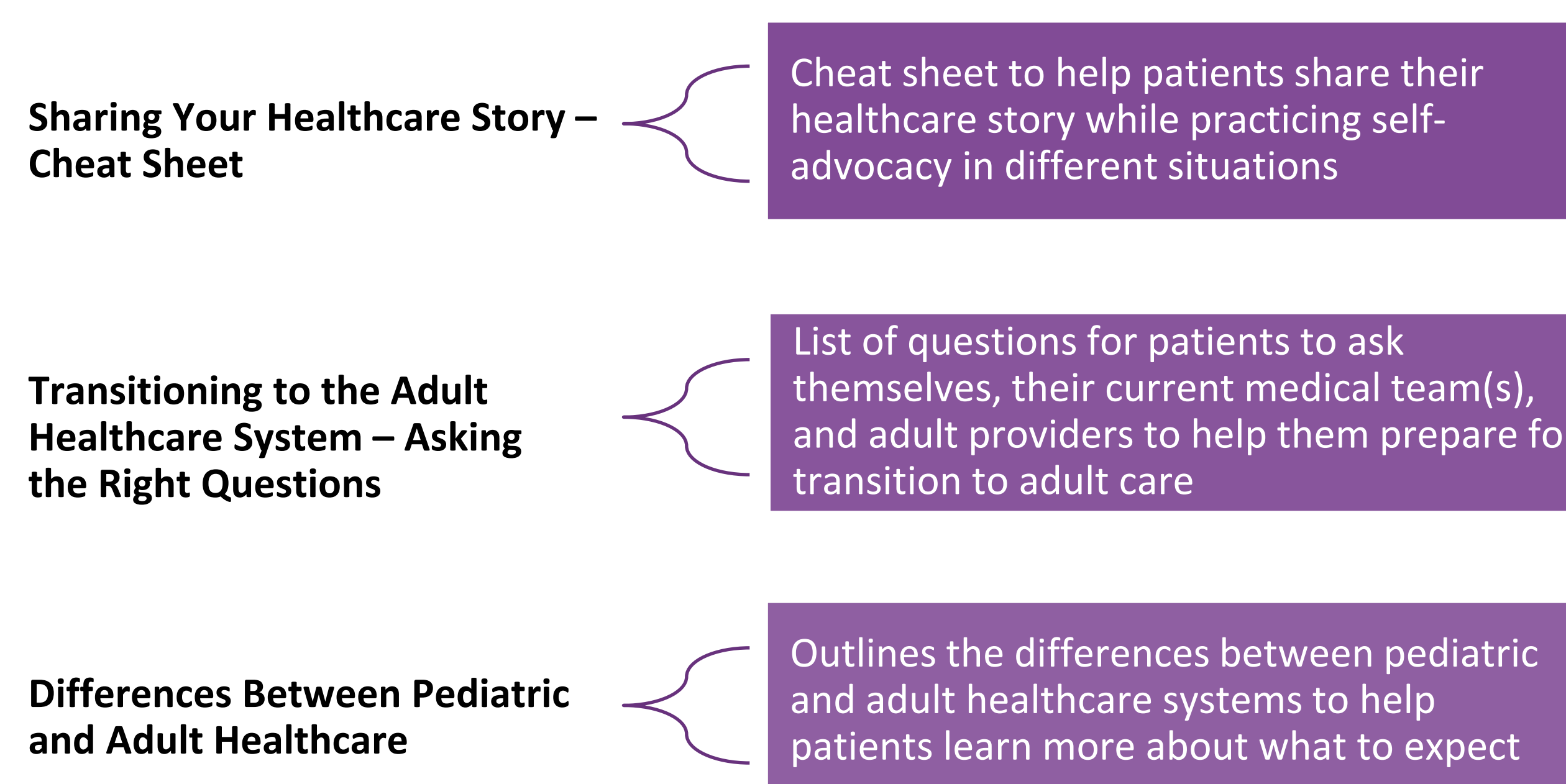


Table 2. Workshop Attendance

Workshop attendees	Workshop #1 n (%)	Workshop #2 n (%)	Workshop #3 n (%)
Total # of Attendees	45	23	18
Identified as parent/caregiver	22 (48.9)	14 (60.9)	9 (50.0)

Table 3. Results from Evaluation Survey

All workshops (n=25)	n (%)
How helpful was this workshop?*	
Unhelpful	1 (4.0)
Neutral	3 (12.0)
Helpful	11 (44.0)
Very Helpful	10 (40.0)
Workshop #1 (n=6)	
The workshop helped me feel more confident in preparing for transfer to adult care**	
Disagree	1 (16.7)
Agree	4 (66.7)
Strongly Agree	1 (16.7)
Workshop #2 (n=9)	
The workshop helped me learn about different types of health insurance **	
Agree	4 (44.4)
Strongly Agree	5 (55.6)
Workshop #3 (n=9)	
The workshop helped me learn different ways to cope with stress**	
Agree	4 (44.4)
Strongly Agree	5 (55.6)

* Scale: very unhelpful, unhelpful, neutral, helpful, very helpful; Across all three workshops
 ** Scale: strongly disagree, disagree, neutral, agree, strongly agree

Results

- Co-designed workshop flyer that includes workshop titles, layout, and colors to appeal to AYA patients while abiding by PFE and marketing guidelines (Figure 1)
- Tailored workgroup involvement in each workshop based on content and level of expertise required (Figure 2)
- Developed supplemental material introduced to patients in Workshop #1 (Figure 3)
- 149 patients/parents registered for the workshop series
- 86 patient and parent/caregiver attendees across all three workshops (Table 2)
- 47.8% of workshop #2 attendees also attended workshop #1 and 68.4% of workshop #3 attendees attended at least one other workshop
- 25 workshop evaluation surveys completed across all three workshops
- Survey responses indicated most attendees found the workshops helpful (Table 3)
- Respondents agreed that workshops helped them feel more confident in preparing for transfer to adult care and helped them learn about different types of health insurance and ways to cope with stress (Table 3)

Conclusions

- AYA Advisory council members were successfully incorporated in the co-design and development of three workshops implemented in the summer of 2024
- Despite being advertised as an opportunity for patients, workshop registration and attendance indicated strong interest in topics among parents/caregivers
- Continuing discussions with AYA and Family Advisory Council members around the inclusion and/or engagement of parents/caregivers in this workshop series
- Evaluation data and council member feedback will inform modifications to workshops, marketing material and strategies, and registration and evaluation surveys
- AYA virtual workshop series will take place twice a year