

PATCH Toolkits: PATCH for Teens & PATCH for Parents

Helping Teens and Their Parents Understand Adolescent Rights & Responsibilities in Health Care Settings

An Innovation Station Cutting-Edge Practice

Purpose: This document is intended to support MCH professionals to implement a practice found in Innovation Station. This resource provides the information needed to replicate the practice and is divided into two sections: the first section provides a high-level overview of the practice while the second section describes how to implement the practice. For additional information on any of the content provided below, please reach out to the practice contact located at the bottom of this document.

Section I: Practice Overview

Location:	Wisconsin	Title V/MCH Block Grant Measures Addressed
Category:	Cutting-Edge	Adolescent Health Care NPM 10: Adolescent Well-Visit NPM 11: Medical Home NPM 12: Transition
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Practice Description

The *PATCH for Teens* and *PATCH for Parents* Toolkits are resources for all educators – including those that work in schools, community- and faith-based organizations, businesses, health care systems, and public health agencies – who want to help young people gain more independence and responsibility over their health and health care decisions. Each Toolkit contains a step-by-step guide that provides information, materials, and activities necessary to deliver an empowering and interactive health education session.

Purpose

The PATCH Toolkits are initiatives of the Providers and Teens Communicating for Health (PATCH®) Program – a program committed to improving adolescent health outcomes alongside and in true partnership with youth. The *PATCH for Teens* and *PATCH for Parents* Toolkits were created to capitalize on, and enhance the impact of, existing PATCH efforts which are working to change the way adolescents receive, experience, and utilize health care.

The *PATCH for Teens* Toolkit aims to empower young people to begin managing their own health care, and equip them with the knowledge and skills needed to navigate and advocate for youth-friendly services.

The *PATCH for Parents* Toolkit is intended to engage and educate parents, guardians, and caregivers on teen rights and responsibilities in health care settings, and help them to support young people in becoming responsible managers of their own health.

Practice Formation

Adolescence is known as an important transitional period, providing youth an opportunity to develop critical knowledge and skills needed for adulthood. Just like driving a car or preparing a meal, learning how to navigate and manage health care is an important life skill that we teach young people. Youth who gain more independence and responsibility over their health and health care decisions are more likely to access and appropriately use health care services during adolescence and into adulthood, resulting in higher satisfaction, better health outcomes, and overall lower costs. While longstanding efforts have been in place to aid children and youth with special health care needs, there is an added interest in ensuring all youth receive the necessary information, support, and resources to actively participate in and begin to manage their own health and health care.

According to the National Survey of Children's Health, in 2018:

- 64.8% of adolescents, ages 12 through 17 years, had one or more preventive medical visits in the past year (NPM 10).
- 42.8% of adolescents, ages 12 through 17 years, with special health care needs met the criteria for having a medical home (NPM 11).
- 46.3% of adolescents, ages 12 through 17 years, without special health care needs met the criteria for having a medical home (NPM 11).
- 20.8% of adolescents, ages 12 through 17 years, with special health care needs received services necessary to make transitions to adult health care (NPM 12).
- 14.8% of adolescents, ages 12 through 17 years, without special health care needs received services necessary to make transitions to adult health care (NPM 12).

Data retrieved July 21, 2020

Since 2010, the PATCH Program has cultivated a space for youth from all walks of life to make their voices heard in the program, policies, and decisions impacting them and their generation. PATCH is guided and influenced by the input of teens and professionals who offer strength, diversity, and breadth -- bringing fresh perspectives, new ideas, creative problem-solving, and innovative solutions to the field of adolescent health. Furthermore, the small leadership team is well-rounded with diverse strengths and expertise.

Specific program initiatives have sought to address the underlying interpersonal challenges that impact the way youth receive, experience, and utilize health care. With youth voice and perspective at the forefront, the PATCH Toolkits are a byproduct of ensuring health care providers, adolescents, and parents/guardians/caregivers of adolescents feel ready and well-equipped to navigate the often complex interactions that take place in health care settings. While PATCH has had long-standing, innovative programming for health care providers and teens, the *PATCH for Teens* Toolkit enhances reach and feasibility of the existing peer-to-peer education component, and the *PATCH for Parents* Toolkit fulfills a significant need to include parents, guardians, and caregivers in the conversation. The *PATCH for Teens* Toolkit was released in 2017 followed by the *PATCH for Parents* Toolkit in 2018; both underwent an initial pilot and small-scale implementation phase before being released to the public. PATCH Toolkits were drafted by program staff based on its existing evidence-based programming with added input from youth, academic partners, community stakeholders, literature, and recommendations of medical professional organizations. Various program stakeholders reviewed the content, and initial pilot projects examined feasibility, time, effectiveness, and adaptations needed based on different populations and settings.

Based on evidence and youth experience, the following are three key principles of the PATCH Toolkits:

- Teens need and deserve a good *relationship* with their health care providers.
- Teens have legal health care *rights*.
- Teens have a personal *responsibility* to learn to manage their own health care.

Below is an abridged list of scientific evidence that influenced and informed the PATCH Toolkits:

- Ambresin, A.E., Bennett, K., Patton, G.C., Sanci, L.A., & Sawyer, S.M. (2013). Assessment of youth-friendly health care: a systematic review of indicators drawn from young people's perspectives. *Journal of Adolescent Health, 52*(6), 670-681.
- American Academy of Pediatrics Committee on Adolescence. (2016). Achieving quality health services for adolescents. *Pediatrics, 138*(2), e20161347.
- Betz C.L. (2017). SPN position statement: Transition of pediatric patients into adult care. *Journal of Pediatric Nursing, 35*, 160-164. DOI: 10.1016/j.pedn.2017.05.003.
- Burrus B., Leeks K.D., Sipe T.A., Dolina S., Soler R., Elder R., Barrios L., Greenspan A., Fishbein D., Lindegren M.L., Achrekar A., Dittus P., & Community Preventive Services Task Force. (2012). Person-to-person interventions targeted to parents and other caregivers to improve adolescent health: A community guide systematic review. *American Journal of Preventive Medicine, 42*(3), 316-326. DOI: 10.1016/j.amepre.2011.12.001.
- Daley, A.M., Polifroni, E.C., & Sadler, L.S. (2017). "Treat me like a normal person!" a meta-ethnography of adolescents' expectations of their health care providers. *Journal of Pediatric Nursing, 36*, 70-83.
- Dennison, D., & Golaszewski, T. (2002). The activated health education model: Refinement and implications for school health education. *Journal of School Health, 72*, 23–26. doi:10.1111/j.1746-1561.2002.tb06507.x
- Eaton C.K., Davis M.F., Gutierrez-Colina A.M., LaMotte J., Blount R.L., & Suveg C. (2017). Different demands, same goal: Promoting transition readiness in adolescents and young adults with and without medical conditions. *Journal of Adolescent Health, 60*(6), 727-733. DOI: 10.1016/j.jadohealth.2017.01.002.
- English, A., Bass, L., Boyle, A.D., & Eshragh, F. (2010). *State Minor Consent Laws: A Summary*. 3rd ed. Chapel Hill, NC: Center for Adolescent Health & the Law.
- Ford C.A., Davenport A.F., Meier A., & McRee A.L. (2011). Partnerships between parents and health care professionals to improve adolescent health. *Journal of Adolescent Health, 49*(1), 53-57. DOI: 10.1016/j.jadohealth.2010.10.004.
- Ford, C., English, A., & Sigman, G. (2004). Confidential health care for adolescents: position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 35*(2), 160-167.
- Gilbert, A. L., Rickert, V. I., & Aalsma, M. C. (2014). Clinical conversations about health: The impact of confidentiality in preventive adolescent care. *Journal of Adolescent Health, 55*, 672–677. doi:10.1016/j.jadohealth.2014.05.016
- Gray W.N., Schaefer M.R., Resmini-Rawlinson A., & Wagoner S.T. (2018). Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology, 43*(5), 488-502. DOI: 10.1093/jpepsy/jsx142.
- Hargreaves D.S., Elliott M.N., Viner R.M., Richmond T.K. & Schuster M.A. (2015). Unmet health care need in US adolescents and adult health outcomes. *Pediatrics, 136*(3), 513-520. DOI: 10.1542/peds.2015-0237.
- Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs, 32*, 207–214. doi:10.1377/hlthaff.2012.1061
- Irwin, C. E., Adams, S. H., Park, M. J., & Newacheck, P. W. (2009). Preventive care for adolescents: Few get visits and fewer get services. *Pediatrics, 123*, e565–e572. doi:10.1542/peds.2008-2601
- Kim, B., & White, K. (2018). How can health professionals enhance interpersonal communication with adolescents and young adults to improve health care outcomes?: systematic literature review. *Journal of Youth and Adolescence, 23*(2), 198-218.
- Kirkpatrick, J. D., & Kirkpatrick, W. K. (2016). *Kirkpatrick's four levels of training evaluation*. Alexandria, VA: ATD Press.
- Lebrun-Harris L.A., McManus M.A., Ilango S.M., Cyr M., McLellan S.B., Mann M.Y., & White P.H. (2018). Transition planning among US youth with and without special health care needs. *Pediatrics, 142*(4), e20180194. DOI: 10.1542/peds.2018-0194.
- Rosen, D.S., Elster, A., Hedberg, V., & Paperny, D. (1997). Clinical preventive services for adolescents: position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 21*(3), 203-214.
- U.S. Preventive Services Task Force. (2014). *The Guide to Clinical Preventive Services*. Rockville, MD: Agency for Healthcare Research and Quality.
- White P.H., Cooley W.C.; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; & American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 142*(5), e20182587. DOI: 10.1542/peds.2018-2587.

Core Components

Interested parties purchase either the *PATCH for Teens* and/or the *PATCH for Parents* Toolkit via www.patchprogram.org; one authorized facilitator per Toolkit. Each Toolkit contains all the information, materials, and resources needed to facilitate an interactive, educational session with its intended audience(s). A Facilitator Guide provides detailed information about how to utilize and integrate the Toolkit into existing programming, and a script gives step by step instructions and sample language to utilize when facilitating a session. Additional facilitation materials (e.g., Activity Sheets, Emoji Booklets, Video Clips, brochures, take-home activities, and evaluations) are also included. While printed copies are sent in the mail, electronic versions are provided at PATCH Online. PATCH Online provides Facilitators access to downloadable materials, additional resources, and an interactive platform (PATCH Chat) to connect with PATCH Staff and other individuals across the nation who are also using the Toolkits. Facilitators are given a User ID and temporary password upon purchase.

Practice Activities

Core Component	Activities	Operational Details
Exploration and Assessment	Determine contextual fit and feasibility factors	Consider asking questions such as: <i>To what extent can the PATCH Toolkits enhance existing efforts? Who is best suited to implement successfully? How can this practice be sustainable?</i>
Installation and Preparation	Secure needed resources; Purchase Toolkit(s); Review Facilitator Guide & Contents; Prepare for Implementation	Determine who is going to support, implement, and sustain these efforts. Interested parties purchase the <i>PATCH for Teens</i> and/or the <i>PATCH for Parents</i> Toolkit via www.patchprogram.org ; one authorized facilitator per Toolkit. Facilitator reviews Toolkit(s) in its entirety to determine integration, adaptations, and appropriate implementation plan.
Implementation	Plan, implement & evaluate programming	Determine and plan for session logistics (e.g., promotion, location, and time) and considerations (e.g., specific needs of audience and tailored resources). The included script serves as a step-by-step guide, providing sample instructional language, activities, and resources for an interactive and educational session. The time needed to facilitate a session depends on various factors such as group size, learner needs, and how much discussion is encouraged, although sessions typically range from 45 to 90 minutes. Facilitators may also consider doing multiple mini-sessions instead of a longer, single lesson. While the <i>PATCH for Parents</i> session requires no to low technology, the <i>PATCH for Teens</i> session incorporates short youth-driven videos featuring PATCH youth. The videos deliver core content in a virtual peer-to-peer format, while supplemental activities (led by the onsite Facilitator) help teens comprehend, debrief, and apply the information. Facilitators are highly encouraged to evaluate the impact of their efforts and are provided two outcomes-based methods to choose from based on audience and specific need. Additional incentive is provided to those who share their anonymous data with the PATCH Program to aid in program improvement efforts.
Sustainability	Monitor, learn from, and improve upon ongoing implementation	Facilitators are encouraged to be creative and innovative to ensure the content meets the needs and priorities of their community, while staying true to the overall goal and messaging. PATCH's interactive, online platform (PATCH Chat) provides space for those across the nation implementing the Toolkits to share lessons learned, best practices, and new strategies for implementation. Facilitators are also encouraged to work with other people and organizations who have an interest in adolescent health to further their reach and impact (e.g., providing resources and linkages to external community resources).

Evaluation and Effectiveness

Both the *PATCH for Teens* and *PATCH for Parents* Toolkits underwent an initial pilot phase to examine feasibility, time, effectiveness, and adaptations needed based on different populations and settings.

The *PATCH for Parents* Toolkit was pilot tested with small cohorts of program supporters (e.g., parents of PATCH youth) and revised before being integrated into existing Wisconsin-based family engagement efforts. Several changes in funding and priorities among grantees have hindered the momentum of being able to gather quality data; yet, we remain dedicated to determining effectiveness and seek ongoing opportunities to evaluate this resource at large.

The findings from the *PATCH for Teens* Toolkit pilot project, which included 10 school-based health professionals from 6 Wisconsin school districts reaching 430 adolescents, are published in the *Journal of School Nursing*:

Aeschbach CJ, Burrough WB, Olejniczak AB, Koepsel ER. Teaching adolescents to manage their own health care. *J Sch Nurs* 2019. DOI: 10.1177/1059840519867363.

A few publication excerpts are provided below:

As a result of the lesson, over two thirds of students reported that they plan to be more involved in their health care (69.8%), advocate for themselves (68.0%), talk openly and honestly with health care providers (71.9%), and learn more about how to manage their own health care (68.6%).

The following quotes represent the statements made by students: "I will take more control of my health care. I will ask more questions, and make sure I understand what is going on in a health care situation" (15 year-old, white male); "...I can be an advocate for myself. If I don't feel comfortable or they aren't listening I can help stand up for myself and say what is right" (15-year-old, biracial female).

Variances among age, racial, and gender groups were documented. Younger students reported more significant changes in knowledge-based measures, which may be linked to health literacy levels and first exposure to the information. Students who self-identified non-White were also more likely to report newfound knowledge but ranged on their intended behaviors. It is assumed that cultural norms and previous health-care experiences may have attributed to their responses. Furthermore, students who self-identified as female indicated higher intentions of responsibility and self-advocacy over their self-identified male counterparts which could be associated with their level of utilization and comfort in health-care settings.

Although time was a significant barrier, facilitators were able to easily adapt the lesson to ensure all the core content was covered to meet their student's learning needs. Both facilitators and students believed the topic was important and beneficial to address, especially since transition of health-care responsibility is not often clearly taught to youth.

Based on input and findings from these initial pilot projects, Toolkits were revised before being released to the growing network of professionals who are integrating these resources into their existing efforts.

As these initiatives have moved into larger-scale implementation, we internally continue to review and assess the Toolkit contents based on evidence, guidelines, standards, and emerging trends. We are also committed to ongoing data collection, analysis, and dissemination – highly encouraging all Facilitators to opt-in to the program's evaluation efforts by sharing any anonymous data that has been collected.

Each Toolkit contains two evaluation methods: a session survey and an exit slip. Facilitators are asked to choose *one* method based on audience and intended purpose. The evaluation survey assesses participants' self-perceived changes as a result of attending the session (e.g., Because of PATCH, I now know... and Because of PATCH, I intend to...), as well as space to provide feedback for implementation improvements; the exit slip is simply one-question used to determine participants' main takeaway(s). We work with those who choose to share their anonymous data with us to ensure the data-sharing process is simple and efficient based on each individual's capacity and needs. In return, they receive a 25% discount on PATCH merchandise (e.g., educational brochures and program swag). We also are working to develop a community of practice by incorporating an online, interactive platform (PATCH Chat) for Facilitators to connect with PATCH Staff and other individuals across the nation who are also using the Toolkits. PATCH Chat is another way to gather implementation feedback, input and best practices.

To date, evaluations from these short, one-time sessions have shown promising self-perceived change in participant knowledge, confidence, and intended behavior.

Replication

These Toolkits have been created specifically for replication in several settings and have been implemented among various populations. Facilitators (i.e., those in schools, community- and faith-based organizations, businesses, health care systems, and public health agencies) are encouraged to be creative and innovative to ensure the content meets the needs and priorities of their community, while staying true to the overall goal and messaging.

Section II: Practice Implementation

Internal Capacity

One Facilitator is authorized and responsible for delivering PATCH content. With the information provided in the Toolkit(s) and support provided by the PATCH Program, Facilitators should be well-equipped to deliver an empowering and interactive health education session.

Collaboration/Partners

Facilitators should understand the needs, priorities, people, resources, and organizations who may help or hinder their success in implementing the Toolkit(s). With guidance from the PATCH Program and others implementing these resources, Facilitators are encouraged to work with others who have an interest in adolescent health to further their reach and impact (e.g., providing resources and linkages to additional community resources).

As a program at large, it is our intent to foster cross-sector collaboration to reach and educate adolescents and their families. By partnering with schools, community- and faith-based organizations, businesses, health care systems, and other unique sectors, it is our hope to provide youth-driven materials, resources, and information that will help prepare adolescents for health care transition and managing their own health care.

Practice Cost

Each Toolkit costs \$250 or \$450 if purchased as a bundle (i.e., both purchased at the same time). Some organizations have had grants to cover strategic Toolkit distribution within their

community, while others have had organizations who sponsor and pay for the Toolkit to be used in a specific setting or priority population.

Practice Timeline

Upon purchase, Facilitators gain access to downloadable materials and resources via PATCH Online. Printed copies are mailed within 7-10 business days. Implementation timelines vary and is up to the discretion of each Facilitator.

Resources Provided

Toolkit Contents		
Item	Brief Description	Quantity
Facilitator Guide	Spiral-bound document that provides detailed information about how to use the associated Toolkit and its contents	1 per Toolkit
Workshop Script	Step-by-step instructions and sample language to utilize when facilitating an educational session	-
Participant Activity Sheet	A worksheet providing participants a space to write or draw notes and participate in workshop activities	Can be copied from Toolkit or downloaded for print at PATCH Online
Emoji Booklets	An interactive teaching tool providing a way for teens to choose and share their emotional response to questions, scenarios, and activities in the form of an emoji.	30 in the <i>PATCH for Teens Toolkit Only</i>
PowerPoint Template	A supplemental facilitation tool that can be downloaded and customized.	-
Additional Activity Materials	Additional facilitation resources are provided as needed to implement with success.	-
Workshop Evaluations	Two different methods are provided to help facilitators measure impact and gather participant feedback.	-
Teens Brochures – “Getting the Health Care You Need & Deserve”	A resource helping teens understand the importance of health care and the steps they can take to start becoming responsible managers of their own care.	50 per Toolkit
Supportive Adult Brochures – “Your Teen’s Right to Privacy in Health Care Settings”	A guide helping parents, guardians, and other caregivers understand the health care rights and responsibilities of teens in health care settings.	50 per Toolkit
Transition Checklist	A take-home resource helping families understand the important skills a teen should have so they can successfully manage their own health care as an adult.	Can be copied from Toolkit or downloaded for print at PATCH Online
Dear Provider Letter	A take-home resource to help facilitate healthy conversations between teens, their health care providers, and their parents/guardians/caregivers.	Can be copied from Toolkit or downloaded

		for print at PATCH Online
Access to PATCH Online & PATCH Chat	Facilitators receive a unique User ID and password to access downloadable materials, videos, and resources, as well as access to PATCH Chat, an online forum to communicate with others using these Toolkits.	One authorized user receives a unique User ID and password

Lessons Learned

1. Need: Ongoing research and feedback from the projects have indicated a significant gap being addressed by the *PATCH for Teens* and *PATCH for Parents* Toolkits, and the need for the fundamental and basic information covered in these short health education sessions has become quite apparent. Furthermore, when used simultaneously, these resources can help parents and teens gain a mutual understanding and basis for ongoing conversations about health care.
2. Interdisciplinary: By addressing the underlying factors impeding important interpersonal communication in health care settings, various quality improvement initiatives see the benefit of using the Toolkits to address their specific goals and outcomes (e.g., health care transition, mental health, and sexual health). The ability to foster cross-sector collaboration towards a common goal is exciting and holds great potential.
3. Time: Time constraints and competing priorities can be significant barriers to adoption and implementation of a new practice. The Toolkits have served as a guide and have provided flexibility based on individual circumstances. The initial preparation and planning phase is, inevitably, most time consuming. However, once Facilitators are familiar with the content and have implemented a few times, it naturally becomes less and less burdensome.
4. Parent Engagement: Unlike youth, there often is not a universal space where parents congregate (e.g., school) which forces Facilitators to be more innovative and creative in their efforts. The well-documented barriers of parent engagement are also applicable to the *PATCH for Parents* Toolkit.
5. Fidelity: Facilitators are not staff and have purchased the product. As a result, one of the major trade-offs is the inability to fully control implementation fidelity.

Next Steps

Evaluation, monitoring, and ongoing quality improvement efforts are extremely important and central to our work. PATCH Staff annually reviews and revises (as deemed necessary) Toolkit content and materials. We are also in the process of trans-creating the *PATCH for Teens* and *PATCH for Parents* Toolkits for Spanish-speaking populations. We strive to keep the program relevant in an ever-changing society, and aim to meet the growing demands of a heterogeneous adolescent population. We take into consideration evaluation data, recent evidence-base, and community/key stakeholder input. Our original Wisconsin-based PATCH communities serve as our model while we explore ongoing adaptation, pilot new material and programs, and continually improve upon our current efforts.

Practice Contact Information
<p><i>For more information about this practice, please contact PATCH Program Staff at staff@patchprogram.org or visit www.patchprogram.org</i></p>