Six Core Elements of Health Care Transition™ 3.0

An Implementation Guide

Transitioning Youth to an Adult Health Care Clinician

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How to Implement the Six Core Elements of Health Care Transition™

Introduction

The Six Core Elements of Health Care Transition™ (HCT) offer a structured approach for pediatric-to-adult transitional care recommended by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) Clinical Report on HCT.[1] This approach incorporates a set of steps and sample tools for transition planning in pediatric care, transfer to adult care, and integration into adult care. Having a structured HCT process has been shown to significantly improve population health, patient experience, and health care utilization[2] and has been successfully incorporated into many different health care settings for youth and young adults with and without chronic physical, developmental, and behavioral health conditions.[1]

The goal of the Six Core Elements approach is to guide systems of care and health care professionals and clinicians in improving the ability of youth and young adults to manage their own health and safely and effectively use health care as they transition to an adult approach to care and/or to an adult clinician, all while partnering with youth, young adults, and their families in the process. To implement the Six Core Elements, quality improvement (QI) methods are recommended. The Model for Improvement, developed by the Associates in Process Improvement, is one such framework (www.IHI.org), which is used in this implementation guide. This guide can be used as a resource for payers, managed care organizations, health care systems, public health professionals, and individual clinicians as they implement a structured HCT improvement process.

How to Use This Implementation Guide

There are three Six Core Element packages:

- ***Transitioning Youth to an Adult Health Care Clinician*** for use by pediatric, family medicine, and med-peds clinicians
- ***Transitioning to an Adult Approach to Health Care Without Changing Clinicians*** for use by family medicine and med-peds clinicians
- ***Integrating Young Adults into Adult Health Care*** for use by clinicians caring for adults, including family medicine and med-peds clinicians

This guide is a supplement to the *Transitioning Youth to an Adult Health Care Clinician* package and is organized into nine steps a health care delivery system or individual practice can consider when implementing a QI process for HCT. To access guides for the other two packages, click here.

Systems/clinicians can draw on the practical ideas presented in this guide when developing a HCT implementation plan, when experiencing challenges, or when the way forward seems unclear. The plan should be customized to fit the system/practice resources, patient population, health care setting and the local context. For example, the scope of Pediatrics/ Internal Medicine/Family Medicine/General Practice is different in different countries and thus the transition process needs to be locally adapted.

Note: The term "practice" will be used generically throughout the guide, and some of the points in each of the steps need to be interpreted in light of the size of your practice/health care delivery or public health system/program.

The implementation steps are outlined below with suggested strategies and tips and include:

Step 1: Secure Senior Leadership Support
Step 2: Form the HCT Quality Improvement Team
Step 3: Develop an HCT Improvement Plan
Step 4: Raise Awareness About HCT Activities
Step 5: Implement the Six Core Elements of HCT
Step 6: Plan for Sustainability
Step 7: Plan for Spread
Step 8: Communicate Successes
Step 9: Tips for Success

Step 1: Secure Senior Leadership Support

Obtaining senior leadership support within your system or practice before your HCT QI project starts, or shortly thereafter when you have identified the key HCT gap areas in your system/practice to focus on, is essential. To gain their support, align your HCT priorities with existing practice, departmental, or health system priorities – e.g., discuss how investing in HCT will help with retention of young adult patients, improve patient satisfaction, meet criteria for medical home certification, and increase adolescent and young adult primary care access and preventive care use. In addition, provide data on the need for HCT, such as the number of youth who will need transition services over the next 5 years in your system/state/practice or the percentage of youth not receiving HCT services from health care providers in your state from the National Survey of Children's Health. Make leadership aware of the evidence that population health, satisfaction, and utilization outcomes are improved with a structured HCT approach. Further, have the practice/system of services fill out Got Transition's Current Assessment of HCT Activities to show where the practice/system of services is in implementing the evidence-informed Six Core Elements approach. Be sure to share any data about HCT gaps in your practice/system of services in a clear, concise manner. Personal stories about youth/young adults/parents/caregivers experience with HCT are useful as well.

Gaining explicit support of key senior leader(s) who are in a position to develop long-range goals means they are willing to:

- Back the project publicly and actively
- Align with other strategic activities
- Ensure dedicated time for both administrative support and the clinical transition improvement team to pilot incorporating the Six Core Element approach into the clinic process including utilizing appropriate billing codes[3]
- Ensure availability of resources, such as health information technology
- Endorse/guide expansion from pilot to full implementation
- Communicate with other senior leader counterparts when needed (e.g., between pediatric and adult institutions or settings)

Step 2: Form the HCT Quality Improvement Team

Implementing and sustaining changes in your practice requires strong, effective partnerships. These partnerships should not only be within your practice but also with adult partners and community-based organizations. You will need a dedicated team. This team should be led by a practice employee who is vested with the authority to coordinate the team's efforts and implement practice changes. The most effective teams include representatives from clinical and administrative staff, and families, youth, and young adults.

A. Identify Team Members

Choose an energized and empowered team leader

The team leader must have both enthusiasm for QI and the clout to spearhead practice change. If the team leader is not part of the practice's senior leadership, senior leadership must make it clear that the team leader has the authority to lead. In addition, the team leader should be able to facilitate input from all team members, including families and youth/young adults.

Involve key stakeholders

Key stakeholders include, but are not limited to, pediatric care champion(s), adult care champion(s), care coordinators, parents/caregivers, and youth/young adults. Having a youth/young adult patient and/or parent/caregiver on the team is essential. These team members can provide invaluable first-hand insight on what they experience and how systems and communication can be improved. To identify youth/young adults and parents/caregivers consider the following:

- Ask for volunteers – including current youth or former young adult patients or parents/caregivers of transition-aged youth who are typical of your patient population – to join the HCT improvement team.
- Connect with a family based organization, such as the Family-to-Family Health Information Center in your area/state or other entity that could connect with/find youth/young adults and parents/caregivers.
- Provide compensation unless they are paid staff members.
- Be flexible about meeting times and modalities (phone, Skype) to accommodate participation.
- Consider recruiting more than one youth/young adult and parent/caregiver so their views and opinions are always represented.
- Articulate roles and provide training, if needed (including from other consumers who have taken leadership roles in the practice)

Include at least one motivated and respected representative from each area of your practice/system

In small practices, it often works best to include most or all of your clinical and administrative staff members. In large practices, it is important to include at least one representative from each area of your practice. Team members may include but are not limited to:

- Clinician
- Nurse
- Social worker
- Medical assistant
- Practice manager
- Front office staff
- Billing staff/payers
- Community-based organization that, for example, can assist in providing services in your transition process such as patient education.
- Public health programs that, for example, can assist by raising awareness around HCT needs and improving services
- Others (as part of the team or to participate on *ad hoc* basis) such as epidemiologists, care coordinator/key support staff, clinic support staff from both pediatric and adult practices/clinics, electronic medical record (EMR) representative, data administrator who can pull system/practice data to support the initiation and evaluation of the process, senior leader, or payer. While a data person and an EMR analyst don't need to attend all the meetings, they are critical as the process evolves, so plan on and budget their involvement early.

Tip: If you've done QI work before, build on former or existing teams to populate your HCT team.

Keep the size of your team manageable
A team with more than 12 members can make it hard to get things done.

B. Bring Team Members Together

- Have an initial meeting to introduce the topic and educate your team, introduce the Six Core Elements package and its sample tools, and review the goals of implementing HCT in your practice.
- Ask at least one or two team members to review the full Six Core Elements package carefully to become familiar with its contents.

C. Have Subsequent Meetings and Establish Routine Reporting

- Schedule regular team meetings. Frequent meetings may be needed at the outset (e.g., twice a month). Meetings can take place less frequently once your implementation activities are underway.
- Early on and throughout the process, it is important to clarify each team member's role and responsibilities.
- Report progress on a monthly basis in a templated format, including data, to the practice's senior leadership to maintain accountability and team engagement.

Step 3: Develop an HCT Improvement Plan

Prior to beginning your HCT improvement plan, assess your practice's current implementation of the Six Core Elements using Got Transition's Current Assessment of HCT Activities or HCT Process Measurement Tool (see *here*) to obtain a baseline. This will help your practice identify current strengths and areas for improvement. Once you assess your practice using either the

Current Assessment or HCT Process Measurement Tool, prioritize your area of focus. For example, you may decide to start with Core Element 1 and progress through each of the Six Core Elements, or your assessment may indicate you need a different prioritization. You do not need to focus on all of the Six Core Elements at the outset, nor do you have to aim to reach the highest score for each of the core elements you prioritize (e.g., Level 4 in the Current Assessment of HCT). It is important to develop goals that are realistic and achievable for your practice.

During the plan development process, keeping an eye on where the youth will transfer is important. Develop a strategy to maintain a database of interested adult providers, and who will curate it and how often. This will help all involved in the process.

To start the HCT improvement plan, use a known improvement methodology. The Model for Improvement has been adopted by many health care organizations for its simple but robust model (see *QI Primer* for more detail). Consider practice/system strategies or initiatives that can help to push the project forward.

Include an overall aim, specifying the following (see *QI Primer* for more detail)**:**

- Scope (single clinic, primary care, specialty care, institution-wide)
- Population – e.g., all youth vs. youth with special health care needs vs. youth with selected conditions vs. all young adults 20 and over
- Timeline for improvement activities (what you need to do and how it will get done)
- Measurement plan (what data are needed to show improvement?) (see *here* for more information)
  Note: The Current Assessment of HCT or HCT Process Measurement Tool can be used as part of that measurement plan to assess process improvements over time and fidelity to the Six Core Elements. Other measures could include an HCT experience survey, using for example Got Transition's HCT Feedback Survey, that could be anonymously given out after the initial visit to the adult practice.

Step 4: Raise Awareness about HCT Activities

Plan and conduct educational activities to help the members of your practice and youth, young adults, and parents/caregivers become more aware about transitioning youth to adult care, why it is important, how it affects your patients, and how you can work together to make transition improvements.

For example:

- Hold learning sessions over lunch or other already scheduled times to introduce professional recommendations and build buy-in for this work.
- Use the results from your baseline assessment of the practice's implementation of the Six Core Elements to demonstrate the need.
- Try quick reminders to help your practice develop knowledge and skills in a particular area of transition. For example, some reminders could be having a list of potential adult providers or a laminated card that shows which specialists transition when.

- Discuss at practice team meetings, huddles, and other opportunities to teach and reinforce HCT strategies.
- Make information and resources readily available and visible to keep practice staff members and youth, young adults, and parents/caregivers engaged in transition work.
- Publicly display information (e.g., in the waiting room) and share resources to raise awareness of the importance of HCT to youth, young adults, and parents/caregivers.
- Find a bright spot – a youth who has made the transition and can help inform what worked and what were barriers.

Step 5: Implement the Six Core Elements of HCT

Start by reviewing each of the Six Core Elements in light of what your assessment reveals and your decision about what areas to prioritize. Be sure the tools for each of the Six Core Elements go through a QI process, such as a plan/do/study/act (PDSA) cycle (see *QI Primer* for more detail), to ensure the staff, youth, and parents/caregivers have a chance to review, "try out," make changes, and approve. Decide how to incorporate tools into clinic work flow and test in a similar PDSA cycle process so that if the clinician champion is not there, the transition process still moves forward.

The Implementation Guide for each of the Six Core Elements is organized into the following sections:

I. Purpose, Objectives, and Considerations
II. Quality Improvement Considerations, Tools, and Measurement
III. Sample Tools
IV. Additional Resources

Implementation guides for each of the Six Core Elements can be accessed here.

In addition, the QI Primer contains additional examples and materials. It further outlines how to use improvement science to improve your transition process.

The QI Primer has the following sections:

I. What is Quality Improvement?
II. Selecting Improvement Projects
III. Successful Teams
IV. The Model for Improvement
V. Measuring for Improvement
VI. Tools for Improvement
VII. Sustaining Improvement
VIII. Spreading Improvement
IX. Health Literacy
X. Co-Production
XI. Resources and References
Appendix

Step 6: Plan for Sustainability

Once your data shows that you have reached the goal you set for six months you should think about sustaining your work. If not, it is common for processes to erode and in one or two years find yourself starting over.

There are five key strategies to support sustainability:

1. Assign a process lead. This person can be someone on the original team or another member in the practice. They are responsible for calling team meetings when needed, monitoring the data for any slippage, and planning any new tests that may need to be completed.
2. Hardwire the process into the practice. Make sure people are trained and know what to do and ensure training for new staff. Crosstrain critical steps of your process so success does not depend on one person. Encourage people to build generic tools that can be used across divisions.
3. Continue to measure but less frequently, eventually only twice a year.
4. Update your leadership periodically to keep the work visible. Finally, use the sustainability checklist found in the QI Primer.
5. Consider the financial aspects of transition in creating your sustainability plan, e.g. better coding, the financial model used at your site (fee-for-service, accountable care, or value-based payment, etc.).

Step 7: Plan for Spread

Depending on how you implemented the core elements, you may need to plan for spread. Do you need to spread to other physicians, other practices, other specialties, or throughout a health care system? Create a plan for spread. Who is the target for the spread? Identify your opinion leaders, messengers, and allies. Is there both senior leadership and front line leadership for spread? Is improvement methodology understood by the target areas? Allow testing of any generic tools you've created and allow further adapting to the spread practices. You can spread one element at a time, or all six simultaneously. Identify a spread champion who can help the other providers and/or practices throughout the process. If possible, target your early adopter providers or practices first. Find your opinion leaders or influencers to help. Engage both front line leadership and formal leadership for resources. Identify what measures are needed to demonstrate successful spread. They may be the original measures, and/or any additional measures (see *here* for more information). Use the spread checklist found in the QI Primer.

Step 8: Communicate Successes

There is a saying in improvement work: communicate five ways five times. Communication is critical in all aspects of the work. During testing, raise awareness so other practice members and patients are aware of the work. Use your run charts in breakrooms, on posters, etc. Honor those who are doing the front-line work. During implementation, communicate the wins and the progress within the practice. During sustaining, communicate the data, any new modifications, and continued wins. And finally during spread, communicate the timing, the

plan, the deliverables, and the specific changes to be spread. Find ways to communicate your success: post run charts, send newsletters to youth/young adults and parents/caregivers, apply to institutional quality events, consider publishing or presenting at regional or national programs, etc. If you have access, include public relations and marketing departments. Consider working with your state Title V program to communicate and disseminate your successes.

Step 9: Tips for Success

- Make sure there is a champion for transition improvement in the practice.
- Select which of the Six Core Elements to use based on your practice's needs and capacities.
- Do not try to do too much too quickly. Practices that try to implement too many changes at once risk doing none of them well. Do not lose sight of the fact that your long-term goal is to redesign your systems to improve patient care, which takes longer than making incremental changes.
- Develop a registry so the team can keep track of the activities being offered to which youth/young adults.
- Connect with other transition improvement efforts regionally and/or nationally to learn and share best practices.
- Do not forget to measure and track progress for each core element. This step is critical to help you implement successful transition changes in your practice.
- Linking implementation activities for two or more of the Six Core Elements can foster efficiencies and bring about added clarity and connectedness for your practice staff.
- Choose Core Elements that can build on or complement other QI and/or practice transformation efforts, such as Patient-Centered Medical Home certification. Connecting these efforts can help staff to see transition work as a logical extension to existing efforts.
- Communicate progress regularly. Ways to do this include updates at staff and team meetings, posters in the waiting room explaining the project, participation in a learning collaborative, or direct reporting to a practice improvement committee. These activities can help build and support for this work.
- Plan a process that starts early (ages 12-14), but also plan a fast track process for "20-21 year olds" still in the pediatric system who need to transfer within the next year.
- It is important to have early wins to test the process. Consider not beginning with youth/young adults with complex conditions as the initial pilot population as they often require multiple transfers.

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[1] White, PH, Cooley, WC, Transitions Clinical Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.

[2] Schmidt A, Ilango SM, McManus MA, Rogers KK, White PH. Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of Pediatric Nursing*. 2020;51:92-107.

[3] McManus M, White P, Schmidt A, Kanter D, Salus T. *2020 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care.* Washington, DC: Got Transition and American Academy of Pediatrics, March 2020.

Transitioning Youth to an Adult Health Care Clinician

Core Element 1 - Transition and Care Policy/Guide

I. Purpose, Objectives, and Considerations

Purpose

A transition and care policy/guide is the first element in the Six Core Elements of Health Care Transition™ (HCT). The transition and care policy/guide is intended to be shared with youth and parents/caregivers early in adolescence and periodically repeated. Developed by your practice or health system, with input from youth and parents/caregivers and staff, the policy/guide formalizes the practice/system approach to HCT. It represents a consensus among the practice staff and youth and parents/caregivers about the HCT approach involved. It can also represent structure for evaluation. It should be at the appropriate reading level, offered in languages common among your clinic population, and concise (no more than one page). *See sample transition and care policies/guides in Section III.*

Objectives

Develop a transition and care policy/guide with input from youth and parents/caregivers that describes the practice's approach to transition, an adult approach to care in terms of privacy and consent, and age of transfer to an adult clinician.

Educate all staff about the practice's approach to transition and the distinct roles that youth, parent/caregiver, and the pediatric and adult health care team play in the transition process, taking into account cultural preferences.

Display the transition and care policy/guide somewhere accessible in practice space, discuss and share with youth and parent/caregiver, beginning at age 12 to 14, and regularly review as part of ongoing care.

Considerations

CONTENT

What should be included in the transition and care policy/guide?

Below are some questions and ideas to think about.

- *At what age will your practice start the HCT planning process?*
- *When are youth expected to leave your practice?*
- *What will your practice offer youth and parents/caregivers to assist them in transition—e.g., a readiness assessment, plan of care that includes transition, medical summary, transfer package?*
- *What will your practice do to prepare youth for changes in privacy and consent that happen at age 18?*
- *Will your practice have them sign a HIPAA form to allow others to be present in their visit or see their health records?*
- *What does your practice offer to assist youth and parents/caregivers to consider if there is a need for supported decision-making and how to begin the legal process, if needed? For more information about resources, see the National Resource Center for Supported Decision-Making and The Arc.*
- *Does your practice have information for youth and parents/caregivers on sensitive services available for youth in your state?*
- *Does your practice have information for parents/caregivers to let them know when they no longer have legal access to their youth's electronic medical records on the practice's portal?*

PROCESS

What is the process to develop the transition and care policy/guide?

Below are some questions and ideas to think about.

- *Does it describe the practice's approach to transition, including privacy and consent information?*
- *Is the reading level appropriate for your youth and parents/caregivers?*
- *Test the policy/guide with 1-3 youth and parents/caregivers and consider asking:*
  - *Are there any words you do not understand?*
  - *What does this policy/guide mean to you?*
  - *How could the policy/guide be clearer?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

What is the process to implement the transition and care policy/guide?

Below are some questions and ideas to think about.

- *Whose job is it to share and discuss the HCT policy/guide with the youth and parent/caregiver?*
- *Whose job is it to ask if the youth and parent/caregiver have any questions?*
- *How do we inform all staff about the practice's approach to transition?*
- *How do we inform all staff about the practice's expectations for youth, parent/caregiver, and pediatric and adult health care teams during the transition process?*
- *How do we discuss with all staff the different ways the practice is taking cultural preferences of their youth/young adults/parents/caregivers into account throughout the transition process?*
- *How often will your practice share the policy/guide during the transition planning process?*
- *Regularly review the policy/guide as part of ongoing care.*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

Examples of Process

1. Mail the transition and care policy/guide to all 12 to 14-year-olds and their parents/caregivers annually.
2. Have the front desk hand out the transition and care policy/guide when all 12 to 14-year-olds and their parents/caregivers check in for their appointment, or when they are waiting in the exam room at their annual preventive visit.
3. Display the transition and care policy/guide on the practice website and on the patient portal or make it a poster to be displayed in the clinic.
4. Include the transition and care policy/guide as part of the after-visit summary in the electronic medical record (EMR).
5. Discuss your practice's approach to transition during a lunch and learn or during a staff meeting.

II. Quality Improvement Considerations, Tools, and Measurement

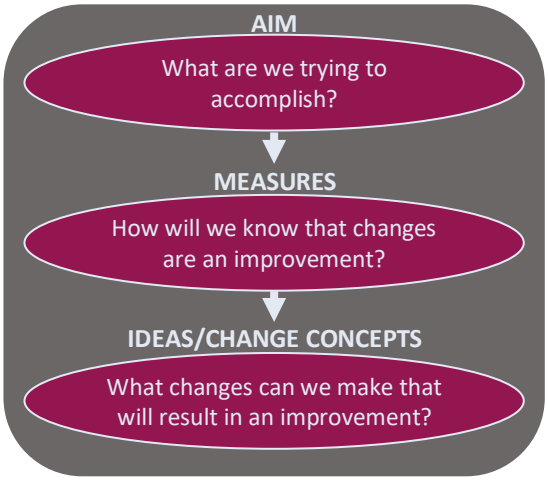
Quality Improvement Considerations

What should be thought about when forming a team? (See *Successful Teams* in the *QI Primer*)

- Include a representative from all areas of your practice
- Include a youth/parent/caregiver whenever possible
- Depending on what you are aiming to improve, consider any ad hoc members you might need (e.g., information services, lab, pharmacy, supply distribution, etc.)
- Schedule meetings or huddles

What is the Model for Improvement?

The Model for Improvement (see *Model for Improvement* in the *QI Primer*) is an approach to process improvement, developed by Associates in Process Improvement, which helps teams accelerate the adoption of proven and effective changes. The figure here illustrates the three questions that make up the Model for Improvement. This is a simple but robust model widely used for improvement in many industries, including health care.



Adapted from Langley GL, et al. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, 2nd ed. San Francisco: Jossey-Bass Publishers, 2009.

As you continue to work through this document and the Six Core Elements, you will find that the QI tools and other items below have been customized to each Element for each kind of practice. However, you will find the basic team considerations described above remain the same for most if not all of your QI work.

Quality Improvement Tools

The most important QI tools to guide a team's improvement work include ***Tools 1-5*** listed below. Using these tools in the following order will increase your chances of success, but teams can make modifications as needed. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

- ***Tool 1: An aim statement*** is a fundamental element of this model and answers the question of what you are trying to accomplish.
- ***Tool 2: Key driver diagrams*** allow teams to visualize the relationship between the project aim and contributing factors, helping them determine key actions necessary to meet this aim.
- ***Tool 3: Process flow maps*** can help you visualize the steps in your change process.
- ***Tool 4: The simplified failure mode and effects analysis*** form helps teams recognize what problems might arise in each step of the process and think of possible solutions.
- ***Tool 5: Plan-Do-Study-Act (PDSA) cycles*** allow teams to trial and learn from their process changes. Using Tools 1-4 before initiating a PDSA cycle helps teams assess root causes before jumping to solutions.

Tool 1: Aim Statement

The aim statement is a written statement that describes the improvement effort and includes the rationale for doing the work, the target population, the time period of the work, and measurable numeric goals. For more information and examples, see *Model for Improvement* in the *QI Primer*.

Example Aim Statement 1

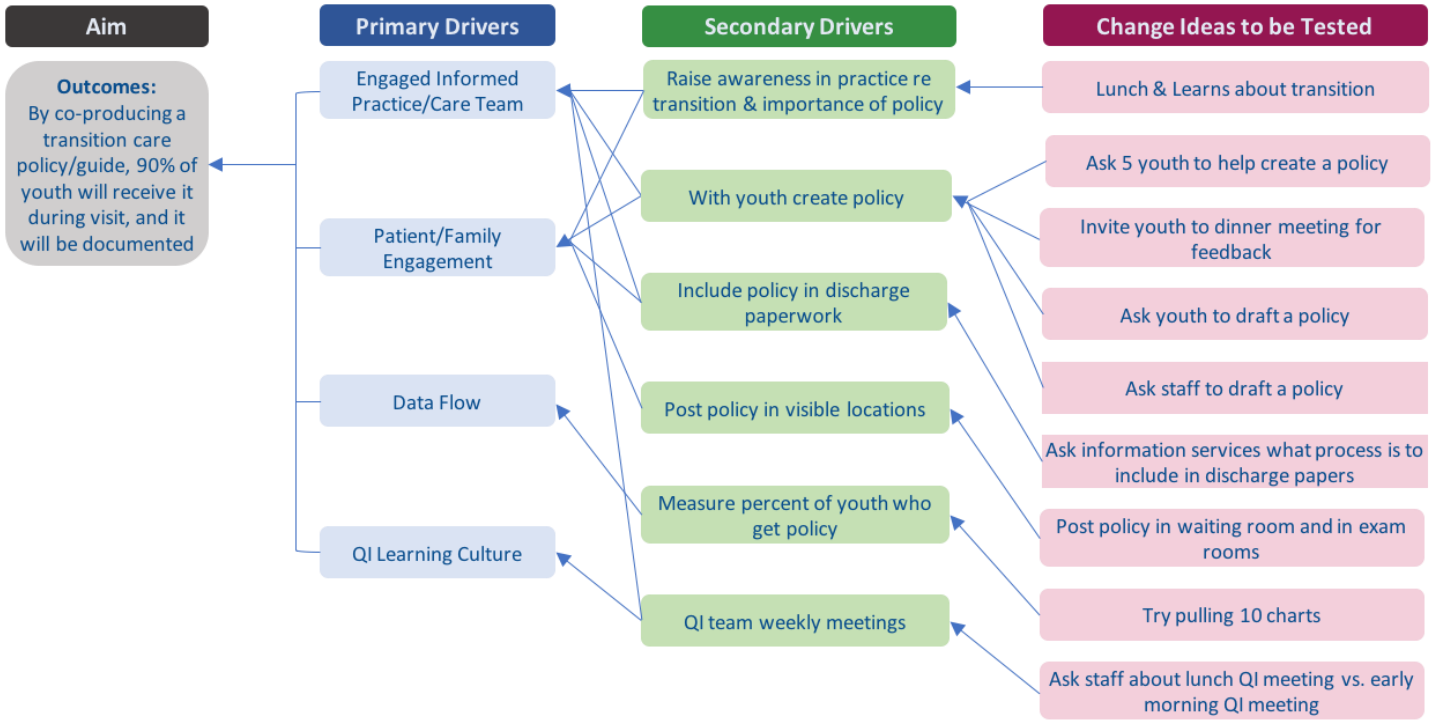
We aim to inform our youth and parents/caregivers about the practice's HCT approach by ensuring they receive our current transition and care policy/guide. By [insert date], 85% of 14-year-old patients and their parents/caregivers will be given the transition and care policy/guide and have this documented in their medical record.

Example Aim Statement 2

Understanding when to transition from pediatric to adult care is important for parents/caregivers. By [insert date], we will co-produce (with youth and parents/caregivers) a transition and care policy/guide, and 90% of youth will receive it during their preventive care visit, which will be documented in their medical record.

Tool 2: Key Driver Diagram

Key driver diagrams (KDDs) require teams to identify their theories or "key drivers" which lead to outcomes. They help teams see relationships and organize work, especially in complex systems. They are frequently used for analysis, organization, and communication to direct improvement work. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



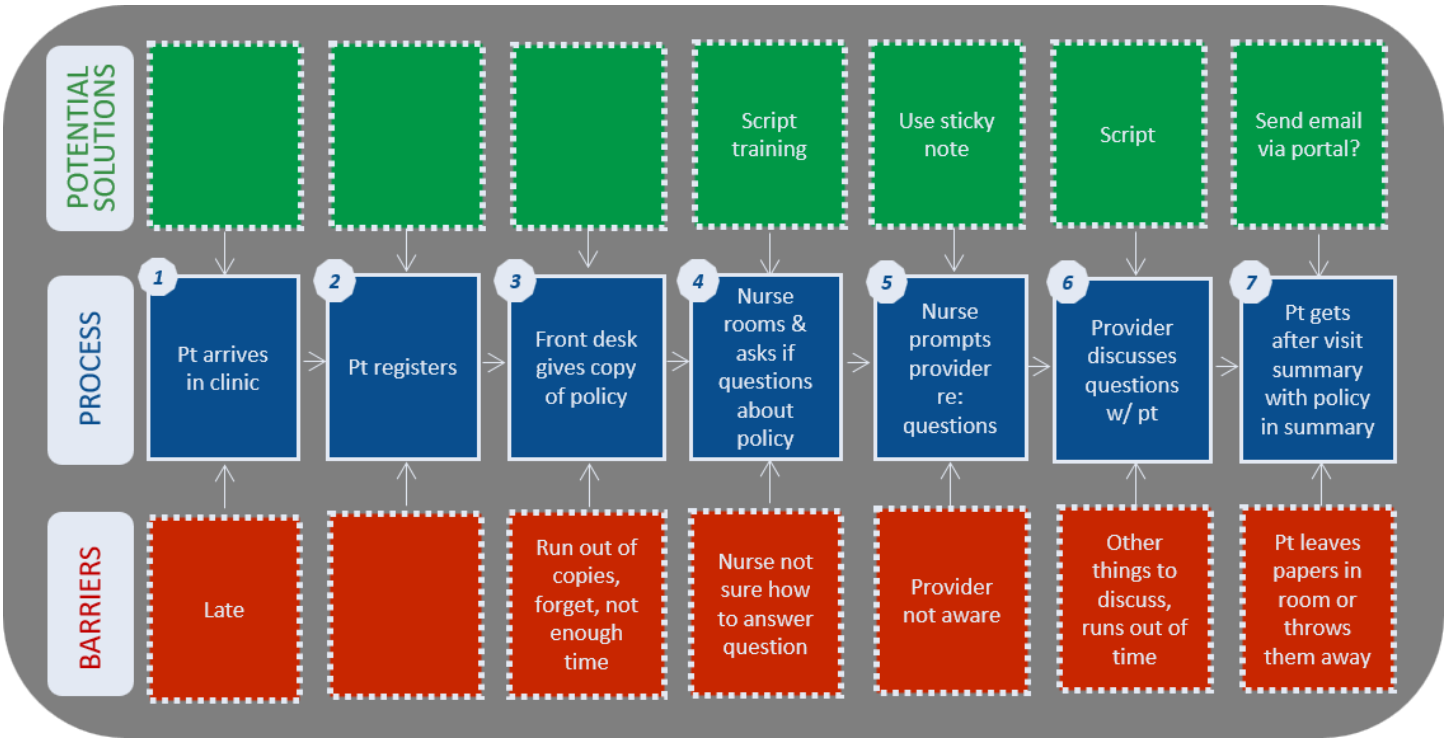
Adapted from ST3P UP, a collaborative sponsored by Patient Centered Outcomes Research Institute® (PCORI) Award MCSC-1608-35861 Titled A Comparative Effectiveness of Peer Mentoring Versus Structured Education Based Transition Programming For The Management Of Care Transitions In Emerging Adults With Sickle Cell Disease.

Tool 3: Process Flow Map

A flow map is a visual display of the separate steps in a process placed in sequential order. It is extremely helpful in documenting different views of the same process. It can show the sequence of actions, materials/inputs entering and leaving the process, decision points, and people involved. Flow maps can be used to document steps in the process of either how things are or how things could be. Posting the flow map gives staff an opportunity to clarify the steps in the process and can uncover conflicting understandings. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

Tool 4: Simplified Failure Mode and Effects Analysis (sFMEA)

Simplified Failure Mode and Effects Analysis (sFMEA) is a proactive method for evaluating a process to identify where and how it might fail and to assess the relative impact of different failures, in order to identify the parts of the process that are most in need of change and help generate ideas to prevent those possible failures. This is a good companion to the flow map – a flow map lets you see the process as it is, and the sFMEA helps you look more closely to identify breakdowns. The example below has a few solutions filled in, to illustrate how teams might start completing an sFMEA. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



Adapted from the copyrighted Simplified Failure Mode Effects Analysis Worksheet (sFMEA) from Cincinnati Children's Hospital Medical Center. This version of the sFMEA has been modified and has been reprinted with permission.

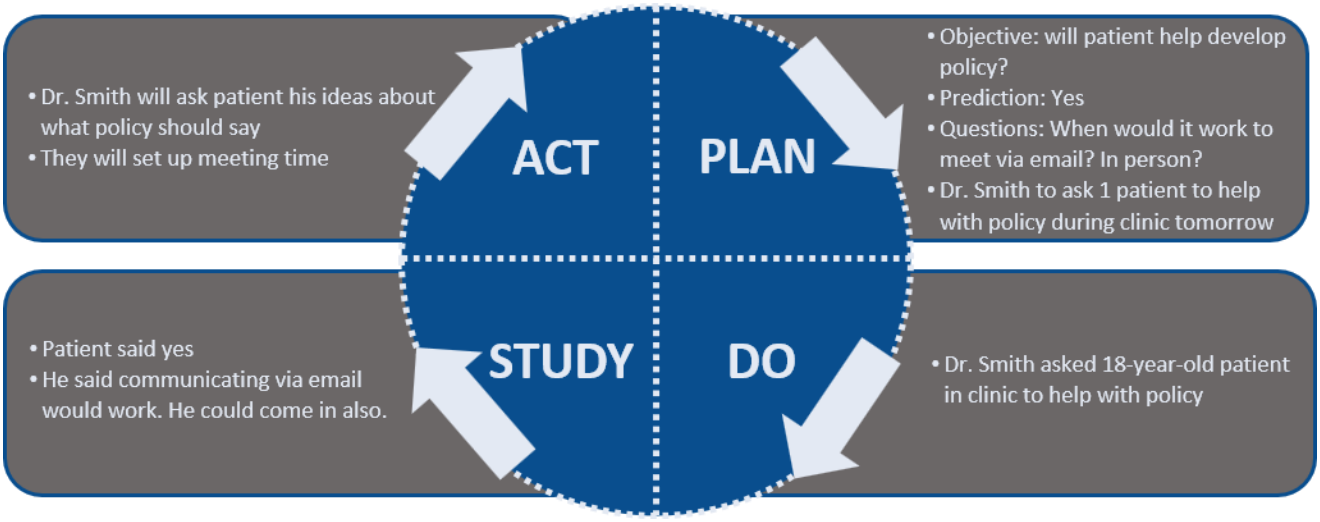
Tool 5: PDSA Cycles

PDSA cycles are a structured test of a process change. These are meant to be done rapidly, for example one patient, one afternoon, with one doctor. To accelerate learning and improvement, small tests with reflection allow for change ideas to be adapted, adopted, or abandoned easily within busy healthcare settings. Learning to do rapid cycle testing is key to keeping the momentum going; it is not necessary to schedule a full separate meeting, just a quick huddle allows teams to plan the next cycle. For more detailed explanation and a blank form, see *Model for Improvement* in the *QI Primer*. This effort includes:

- **Plan** the test: who, what, where, when;
- **Do** try the change and observe what happens;
- **Study** reflect on what was learned from the test; and
- **Act** decide next steps based on the reflection.

Examples of Ideas to Test

- Developing the policy/guide with youth and parents/caregivers
- Posting the policy/guide in the clinic
- Adding the policy/guide to the discharge paperwork



Adapted from AHEC QI 101, a Quality Improvement course sponsored by Charlotte Area Health Education Center.

Quality Improvement Measurement

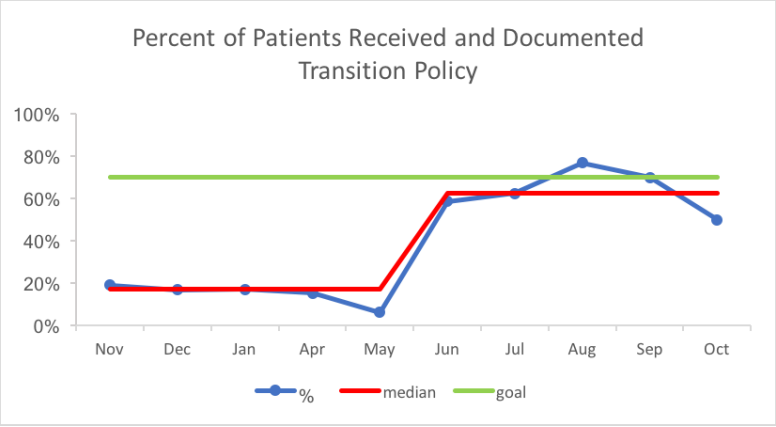
This step will sometimes be informal, while other situations will require a more formal process. Tracking your progress can be as simple as using a check sheet for a short period of time or a more formal use of a run chart which displays improvement over time. Specifically, the Current Assessment of HCT Activities or the HCT Process Measurement Tool in the Six Core Elements package can be used by teams to track progress of specific core elements or the overall HCT process. For more information and examples, see *Measuring for Improvement* in the *QI Primer*.

Example Data Collection Check Sheet

- ☐ A few weeks after giving the policy/guide out, track how many youth received it.
- ☐ For one week, track how many were found in the trash or left behind in the room.
- ☐ Track how many youth had questions about the policy/guide.
- ☐ Share feedback with the team to help refine the policy/guide and the process.
- ☐ Periodic scoring using Current Assessment of HCT Activities or the HCT Process Measurement Tool in the Six Core Elements package.

	Mon	Tues	Wed	Thurs	Fri
Policy/guide given	||	||||	|||	|	||
Left in room or trash		||||			|
Pt questions	|			|	

Data display is important for teams to assess the impact of the changes they are making. In QI, run charts are most often used. Run charts are a dynamic display of data over time. They require no statistical calculations and should be easily understood. Use a clear title. Data points are plotted around a median line. When possible, adding annotations to the chart to explain when certain changes were introduced can make the chart more informative and robust.



Sustain & Spread

For strategies on how to sustain and spread your work, please see Steps 6 and 7 in *How to Implement the Six Core Elements of Health Care Transition*.

III. Sample Transition and Care Policies/Guides

As you develop your transition policy, you should strive for a 6th grade reading level using common words with a concise message, plenty of white space, and an easily readable format. Please see the *QI Primer* for in depth information about health literacy, including strategies for implementation, which are crucial to creating a transition policy that will be understandable and usable for teenagers, young adults, and their families.

Sample Transition and Care Policies/Guides from the Six Core Elements of HCT™

- Sample policy from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

Sample Transition and Care Policies/Guides at Different Reading Levels

- See a policy in the middle of revisions at 8th grade reading level and then see the final version of the policy at 6th grade reading level *(click here)*

Sample Transition and Care Policies/Guides in Different Clinical Settings

- Sample policy from a practice from Weiss Pediatric Care *(click here)*
- Sample policy from a system at Children's Mercy/Henry Ford *(click here)*
- Sample welcome and care policy from a school-based health center *(click here)*

Sample Transition and Care Policies/Guides for Youth with Specific Conditions

- Sample policy from American College of Rheumatology *(click here)*
- Sample sickle cell disease policy from Johns Hopkins All Children's Hospital *(click here)*

Sample Transition and Care Policies/Guides in Video Format

- Sample standard policy from Children's Mercy Kansas City *(click here)*
- Sample policy for youth with intellectual and developmental disabilities from Children's Mercy Kansas City *(click here)*

IV. Additional Resources

- Turning 18: What It Means for Your Health (*click here*)
- Health Care Transition Timeline for Youth and Young Adults (*click here*)
- Health Care Transition Timeline for Parents/Caregivers (*click here*)
- Online Quiz for Youth/Young Adults: Are you ready to transition to adult health care? (*click here*)
- Online Quiz for Parents/Caregivers: Is your child ready to transition to adult health care? (*click here*)
- Setting up the "Medical ID" Feature on Apple's Health App and on Android Phones (*click here*)
- Questions to Ask Your Doctor About Transitioning to Adult Health Care (for Youth and Young Adults) (*click here*)
- Questions to Ask Your Child's Doctor About Transitioning to Adult Health Care (for Parents and Caregivers) (*click here*)

Transitioning Youth to an Adult Health Care Clinician

Core Element 2 - Tracking and Monitoring

I. Purpose, Objectives, and Considerations

Purpose

Tracking and monitoring receipt of the Six Core Elements of Health Care Transition™ (HCT) is the second element in the Six Core Elements. An individual flow sheet within the electronic medical record (EMR) can be used to track when individual transition-aged youth receive each core element. Information from the individual flow sheet can be used to populate a registry and help monitor the extent to which transition-aged youth in the practice/system are receiving recommended HCT services. *See sample transition tracking and monitoring tools in Section III.*

Objectives

Establish criteria and process for identifying transition-aged youth.

Develop process to track receipt of the Six Core Elements, integrating with electronic medical records (EMR) when possible.

Considerations

CONTENT

What information might be included in tracking and monitoring?

Below are some questions and ideas to think about.

- *Demographic and diagnostic information (e.g., name, date of birth, age, diagnosis).*
- *Medical (e.g., disease complexity including utilization) and social complexity information (e.g., social determinants of health/adverse childhood experiences) information. This will be helpful to risk stratify your transition-aged population.*[1-3]
- *Date of receipt of each core element, including:*
  - *When the transition and care policy/guide was shared with youth and parent/caregiver*
  - *When the HCT readiness assessment was administered*
  - *When the HCT education was provided*
  - *When the HCT plan of care was shared with youth/parent/caregiver*
  - *When the medical summary and emergency care plan were shared with youth/parent/caregiver*
  - *When the age 18 privacy and consent changes were discussed*
  - *When supported decision-making (if needed) was discussed*
  - *When the adult clinician was identified*
  - *When the transfer package was sent to adult clinician*
  - *When communication with the adult clinician occurred*
  - *When the first adult appointment was scheduled*
  - *When the first adult appointment was attended*
  - *When feedback was elicited from young adult/parent/caregiver post-transfer about the HCT supports received in the pediatric practice*

PROCESS

What is the process to implement tracking and monitoring?

Below are some questions and ideas to think about.

- *Develop criteria for what youth will be a part of this transition registry. Will it include all transition-aged youth or will it include youth with selected chronic conditions? (See references at the end of this section.)*
- *Decide at what age the registry will begin to track the youth's receipt of HCT services and at what age they should be transferred to an adult clinician. This age range is often stated in Core Element #1, the practice's/system's transition and care policy/guide.*
- *Decide what patient data should be tracked. Will a complexity score or level be used? If so, will it include a combination of medical and social complexity scores?*
- *Choose the format. Will it be an individual flow sheet or a registry via your EMR, REDCap, or an Excel spreadsheet? (See examples in Section III. Due to the variety and proprietary nature of EMRs, none can be provided as an example.)*
- *Work with your practice/system to decide who will input the data and how progress will be monitored. Will the team or the individual clinician be monitoring if all HCT services were offered? If not, who will be responsible for ensuring all services are provided?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

1. Simon TD, Haaland W, Hawley K, Lambka K, Mangione-Smith R. Development and validation of the Pediatric Medical Complexity Algorithm (PMCA) Version 3.0. *Academic Pediatrics.* 2018;18(5):577-580.
2. Schrager SM, Arthur KC, Nelson J, Edwards AR, Murphy JM, Mangione-Smith R, Chen AY. Development and validation of a method to identify children with social complexity risk factors. *Pediatrics.* 2016;138(3):e20153787.
3. Oregon Health Authority. Health Complexity in Children – Statewide Summary Report. 2018. Available at https://www.oregon.gov/oha/HPA/dsi-tc/ChildHealthComplexityData/Statewide-Summary-pub-2019-March.pdf.

II. Quality Improvement Considerations, Tools, and Measurement

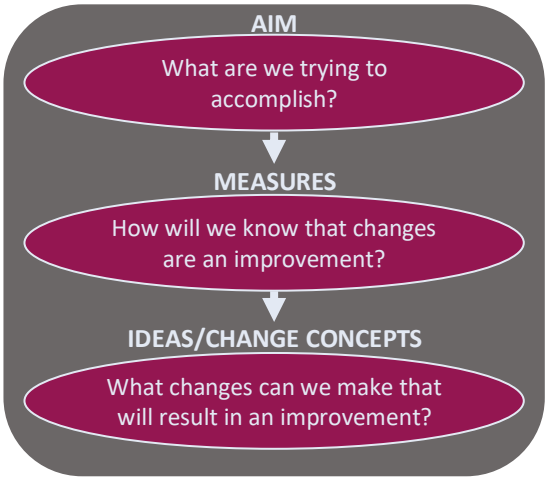
Quality Improvement Considerations

What should be thought about when forming a team? (*See Successful Teams in the QI Primer*)

- Include a representative from all areas of your practice
- Include a youth/parent/caregiver whenever possible
- Depending on what you are aiming to improve, consider any ad hoc members you might need (e.g., information services, lab, pharmacy, supply distribution, etc.)
- Schedule meetings or huddles

What is the Model for Improvement?

The Model for Improvement (see *Model for Improvement in the QI Primer*) is an approach to process improvement, developed by Associates in Process Improvement, which helps teams accelerate the adoption of proven and effective changes. The figure here illustrates the three questions that make up the Model for Improvement. This is a simple but robust model widely used for improvement in many industries, including health care.



Adapted from Langley GL, et al. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, 2nd ed. San Francisco: Jossey-Bass Publishers, 2009.

As you continue to work through this document and the Six Core Elements, you will find that the QI tools and other items below have been customized to each element for each kind of practice. However, you will find the basic team considerations described above remain the same for most if not all of your QI work.

Quality Improvement Tools

The most important QI tools to guide a team's improvement work include ***Tools 1-5*** listed below. Using these tools in the following order will increase your chances of success, but teams can make modifications as needed. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

- ***Tool 1: An aim statement*** is a fundamental element of this model and answers the question of what you are trying to accomplish.
- ***Tool 2: Key driver diagrams*** allow teams to visualize the relationship between the project aim and contributing factors, helping them determine key actions necessary to meet this aim.
- ***Tool 3: Process flow maps*** can help you visualize the steps in your change process.
- ***Tool 4: The simplified failure mode and effects analysis*** form helps teams recognize what problems might arise in each step of the process and think of possible solutions.
- ***Tool 5: Plan-Do-Study-Act (PDSA) cycles*** allow teams to trial and learn from their process changes. Using Tools 1-4 before initiating a PDSA cycle helps teams assess root causes before jumping to solutions.

Tool 1: Aim Statement

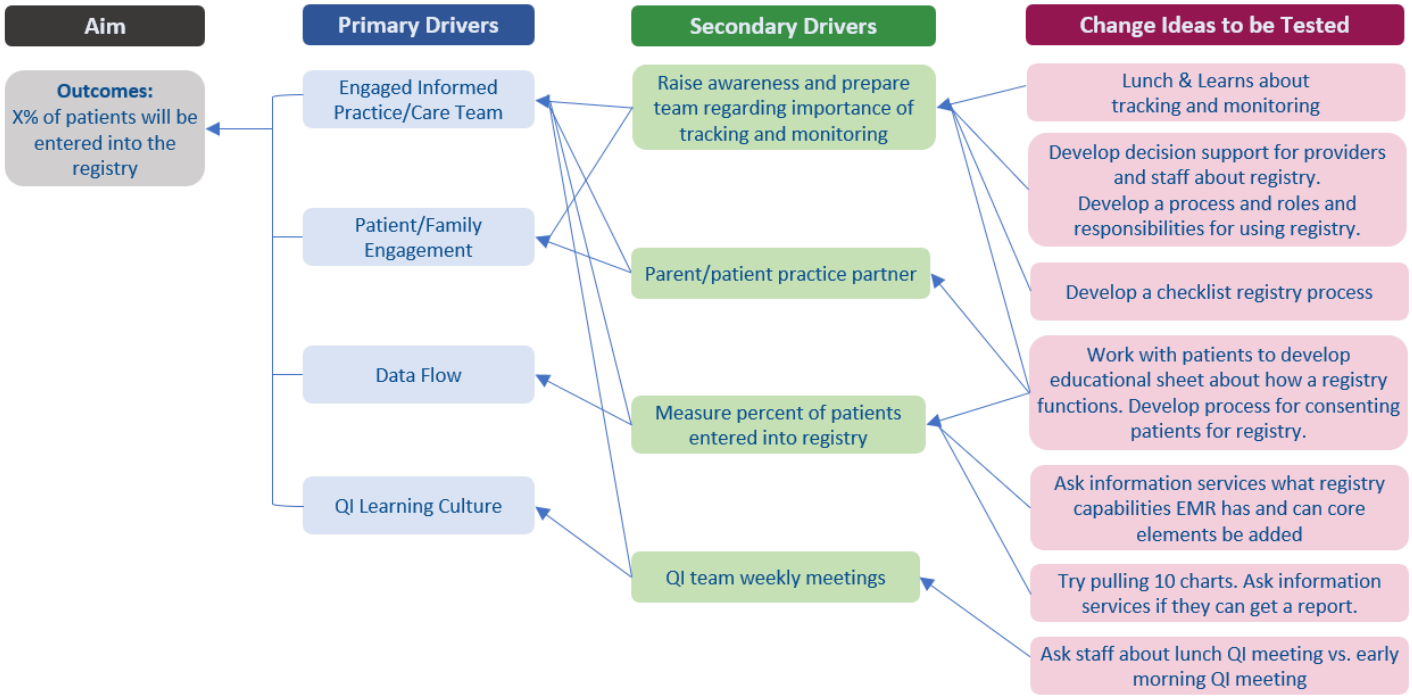
The aim statement is a written statement that describes the improvement effort and includes the rationale for doing the work, the target population, the time period of the work, and measurable numeric goals. For more information and examples, see *Model for Improvement* in the *QI Primer*.

Example Aim Statement

We aim to improve care by implementing a tracking and monitoring database. By [insert date], 80% of patients with sickle cell disease will be in the database.

Tool 2: Key Driver Diagram

Key driver diagrams (KDDs) require teams to identify their theories or "key drivers" which lead to outcomes. They help teams see relationships and organize work, especially in complex systems. They are frequently used for analysis, organization, and communication to direct improvement work. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



Adapted from ST3P UP, a collaborative sponsored by Patient Centered Outcomes Research Institute® (PCORI) Award MCSC-1608-35861 Titled A Comparative Effectiveness of Peer Mentoring Versus Structured Education Based Transition Programming For The Management Of Care Transitions In Emerging Adults With Sickle Cell Disease.

Tool 3: Process Flow Map

A flow map is a visual display of the separate steps in a process placed in sequential order. It is extremely helpful in documenting different views of the same process. It can show the sequence of actions, materials/inputs entering and leaving the process, decision points, and people involved. Flow maps can be used to document steps in the process of either how things are or how things could be. Posting the flow map gives staff an opportunity to clarify the steps in the process and can uncover conflicting understandings. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

Tool 4: Simplified Failure Mode and Effects Analysis (sFMEA)

Simplified Failure Mode and Effects Analysis (sFMEA) is a proactive method for evaluating a process to identify where and how it might fail and to assess the relative impact of different failures, in order to identify the parts of the process that are most in need of change and help generate ideas to prevent those possible failures. This is a good companion to the flow map – a flow map lets you see the process as it is, and the sFMEA helps you look more closely to identify breakdowns. The example below has a few solutions filled in, to illustrate how teams might start completing an sFMEA. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

Adapted from the copyrighted Simplified Failure Mode Effects Analysis Worksheet (sFMEA) from Cincinnati Children's Hospital Medical Center. This version of the sFMEA has been modified and has been reprinted with permission.

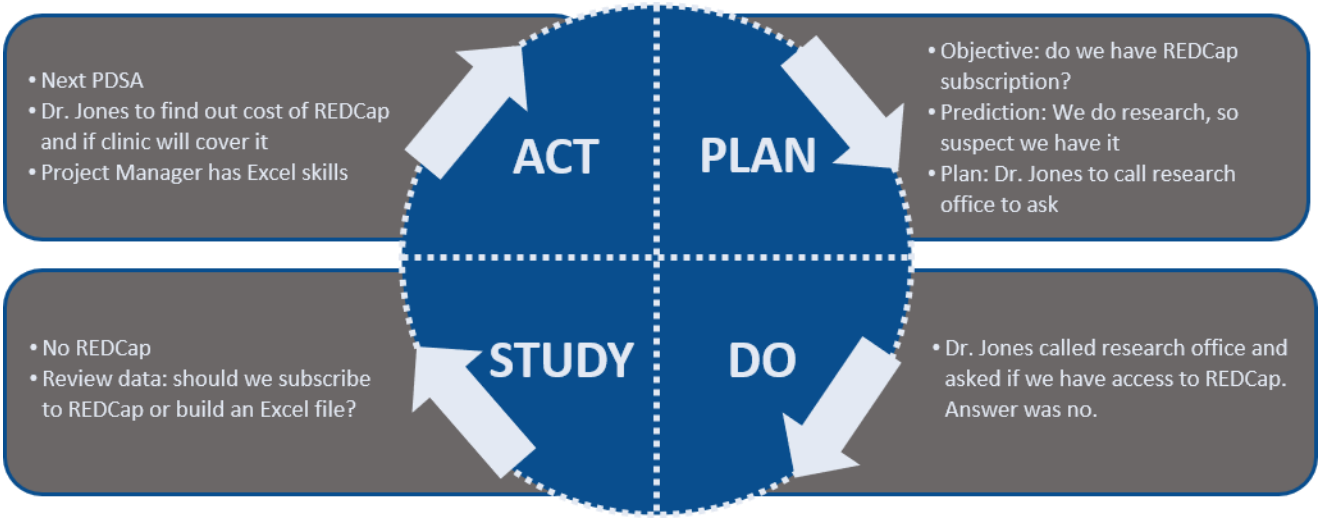
Tool 5: PDSA Cycles

PDSA cycles are a structured test of a process change. These are meant to be done rapidly, for example one patient, one afternoon, with one doctor. To accelerate learning and improvement, small tests with reflection allow for change ideas to be adapted, adopted, or abandoned easily within busy healthcare settings. Learning to do rapid cycle testing is key to keeping the momentum going; it is not necessary to schedule a full separate meeting, just a quick huddle allows teams to plan the next cycle. For more information and examples, see *Model for Improvement* in the *QI Primer*. This effort includes:

- **Plan** the test: who, what, where, when;
- **Do** try the change and observe what happens;
- **Study** reflect on what was learned from the test; and
- **Act** decide next steps based on the reflection.

Examples of Ideas to Test

- Using Excel vs. REDCap
- Creating a mock database and testing, are any key components missing?



Adapted from AHEC QI 101, a Quality Improvement course sponsored by Charlotte Area Health Education Center.

Quality Improvement Measurement

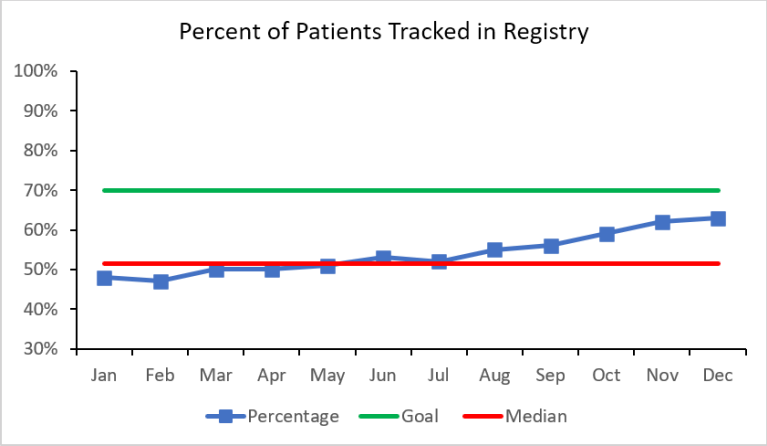
This step will sometimes be informal, while other situations will require a more formal process. Tracking your progress can be as simple as using a check sheet for a short period of time or a more formal use of a run chart which displays improvement over time. Specifically, the Current Assessment of HCT Activities or the HCT Process Measurement Tool in the Six Core Elements package can be used by teams to track progress of specific core elements or the overall HCT process. For more information and examples, see *Measuring for Improvement* in the *QI Primer*.

Example Data Collection Check Sheet

- ☐ Track how long it takes to enter the data per patient.
- ☐ Track the number of patients entered for 1 week.
- ☐ Generate reports.
- ☐ Track how the report is used.
- ☐ Once the process is refined, weekly or daily track the percent of patients seen who are entered into the database.
- ☐ Note what is achieved from the reports.

	Mon	Tues	Wed	Thurs	Fri
# pts put in database	||||	||	||||	|	|

Data display is important for teams to assess the impact of the changes they are making. In QI, run charts are most often used. Run charts are a dynamic display of data over time. They require no statistical calculations and should be easily understood. Use a clear title. Data points are plotted around a median line. When possible, adding annotations to the chart to explain when certain changes were introduced can make the chart more informative and robust.



Sustain & Spread

For strategies on how to sustain and spread your work, please see Steps 6 and 7 in *How to Implement the Six Core Elements of Health Care Transition*.

III. Sample Tracking and Monitoring Tools

Sample Registry Tool from the Six Core Elements of HCT™

- Sample Excel spreadsheet from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

Sample Transition Flow Sheet from the Six Core Elements of HCT™

- Sample transition flow sheet from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

Sample REDCap Tracking and Monitoring System

- *Click here* for information about how to access a customizable REDCap example for a tracking and monitoring system.

Transitioning Youth to an Adult Health Care Clinician

Core Element 3 - Transition Readiness

I. Purpose, Objectives, and Considerations

Purpose

Transition readiness is the third element in the Six Core Elements of Health Care Transition™ (HCT). Use of a standardized transition readiness assessment (TRA) to assess youths' HCT readiness skills is helpful in engaging youth and parents/caregivers to set health priorities, addressing self-care skill needs to prepare them for an adult approach to care at age 18, and preparing them to independently use health care services. Clinicians can use the results of the TRA to jointly develop a plan of care with youth and parents/caregivers. Clinicians should begin conducting TRAs at age 14 to 16 and continue throughout the HCT period until the youth has transferred. The final TRA should be included in the transfer package and sent to the receiving adult clinician. The TRA should be at the appropriate reading level, offered in languages common among your clinic population, and concise (no more than one page). *See sample TRAs in the references and in Section III.*

Objectives

Conduct regular TRAs, beginning at age 14 to 16, to identify and discuss with youth and parent/caregiver their needs for self-care and how to use health care services.

Offer education and resources on needed skills identified through the TRA.

Considerations

CONTENT

What information might be considered in assessing transition readiness?

Below are some questions and ideas to think about.

- *Consider the patient population in your practice/system. What HCT skills and knowledge about health care services do they need to learn?*
- *Decide if only the youth or if both the youth and parent/caregiver will complete the TRA.*
- *Review existing TRAs. Decide if you can use an existing TRA, if you need to customize one, or if a new TRA will need to be developed.*
- *Several TRAs are available; several are disease specific, including ones for youth with intellectual and developmental disabilities. The 2018 Clinical Report on HCT includes a list of published TRAs.[1] For examples of some subspecialty disease TRAs from the American College of Physicians subspecialty societies, see Section III.*
- *Got Transition's TRA contains two motivational interviewing questions. Consider adding them to your selected TRA:*
  - *How important is it to you to move to a doctor who cares for adults before age 22?*
  - *How confident do you feel about your ability to move to a doctor who cares for adults before age 22?*
- *Have the youth complete the TRA several times during the HCT preparation process, beginning at age 14 to 16, usually as part of routine preventive or chronic care.*
- *Use the TRA both as a discussion tool and to plan for HCT skill-building education.*
- *It is important to note that TRAs do not predict HCT success. As of June 2020, the available TRAs have not been externally validated.*

PROCESS

What is the process to implement assessment of transition readiness?

Below are some questions and ideas to think about.

- *If an available TRA has been customized or your practice/system has developed its own, check that the reading level is appropriate and do a test with 3-4 youth in your practice (who will be receiving the TRA) of different ages and educational levels to see if they have any difficulty understanding the questions or specific words. If so, make needed changes to the TRA and test again. A similar approach should be taken if the practice/system decides to also have parents/caregivers complete a TRA.*
- *Once the TRA(s) are ready for use, identify and test the clinic process for conducting it. Below are some questions and ideas to think about.*
    - *Identify eligible youth needing a TRA and decide:*
        - *How often will it be offered? Every year? Every other year?*
        - *Will it be sent to the youth and parent/caregiver before the visit via mail, email, or the EMR portal and the completed form be brought to the clinic visit?*
        - *Will it be completed in the clinic at the time of the visit? Will it be completed in a paper form? If yes, determine who will incorporate the completed TRA into the medical record.*
        - *Who will administer the TRA in the clinic? Will it be completed in the waiting room or while waiting for the clinician in the clinic room?*
        - *Will the parents/caregivers be present (if there is no legal supported decision-making document) when youth is completing the TRA or will the youth complete it on their own?*
        - *Who fills out the TRA when there is a legal supported decision-making agreement in place?*
    - *Will it be completed via a tablet during the visit, and if so, will the results be incorporated into the EMR? Who will assist the youth to prioritize needed skill-building education?*
    - *Who will incorporate the needed skills into an HCT plan of care (for more information about an HCT plan of care, see the implementation guide for Core Element 4)?*
    - *Who will offer the identified needed education?*
    - *What materials or online resources are available in the practice for education around the needed skills for the youth/parent/caregiver?*
    - *Determine how education will be incorporated into follow-up appointments and documented in the medical record.*
- *Create a written document to describe the clinic process that each eligible patient will follow to complete the TRA process.*
- *Educate all team members/staff about the process.*

1. White PH, Cooley WC, Transitions Clinical Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5);e20182587.

II. Quality Improvement Considerations, Tools, and Measurement

Quality Improvement Considerations

What should be thought about when forming a team? (See *Successful Teams* in the *QI Primer*)

- Include a representative from all areas of your practice
- Include a youth/parent/caregiver whenever possible
- Depending on what you are aiming to improve, consider any ad hoc members you might need (e.g., information services, lab, pharmacy, supply distribution, etc.)
- Schedule meetings or huddles

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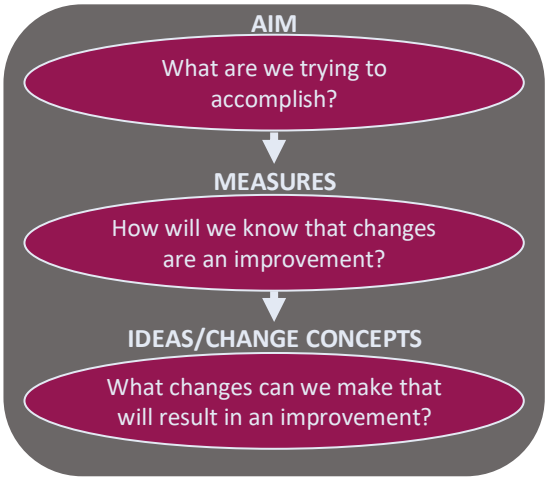

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Tool 1: Aim Statement

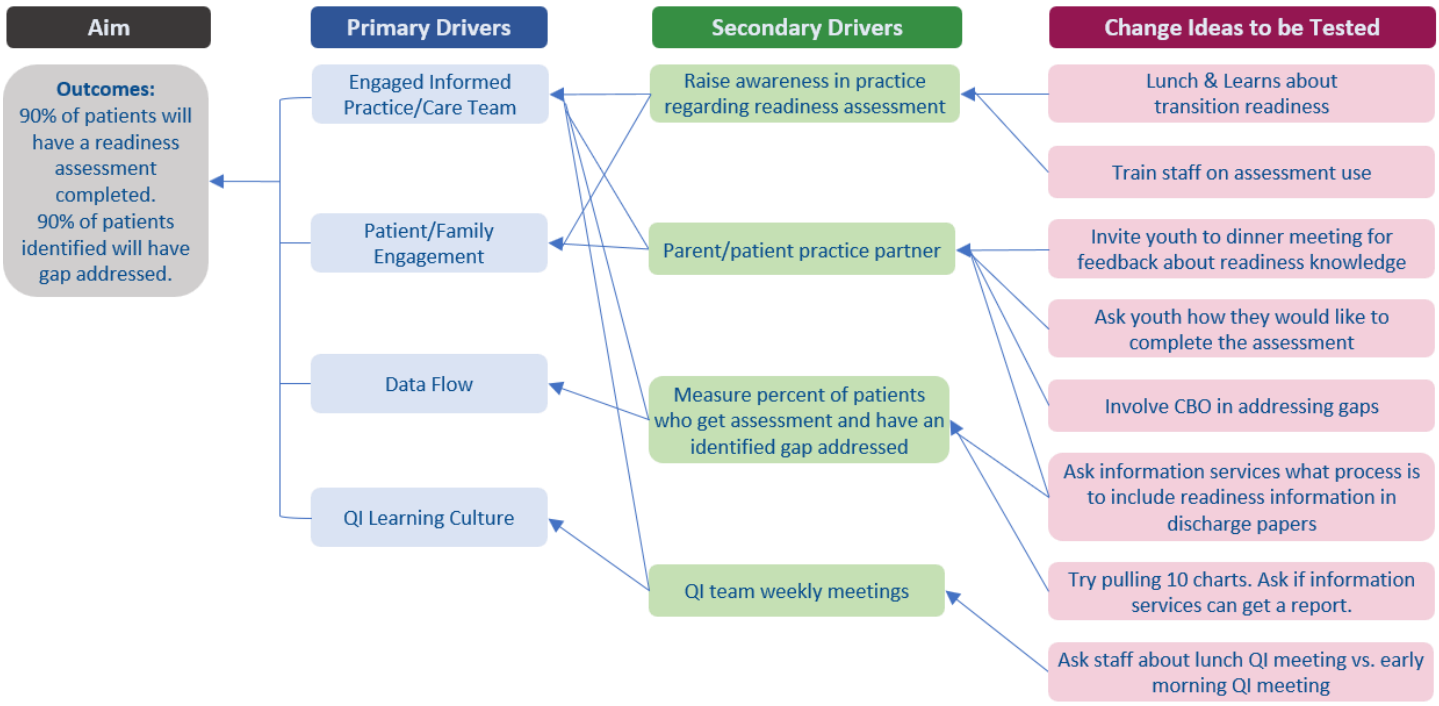
The aim statement is a written statement that describes the improvement effort and includes the rationale for doing the work, the target population, the time period of the work, and measurable numeric goals. For more information and examples, see *Model for Improvement* in the *QI Primer*.

Example Aim Statement

We aim to improve care for patients with sickle cell disease by implementing a readiness assessment and assess gaps identified. By [insert date], 90% of patients will have a readiness assessment and 80% of patients identified will have gap addressed.

Tool 2: Key Driver Diagram

Key driver diagrams (KDDs) require teams to identify their theories or "key drivers" which lead to outcomes. They help teams see relationships and organize work, especially in complex systems. They are frequently used for analysis, organization, and communication to direct improvement work. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



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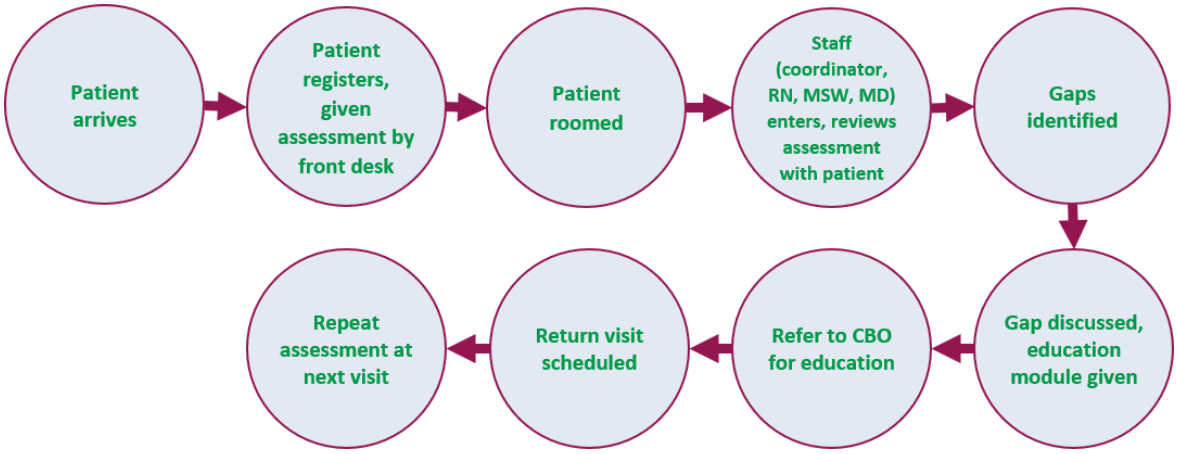
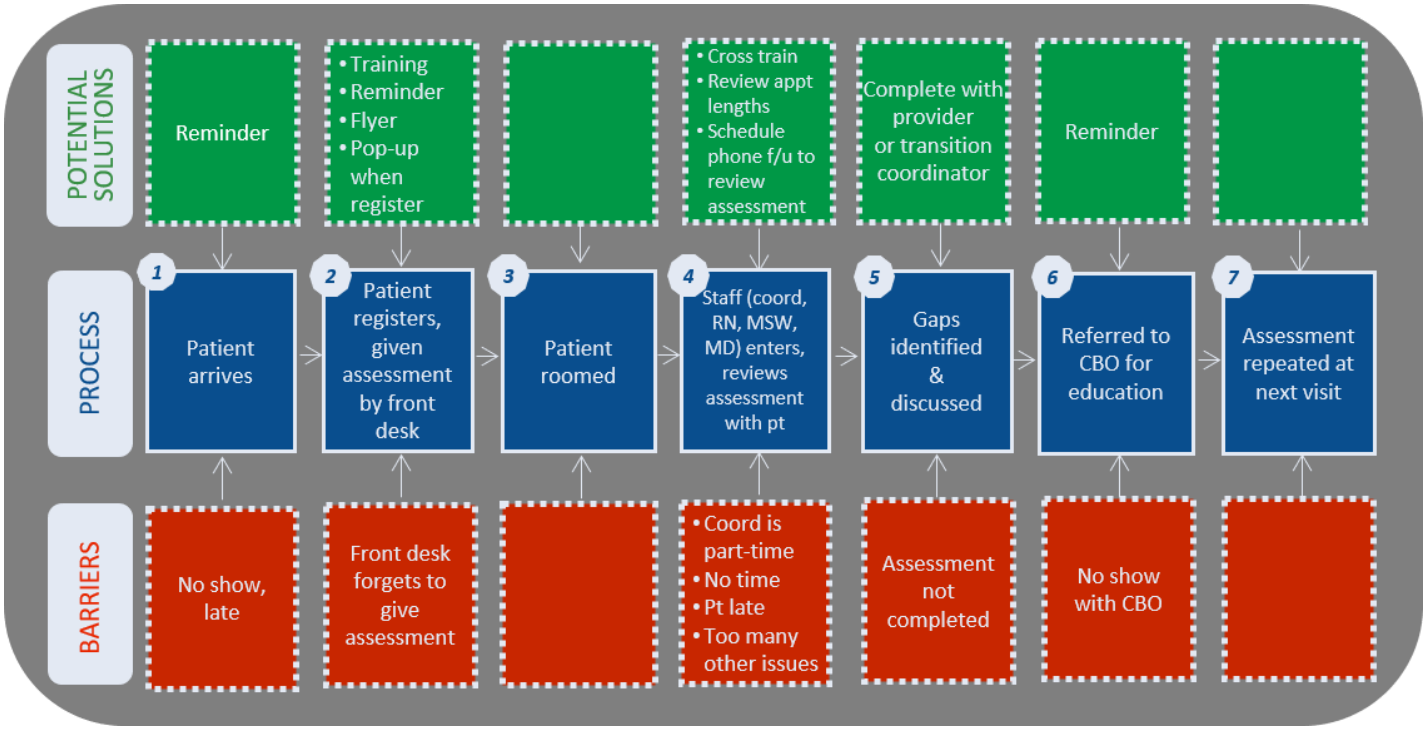


Tool 4: Simplified Failure Mode and Effects Analysis (sFMEA)

Simplified Failure Mode and Effects Analysis (sFMEA) is a proactive method for evaluating a process to identify where and how it might fail and to assess the relative impact of different failures, in order to identify the parts of the process that are most in need of change and help generate ideas to prevent those possible failures. This is a good companion to the flow map – a flow map lets you see the process as it is, and the sFMEA helps you look more closely to identify breakdowns. The example below has a few solutions filled in, to illustrate how teams might start completing an sFMEA. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



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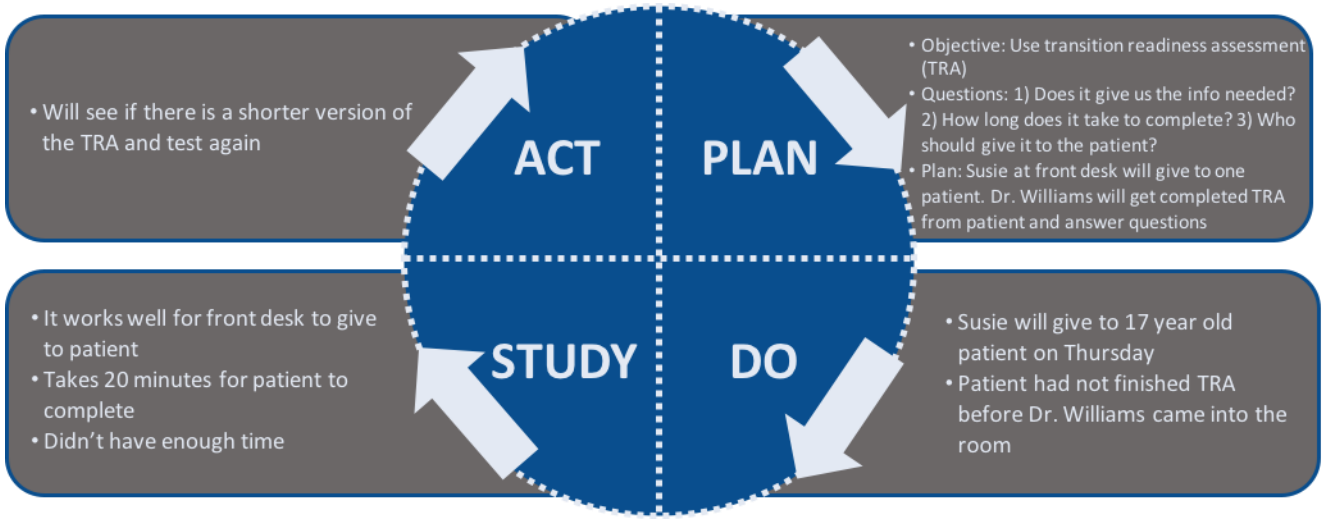
Tool 5: PDSA Cycles

PDSA cycles are a structured test of a process change. These are meant to be done rapidly, for example one patient, one afternoon, with one doctor. To accelerate learning and improvement, small tests with reflection allow for change ideas to be adapted, adopted, or abandoned easily within busy healthcare settings. Learning to do rapid cycle testing is key to keeping the momentum going; it is not necessary to schedule a full separate meeting, just a quick huddle allows teams to plan the next cycle. For more detailed explanation and a blank form, see *Model for Improvement* in the *QI Primer*. This effort includes:

- **Plan** the test: who, what, where, when;
- **Do** try the change and observe what happens;
- **Study** reflect on what was learned from the test; and
- **Act** decide next steps based on the reflection.

Examples of Ideas to Test

- Test the readiness assessment on one patient
- Test the process of completing readiness assessment on one patient



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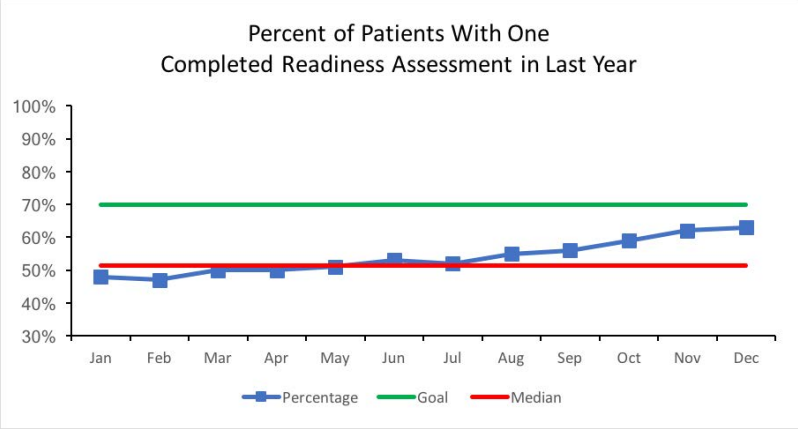
Example Data Collection Check Sheet

- ☐ Assess the need for education
  - Have clinician track for 1 week the number of patients who have a gap identified
  - Track the areas in which gaps appear
- ☐ Track the number of patients who complete the education module
- ☐ Track the number of patients referred to a CBO for further education
- ☐ If possible, track the number of patients the CBO sees from referrals
- ☐ Note what is achieved by either the module or the CBO referral

	Mon	Tues	Wed	Thurs	Fri
# pts put in database	|||	|||	||||	|||	|
# pts finished module		||		|	|
# pts referred to CBO	|		|	|	

Data display is important for teams to assess the impact of the changes they are making. In QI, run charts are most often used. Run charts are a dynamic display of data over time. They require no statistical calculations and should be easily understood. Use a clear title. Data points are plotted around a median line. When possible, adding annotations to the chart to explain when certain changes were introduced can make the chart more informative and robust.



Sustain & Spread

For strategies on how to sustain and spread your work, please see Steps 6 and 7 in *How to Implement the Six Core Elements of Health Care Transition*.

III. Sample Transition Readiness Assessments

Sample Transition Readiness Assessments from the Six Core Elements of HCT™

- Sample transition readiness assessment for youth from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*
- Sample transition readiness assessment for parents/caregivers from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

Sample Transition Readiness Assessments for Youth with Specific Conditions

- Sample transition readiness assessment for youth with intellectual and developmental disabilities from the American College of Physicians *(click here)*
- Additional condition-specific transition readiness assessments from the American College of Physicians *(click here)*

Sample Transition Readiness Assessments for School Health Settings

- Sample transition readiness assessment for students from Children's National Medical Center's school-based health centers *(click here)*
- Sample transition readiness assessment for students receiving mental and behavioral services from Mary's Center's school mental health program *(click here)*
- Sample health care transition readiness assessment for students with an Individualized Education Program (IEP) from Got Transition *(click here)* and sample goals for educators to use in the IEP *(click here)*

IV. Additional Resources

- Turning 18: What It Means for Your Health *(click here)*
- Health Care Transition Timeline for Youth and Young Adults *(click here)*
- Health Care Transition Timeline for Parents/Caregivers *(click here)*
- Online Quiz for Youth/Young Adults: Are you ready to transition to adult health care? *(click here)*
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- Setting up the "Medical ID" Feature on Apple's Health App and on Android Phones *(click here)*
- Questions to Ask Your Doctor About Transitioning to Adult Health Care (for Youth and Young Adults) *(click here)*
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- System Differences Between Pediatric and Adult Health Care *(click here)*
- Planning to Move from Pediatric to Adult Care? Here's How They Can Differ *(click here)*

Transitioning Youth to an Adult Health Care Clinician

Core Element 4 - Transition Planning

I. Purpose, Objectives, and Considerations

Purpose

Transition planning is the fourth element in the Six Core Elements of Health Care Transition™ (HCT). Planning for transition should be accomplished in collaboration with youth and parents/caregivers beginning in early adolescence and continuing until the youth transfers out of pediatric care. Transition planning encompasses several ongoing activities that are intended to build health literacy and independent self-care skills; assist in preparing for changes that happen at age 18; and guide the timing of transfer and the selection of a new adult clinician, taking cultural preferences into account. In addition, addressing the legal issues of supported decision-making should be a part of this planning, if needed. *See sample transition plans of care and medical summary and emergency care plans in Section III.*

Objectives

Develop and regularly update the plan of care, including readiness assessment findings, youth's goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.

Prepare youth and parent/caregiver for an adult approach to care, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.

Determine need for decision-making supports for youth and make referrals to legal resources.

Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult care. If both primary and subspecialty care are involved, discuss optimal timing for each.

Assist youth in identifying an adult clinician(s) and provide linkages to insurance resources, self-care management information, and community support services.

Obtain consent from youth/parent/caregiver for release of medical information.

Take cultural preferences into account throughout transition planning.

Considerations

CONTENT

What information should be considered in developing a plan of care for transition?

Below are some questions and ideas to think about.

- *Does the practice already have a plan of care template and/or an HCT plan of care template? If the practice has a transition plan of care template, does it encompass some or all of the objectives listed above?*
- *At what age will the plan of care for transition be developed with youth and parents/caregivers and how often will it be updated?*

What issues should be considered in creating a medical summary and emergency care plan that is shared with youth and parents/caregivers?

Below are some questions and ideas to think about.

- *Does the practice have a medical summary template in its emergency medical records (EMR) or a way to create a medical summary within its EMR?*
- *Does the practice have an emergency care plan template available, or will the practice use another available template? (See Got Transition's template or those created by the American College of Physicians Subspecialty Society in Section III.)*
- *What is the key information needed in the medical summary and emergency care plan?*
- *Is the emergency care plan incorporated into the medical summary or is it a separate document, such as an asthma or sickle cell emergency care plan?*
- *Note: Include special non-medical information in the medical summary that the youth/parent/caregiver would want the new adult clinician to know about them (e.g., they are excellent at drawing or playing baseball). This information can assist new clinicians to make a connection and engage the young adult during the first visit.*

When does the practice begin offering time alone with the youth without the parents/caregivers present in the visit to foster independence in medical decision-making if supported decision-making documents are not needed?

Below are some questions and ideas to think about.

- *What does the practice offer youth and parents/caregivers to inform them of the timing and importance of time alone?*
- *Does the practice's approach and information shared align with the Bright Futures Guidelines from the American Academy of Pediatrics?*

What changes should the practice put in place to implement an adult model of care with their patients, starting at age 18?

Below are some questions and ideas to think about.

- *Does the practice explain to youth and parents/caregivers, prior to age 18, the changes that will take place in terms of privacy and consent at age 18? (See Got Transition's Turning 18: What It Means for Your Health in Section IV.)*
- *What safeguards are in place to ensure that patients, ages 18 and older, have sole access to their medical information unless they authorize otherwise?*
- *When and how does the practice discuss with youth and parents/caregivers the need for legal decision-making support, if needed?*
- *What does your practice offer to assist youth and parents/caregivers to consider if there is a need for supported decision-making and how to begin the legal process, if needed? For more information about resources, see the National Resource Center for Supported Decision-Making and The Arc.*
- *Does your practice have current information available to youth/parents/caregivers on adult primary and specialty care practices and other community support services for youth transferring out of pediatric care?*

PROCESS

What is the process to implement a transition plan of care?

Below are some questions and ideas to think about.

- *Does the practice have a process to create and update a plan of care with HCT goals and action steps?*
- *Who will generate the HCT plan of care goals with the youth/parents/caregivers, utilizing the needed skills identified in the transition readiness assessment?*
- *Who will address the needed education on the identified skill gaps with the youth/parents/ caregivers?*
- *How will the education sessions be documented in the medical record?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

What is the process to implement a medical summary and emergency care plan?

Below are some questions and ideas to think about.

- *Is the medical summary and emergency care plan built from the EMR data or is it a template that needs to be completed? If the latter, who is responsible for adding it to the EMR?*
- *Who is responsible for completing the medical summary and emergency care plan and keeping it up to date?*
- *How will the practice share the medical summary and emergency care plan with youth and parents/caregivers (i.e., discuss at the visit or send it to the youth/parent/caregiver before an annual visit to review during the visit)?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

What is the process to implement key issues around confidentiality and legal decision-making?

Below are some questions and ideas to think about.

- *What process does the practice have in place to start offering youth time alone without the parent/caregiver present in the room to foster independence in medical decision-making, if supported decision-making is not needed?*
- *When and who will address the need for legal decision-making with the youth and parent/caregiver and offer resources, if needed?*
- *Who in the practice is responsible for explaining what an adult model of care is to the youth/ parents/caregivers before the youth turns 18?*
- *What processes will the practice implement to provide an adult model of care for youth, starting at age 18? For example, to demonstrate the changes that occur in confidentiality and consent, should all youth who do not need a legal decision-making document be asked to sign a HIPAA form if they come to the visit with their parent/caregiver when they are age 18 or older?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

II. Quality Improvement Considerations, Tools, and Measurement

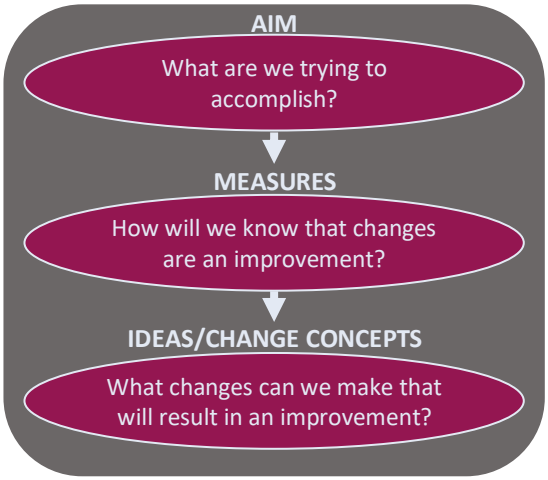
Quality Improvement Considerations

What should be thought about when forming a team? (See *Successful Teams* in the *QI Primer*)

- Include a representative from all areas of your practice
- Include a youth/parent/caregiver whenever possible
- Depending on what you are aiming to improve, consider any ad hoc members you might need (e.g., information services, lab, pharmacy, supply distribution, etc.)
- Schedule meetings or huddles

What is the Model for Improvement?

The Model for Improvement (see *Model for Improvement* in the *QI Primer*) is an approach to process improvement, developed by Associates in Process Improvement, which helps teams accelerate the adoption of proven and effective changes. The figure here illustrates the three questions that make up the Model for Improvement. This is a simple but robust model widely used for improvement in many industries, including health care.



Adapted from Langley GL, et al. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, 2nd ed. San Francisco: Jossey-Bass Publishers, 2009.

As you continue to work through this document and the Six Core Elements, you will find that the QI tools and other items below have been customized to each Element for each kind of practice. However, you will find the basic team considerations described above remain the same for most if not all of your QI work.

Quality Improvement Tools

The most important QI tools to guide a team's improvement work include ***Tools 1-5*** listed below. Using these tools in the following order will increase your chances of success, but teams can make modifications as needed. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

- ***Tool 1: An aim statement*** is a fundamental element of this model and answers the question of what you are trying to accomplish.
- ***Tool 2: Key driver diagrams*** allow teams to visualize the relationship between the project aim and contributing factors, helping them determine key actions necessary to meet this aim.
- ***Tool 3: Process flow maps*** can help you visualize the steps in your change process.
- ***Tool 4: The simplified failure mode and effects analysis*** form helps teams recognize what problems might arise in each step of the process and think of possible solutions.
- ***Tool 5: Plan-Do-Study-Act (PDSA) cycles*** allow teams to trial and learn from their process changes. Using Tools 1-4 before initiating a PDSA cycle helps teams assess root causes before jumping to solutions.

Tool 1: Aim Statement

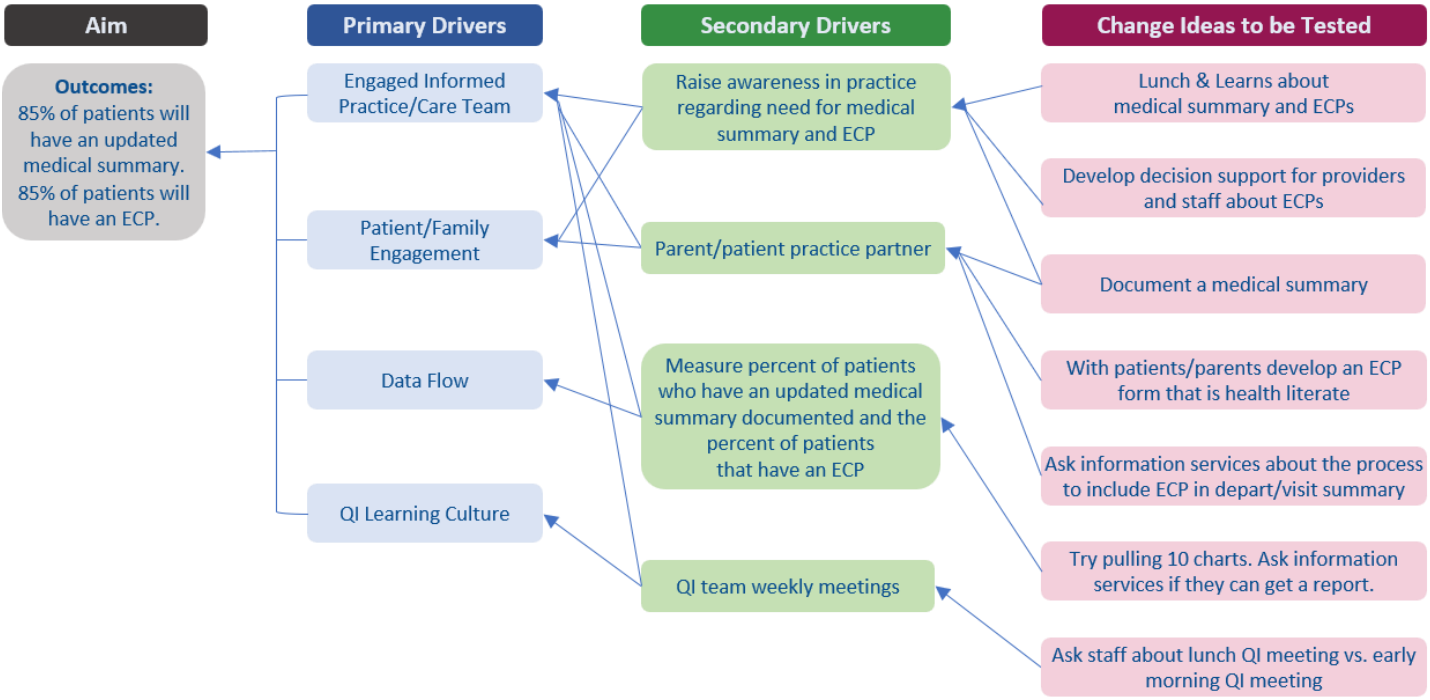
The aim statement is a written statement that describes the improvement effort and includes the rationale for doing the work, the target population, the time period of the work, and measurable numeric goals. For more information and examples, see *Model for Improvement* in the *QI Primer*.

Example Aim Statement

We aim to improve care for patients with sickle cell disease by creating a transition plan. By [insert date], 85% of patients will have an updated medical summary and 85% of patients will have an emergency care plan.

Tool 2: Key Driver Diagram

Key driver diagrams (KDDs) require teams to identify their theories or "key drivers" which lead to outcomes. They help teams see relationships and organize work, especially in complex systems. They are frequently used for analysis, organization, and communication to direct improvement work. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



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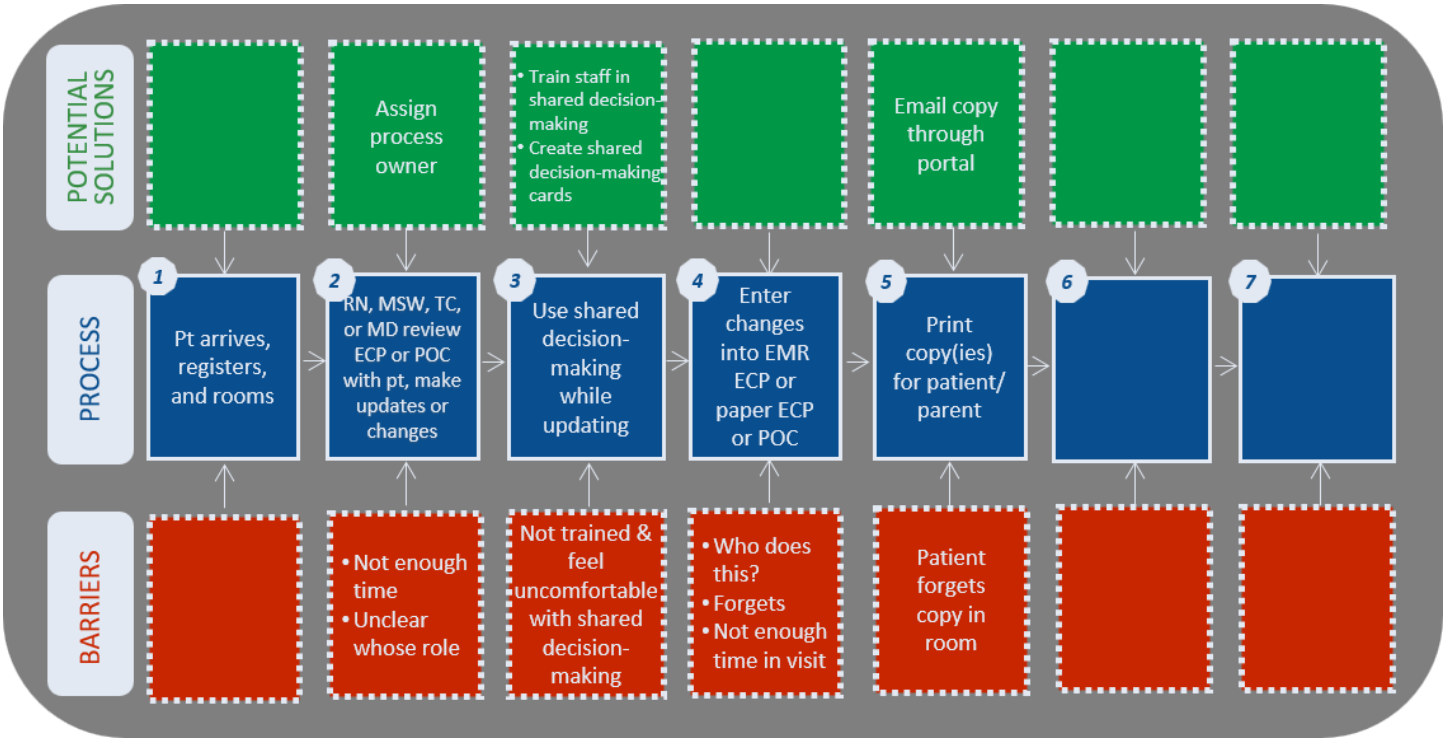
Tool 3: Process Flow Map

A flow map is a visual display of the separate steps in a process placed in sequential order. It is extremely helpful in documenting different views of the same process. It can show the sequence of actions, materials/inputs entering and leaving the process, decision points, and people involved. Flow maps can be used to document steps in the process of either how things are or how things could be. Posting the flow map gives staff an opportunity to clarify the steps in the process and can uncover conflicting understandings. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

Tool 4: Simplified Failure Mode and Effects Analysis (sFMEA)

Simplified Failure Mode and Effects Analysis (sFMEA) is a proactive method for evaluating a process to identify where and how it might fail and to assess the relative impact of different failures, in order to identify the parts of the process that are most in need of change and help generate ideas to prevent those possible failures. This is a good companion to the flow map – a flow map lets you see the process as it is, and the sFMEA helps you look more closely to identify breakdowns. The example below has a few solutions filled in, to illustrate how teams might start completing an sFMEA. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



Adapted from the copyrighted Simplified Failure Mode Effects Analysis Worksheet (sFMEA) from Cincinnati Children's Hospital Medical Center. This version of the sFMEA has been modified and has been reprinted with permission.

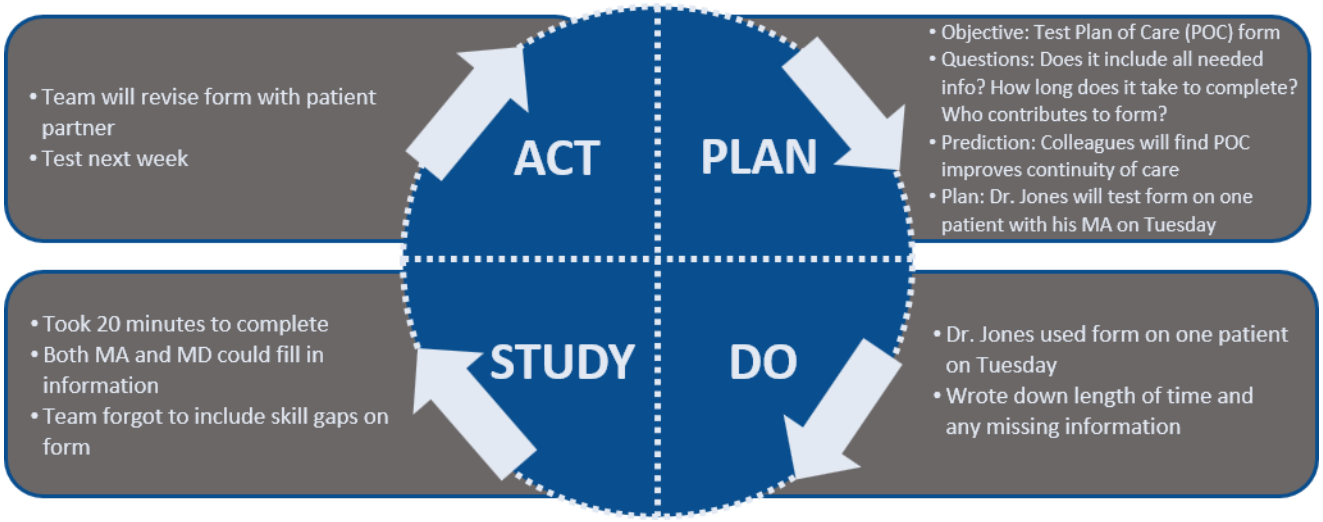
Tool 5: PDSA Cycles

PDSA cycles are a structured test of a process change. These are meant to be done rapidly, for example one patient, one afternoon, with one doctor. To accelerate learning and improvement, small tests with reflection allow for change ideas to be adapted, adopted, or abandoned easily within busy healthcare settings. Learning to do rapid cycle testing is key to keeping the momentum going; it is not necessary to schedule a full separate meeting, just a quick huddle allows teams to plan the next cycle. For more detailed explanation and a blank form, see *Model for Improvement* in the *QI Primer*. This effort includes:

- **Plan** the test: who, what, where, when;
- **Do** try the change and observe what happens;
- **Study** reflect on what was learned from the test; and
- **Act** decide next steps based on the reflection.

Examples of Ideas to Test

- Test the plan of care form (content) on one patient
- Make a mock portable medical summary and test on one patient
- Test an informational flyer about the adult approach to care at age 18 on one patient



Adapted from AHEC QI 101, a Quality Improvement course sponsored by Charlotte Area Health Education Center.

Quality Improvement Measurement

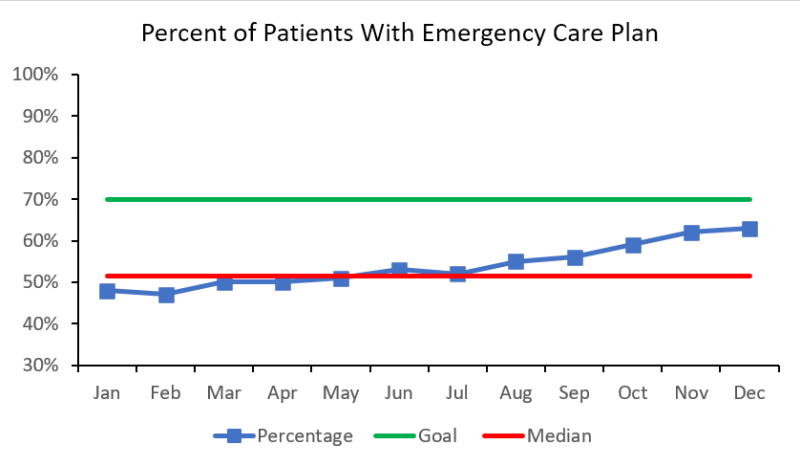
This step will sometimes be informal, while other situations will require a more formal process. Tracking your progress can be as simple as using a check sheet for a short period of time or a more formal use of a run chart which displays improvement over time. Specifically, the Current Assessment of HCT Activities or the HCT Process Measurement Tool in the Six Core Elements package can be used by teams to track progress of specific core elements or the overall HCT process. For more information and examples, see *Measuring for Improvement* in the *QI Primer*.

Example Data Collection Check Sheet

- ☐ Track for 1 week the number of patients given a plan of care or emergency care plan.
- ☐ Track the number of documents left in the room or found in the trash.
- ☐ Call 5 patients and ask if they have used the emergency care plan and if so, in what setting.

	Mon	Tues	Wed	Thurs	Fri
# pts given Care Plan	||	||||	|||	|	||
# forms left in trash		|	|		|
# pts confirm ECP use	|	||		|	

Data display is important for teams to assess the impact of the changes they are making. In QI, run charts are most often used. Run charts are a dynamic display of data over time. They require no statistical calculations and should be easily understood. Use a clear title. Data points are plotted around a median line. When possible, adding annotations to the chart to explain when certain changes were introduced can make the chart more informative and robust.



Sustain & Spread

For strategies on how to sustain and spread your work, please see Steps 6 and 7 in *How to Implement the Six Core Elements of Health Care Transition*.

III. Sample Transition Planning Tools

Sample Transition Planning Tools from the Six Core Elements of HCT™

- Sample plan of care from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*
- Sample medical summary and emergency care plan from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

Sample Wellness Plan for School Health Settings

- Sample wellness plan from Mary's Center's school mental health program *(click here)*

Sample Transition Planning Tools for Youth with Specific Conditions

- Sickle cell disease SMART Phrase resource for incorporating a medical summary into a transfer letter (*click here*)
- Additional condition-specific medical summaries from the American College of Physicians (*click here*)

IV. Additional Resources

- Turning 18: What It Means for Your Health (*click here*)
- Health Care Transition Timeline for Youth and Young Adults (*click here*)
- Health Care Transition Timeline for Parents/Caregivers (*click here*)
- Online Quiz for Youth/Young Adults: Are you ready to transition to adult health care? (*click here*)
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- Questions to Ask Your Doctor About Transitioning to Adult Health Care (for Youth and Young Adults) (*click here*)
- Questions to Ask Your Child's Doctor About Transitioning to Adult Health Care (for Parents and Caregivers) (*click here*)
- System Differences Between Pediatric and Adult Health Care *(click here)*
- Planning to Move from Pediatric to Adult Care? Here's How They Can Differ *(click here)*
- A Family Toolkit: Pediatric-to-Adult Health Care Transition (*click here*)

Transitioning Youth to an Adult Health Care Clinician

Core Element 5 – Transfer of Care

I. Purpose, Objectives, and Considerations

Purpose

Transfer of care is the fifth element in the Six Core Elements of Health Care Transition™ (HCT). Establishing a systematic method for transfer to an adult clinician ensures that key tasks are accomplished; that youth, young adults, and parents/caregivers are informed of and involved in the hand-off of care and current medical information; and that communication and coordination between pediatric and adult clinicians takes place. For youth and young adults with special health care needs, transfer of care often requires coordination among multiple clinicians to ensure a safe and continuous process. Transfer to an adult clinician is recommended before the age of 22. *See sample transfer of care checklists and transfer letters in Section III*.

Objectives

Complete transfer package, including final transition readiness assessment, plan of care with transition goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional clinical records.

Confirm date of first adult clinician appointment.

Prepare letter with transfer package, send to adult clinician, and confirm adult clinician's receipt of transfer package.

Communicate with selected adult clinician about pending transfer of care.

Confirm the pediatric clinician's responsibility for care until youth/young adult is seen by an adult clinician.

Transfer youth/young adult when their condition is as stable as possible.

Considerations

CONTENT

What information should be shared during the transfer of care?

Below are some questions and ideas to think about.

- *What should be communicated to youth/young adults and parents/caregivers about the differences between pediatric and adult care? (See Got Transition's System Differences Between Pediatric and Adult Health Care and Planning to Move from Pediatric to Adult Care? Here's How They Can Differ in Section IV).*
- *Create a checklist of items to include in the transfer package. What will be included in the transfer package for the adult clinician? A transfer checklist can help the practice be sure all the components of the transfer package are done for those youth/young adults leaving the practice (see sample transfer checklists in Section III).*
- *Prepare a transfer of care letter to the adult clinician.*
    - *What will be included in the transfer letter to the adult clinician? The amount of medical history detail included depends on if the letter is taking the place of a medical summary. This might happen, for example, if the youth/young adult has had no major medical problems; the letter could include only basic medical information such as immunization and key family history.*

Continued on next page

- *Decide if you will include in the letter the roles of the pediatric clinicians during the time between the last pediatric and first adult appointment. For example, who is responsible for refilling medications needed once the young adult has left the pediatric practice but not yet seen their new adult clinician?*
- *Decide if you will include in the letter whether the pediatric practice is willing to be available to the adult clinician for consultation throughout the transfer process.*

PROCESS

What is the process to implement a standardized transfer of care by developing a checklist, package and letter?

Below are some questions and ideas to think about.

- *When transfers to many clinicians are involved, it is easier if the transfer to the new adult clinicians (both primary and subspecialty clinicians) does not happen at the same time. Consider starting with transferring to an adult primary care clinician first who can assist the pediatric practice, youth/young adult and parent/caregiver with identifying other adult clinicians (e.g., subspecialists) as needed.*
- *If possible, it is better to transfer the youth/young adult into the adult health care system while they still have health insurance so the youth/young adult does not have to find both health insurance and a new clinician at the same time.*
- *How and when might the pediatric practice communicate with youth/young adults and parents/ caregivers about the differences between pediatric and adult care? Who in the practice might be the one to discuss it?*
- *Transfer checklist and package*
  - *How will you create a process to develop a transfer checklist and package?*
  - *How will you gain youth/young adult/parent/caregiver input into the transfer package?*
  - *What is the process to gather the appropriate up-to-date information for the transfer package?*
  - *Who is responsible for gathering the transfer package materials?*
  - *Who will create the letter of transfer?*
  - *Who obtains the legal approval from the youth/young adult/parent/caregiver to share the medical records in the transfer package?*
  - *Who is responsible for getting the transfer package to the selected adult primary care and, if needed, subspecialty care clinician(s)?*
  - *Who is responsible for confirming that the adult clinicians received the transfer package?*
  - *Who communicates to the youth/young adult/parent/caregiver and adult clinician the role of the pediatric practice in the care of the youth/young adult between the last pediatric and first adult clinician visit?*
  - *How does the pediatric practice standardize the level of communication needed by the pediatric practice with the adult practice for different levels of medical and social complexity for youth/young adults transferring their care (e.g., When is just a call or a letter or an email needed?)? If communicating directly with the new clinician(s), consider team meetings or the use of telemedicine including Facetime and ECHO.*
  - *Who is responsible for making the call, using telemedicine, and/or sending the letter or email?*
- *Create a written document to describe the clinic process to implement a standard transfer of care.*
- *Educate all team members/staff about the process.*

II. Quality Improvement Considerations, Tools, and Measurement

Quality Improvement Considerations

What should be thought about when forming a team? (See *Successful Teams* in the *QI Primer*)

- Include a representative from all areas of your practice
- Include a youth/young adult/parent/caregiver whenever possible
- Depending on what you are aiming to improve, consider any ad hoc members you might need (e.g., information services, lab, pharmacy, supply distribution, etc.)
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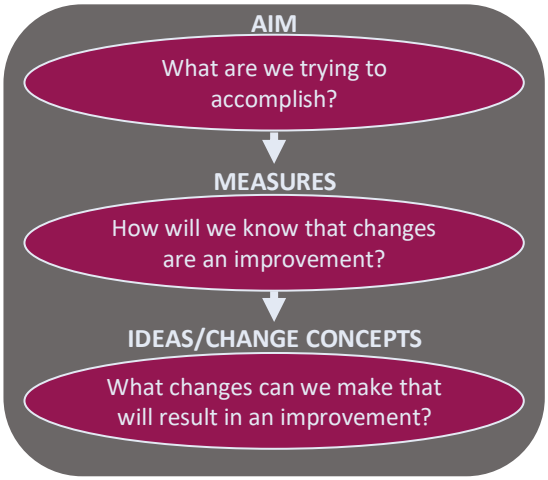

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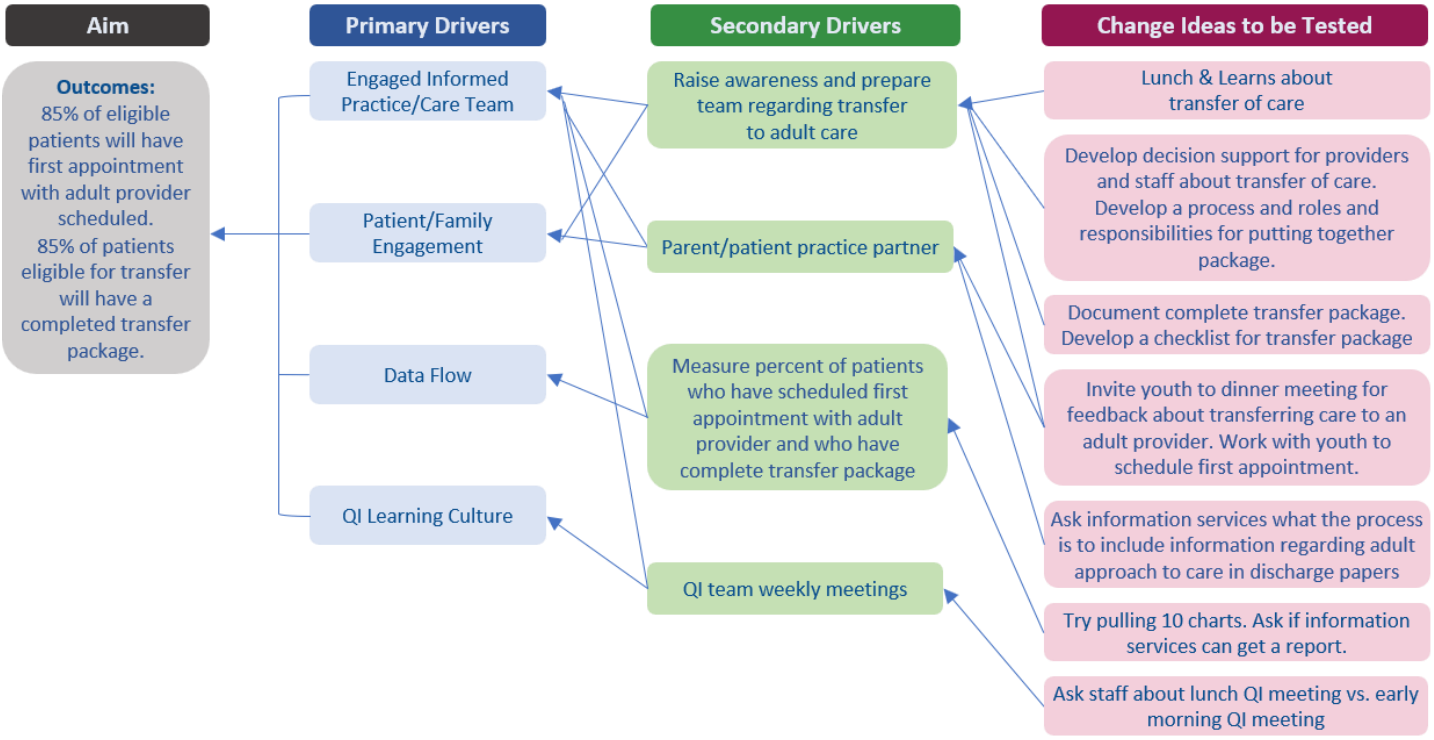
The aim statement is a written statement that describes the improvement effort and includes the rationale for doing the work, the target population, the time period of the work, and measurable numeric goals. For more information and examples, see *Model for Improvement* in the *QI Primer*.

Example Aim Statement

We aim to improve care for patients with sickle cell disease by ensuring effective transfer of care. By [insert date], 85% of eligible patients will have had their first appointment and 85% of eligible patients will have a completed transfer package.

Tool 2: Key Driver Diagram

Key driver diagrams (KDDs) require teams to identify their theories or "key drivers" which lead to outcomes. They help teams see relationships and organize work, especially in complex systems. They are frequently used for analysis, organization, and communication to direct improvement work. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



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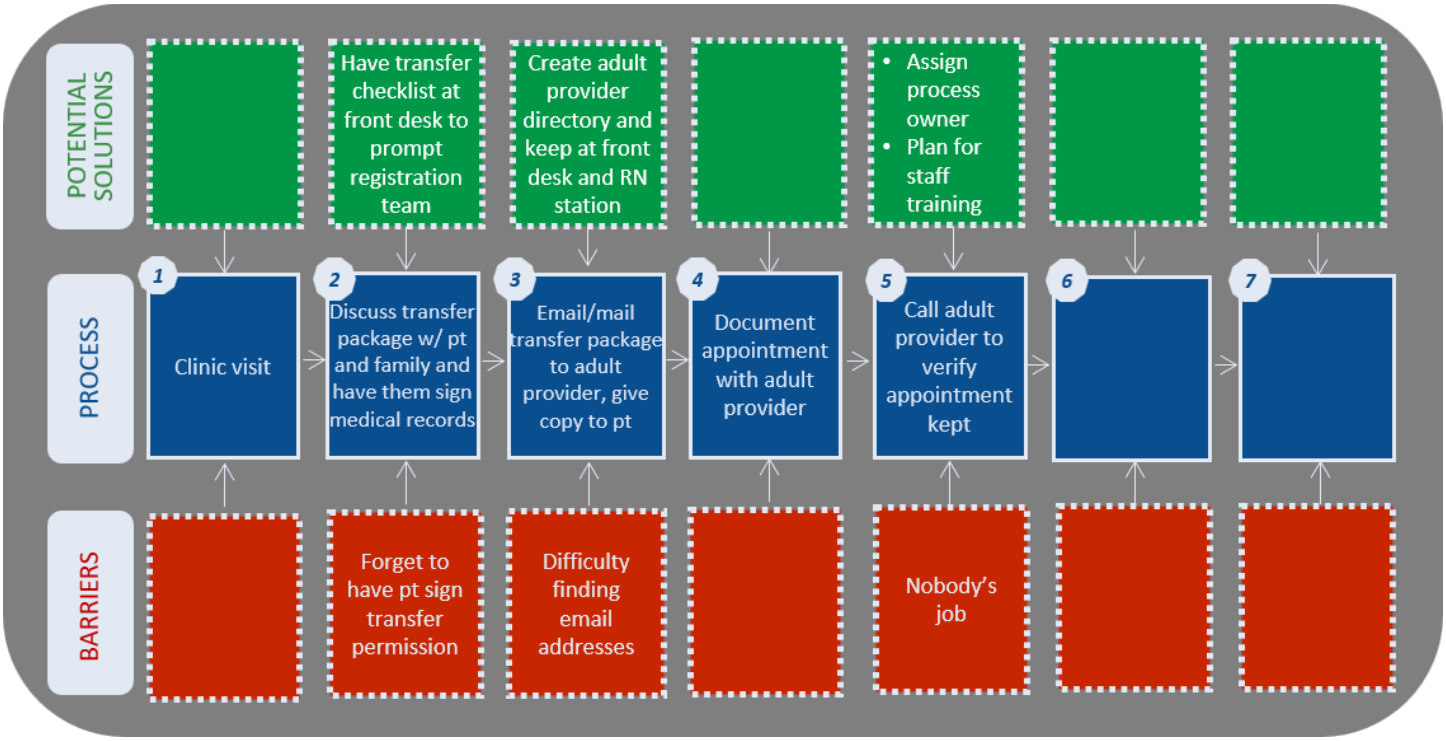
Tool 4: Simplified Failure Mode and Effects Analysis (sFMEA)

Simplified Failure Mode and Effects Analysis (sFMEA) is a proactive method for evaluating a process to identify where and how it might fail and to assess the relative impact of different failures, in order to identify the parts of the process that are most in need of change and help generate ideas to prevent those possible failures. This is a good companion to the flow map – a flow map lets you see the process as it is, and the sFMEA helps you look more closely to identify breakdowns. The example below has a few solutions filled in, to illustrate how teams might start completing an sFMEA. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



Adapted from the copyrighted Simplified Failure Mode Effects Analysis Worksheet (sFMEA) from Cincinnati Children's Hospital Medical Center. This version of the sFMEA has been modified and has been reprinted with permission.

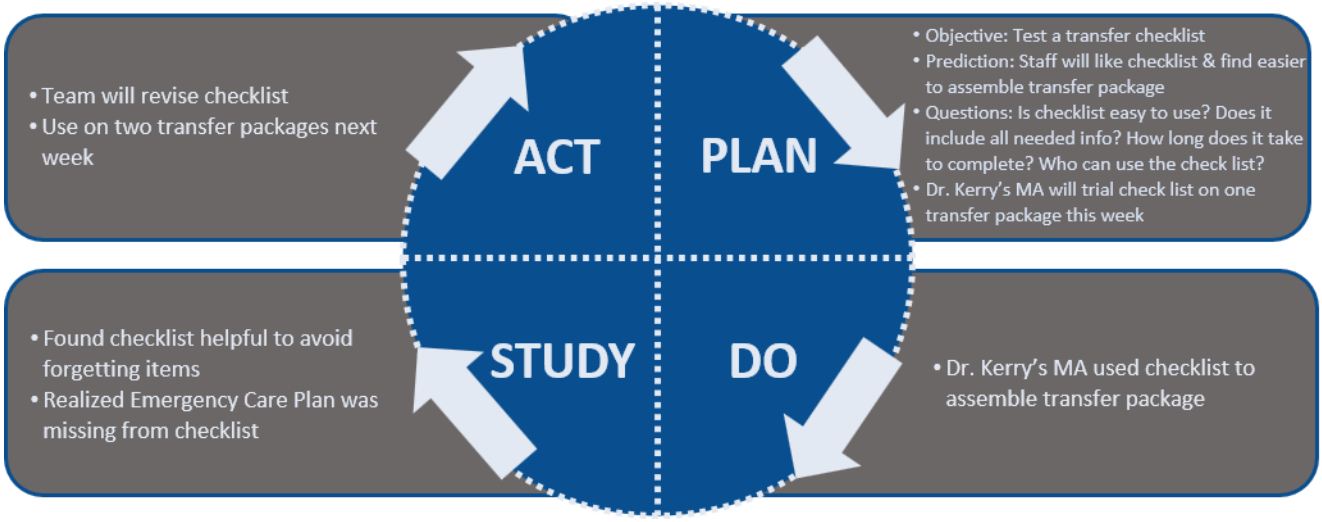
Tool 5: PDSA Cycles

PDSA cycles are a structured test of a process change. These are meant to be done rapidly, for example one patient, one afternoon, with one doctor. To accelerate learning and improvement, small tests with reflection allow for change ideas to be adapted, adopted, or abandoned easily within busy healthcare settings. Learning to do rapid cycle testing is key to keeping the momentum going; it is not necessary to schedule a full separate meeting, just a quick huddle allows teams to plan the next cycle. For more detailed explanation and a blank form, see *Model for Improvement* in the *QI Primer*. This effort includes:

- **Plan** the test: who, what, where, when;
- **Do** try the change and observe what happens;
- **Study** reflect on what was learned from the test; and
- **Act** decide next steps based on the reflection.

Examples of Ideas to Test

- Medical assistant to confirm first adult provider appointment
- Sample letter to adult provider about pending transfer
- Transfer package checklist



Adapted from AHEC QI 101, a Quality Improvement course sponsored by Charlotte Area Health Education Center.

Quality Improvement Measurement

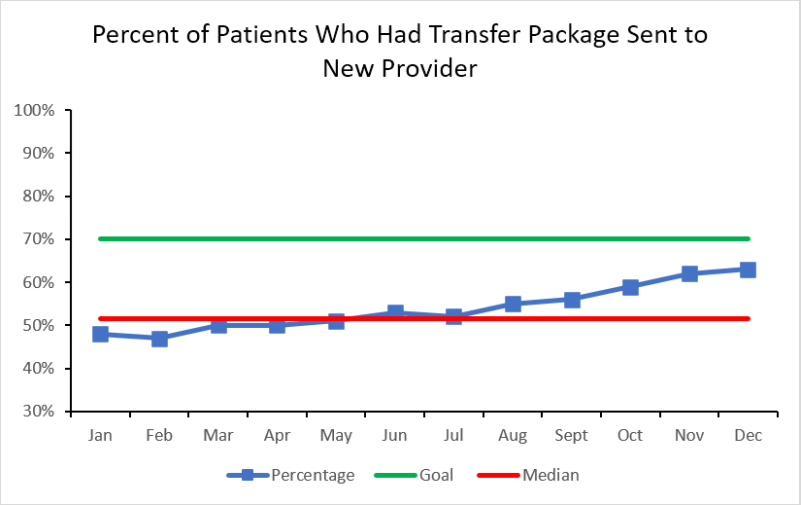
This step will sometimes be informal, while other situations will require a more formal process. Tracking your progress can be as simple as using a check sheet for a short period of time or a more formal use of a run chart which displays improvement over time. Specifically, the Current Assessment of HCT Activities or the HCT Process Measurement Tool in the Six Core Elements package can be used by teams to track progress of specific core elements or the overall HCT process. For more information and examples, see *Measuring for Improvement* in the *QI Primer*.

Example Data Collection Check Sheet

- ☐ Decide on the elements of the transfer package
- ☐ Track the amount of time it takes to complete the package
- ☐ For 2 weeks, track the number of possible transfers
- ☐ Track the number of patients that had an adult appointment

	Mon	Tues	Wed	Thurs	Fri
# possible transfers	||	||	|||	||||	||
# pts with adult appt		||	|	|	|

Data display is important for teams to assess the impact of the changes they are making. In QI, run charts are most often used. Run charts are a dynamic display of data over time. They require no statistical calculations and should be easily understood. Use a clear title. Data points are plotted around a median line. When possible, adding annotations to the chart to explain when certain changes were introduced can make the chart more informative and robust.



Sustain & Spread

For strategies on how to sustain and spread your work, please see Steps 6 and 7 in *How to Implement the Six Core Elements of Health Care Transition*.

III. Sample Transfer of Care Tools

Sample Transfer of Care Tools from the Six Core Elements of HCT™

- Sample transfer checklist from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*
- Sample transfer letter from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

Sample Transfer of Care Tools for Youth with Specific Conditions

- Transfer letter template for youth with sickle cell disease from University of Louisville Physicians *(click here)*
- Transfer letter template for youth with sickle cell disease from St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital *(click here)*
- Transfer of care checklist from St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital *(click here)*
- Transfer of care checklist from Atrium Health Levine Children's *(click here)*
- Sickle cell disease SMART Phrase resource for incorporating a medical summary into a transfer letter (*click here*)

Sample Wellness Plan for School Health Settings

- Sample mental health wellness plan from Mary's Center's school mental health program *(click here)*

IV. Additional Resources

- Turning 18: What It Means for Your Health (*click here*)
- Setting up the "Medical ID" Feature on Apple's Health App and on Android Phones (*click here*)
- System Differences Between Pediatric and Adult Health Care *(click here)*
- Planning to Move from Pediatric to Adult Care? Here's How They Can Differ *(click here)*

Transitioning Youth to an Adult Health Care Clinician

Core Element 6 – Transfer Completion

I. Purpose, Objectives, and Considerations

Purpose

Transfer Completion is the sixth element in the Six Core Elements of Health Care Transition™ (HCT). This includes confirming transfer completion, offering pediatric consultation (as needed), and assessing consumer experience with transition supports. Closing the loop by confirming that the youth/young adult, who has transferred out of pediatric care, has established care with an adult clinician is an essential part of this core element. In addition, evaluating the success of the HCT process, with a mechanism to obtain and incorporate feedback from youth, young adults, and parents/caregivers, will improve the practice's approach to HCT. *See sample feedback surveys in Section III.*

Objectives

Contact youth/young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm attendance at first adult appointment.

Elicit anonymous feedback from youth/young adult and their parent/caregiver on their experience with the transition process.

Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed.

Build ongoing and collaborative partnerships with adult primary and specialty care clinicians.

Considerations

CONTENT

What information might be considered in assessing transition feedback?

Below are some questions and ideas to think about.

- *Does the practice want to gain feedback from youth, young adults and/or parents/caregivers on their structured HCT experience?*
- *Does the practice want only the youth/young adult, or both the youth/young adult and parent/caregiver, to be part of the feedback process?*
- *Consider the HCT process in your practice/system. Which key components of your HCT process do you want feedback on from youth, young adults, and parents/caregivers?*
- *Does the practice want to use or customize Got Transition's HCT Feedback Surveys for Youth/Young Adults and Parents/Caregivers, which are based on components of the Six Core Elements, or use other existing consumer surveys and add HCT feedback questions?*
- *Does the practice/system want to obtain feedback from clinicians about the HCT process in your practice/system?*
    - *Consider the HCT process in your practice/system. Which key components of your HCT process do you want to elicit feedback on from clinicians?*
    - *Decide if you want to use or customize Got Transition's Clinician Feedback Survey. Alternatively, you could use other existing clinician feedback surveys and add HCT feedback questions.*

PROCESS

What process do you have in place to check if the youth/young adult has been seen by an adult clinician?

Below are some questions and ideas to think about.

- *Will the pediatric practice contact the youth/young adult directly or will the practice establish a routine process with the adult practice to be notified when the new youth/young adult comes to their first visit?*
- *Who in the pediatric practice will be in charge of checking whether the youth/young adult has actually been seen by the adult practice?*
- *What plan does the practice have to work with both the adult practice and the young adult if the young adult does not come to their new adult clinician appointment?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

What is the process for offering consultation to the adult clinician?

Below are some questions and ideas to think about.

- *Is offering consultation part of the transfer letter or a call to the adult clinician's office following transfer?*
- *Should consultation be offered for all transferring youth/young adults? Or a subgroup of patients?*
- *What is the extent of consultation support that can be reasonably made available?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

What is the process to obtain consumer and clinician feedback about your practice's transition process?

Below are some questions and ideas to think about.

- *If an available consumer HCT feedback survey has been customized (e.g., Got Transition's HCT Feedback Survey) or your practice/system has developed its own, is the reading level appropriate? Has it been tested with 3-4 older youth/young adults in your practice (who will be receiving the feedback survey) who have different levels of education to see if they have any difficulty understanding the questions or specific words? If so, make needed changes to the feedback survey and test again. A similar approach should be taken if the practice/system decides to also have parents/caregivers complete an HCT feedback survey.*
- *Once the HCT feedback survey is ready for use, identify and test the practice/system process on how it will be completed, ideally 3-6 months after the youth/young adult leaves the pediatric practice:*
    - *Identify eligible youth/young adults to complete the HCT feedback survey and decide:*
        - *When will it be offered? Will it be completed in the last pediatric practice visit or at the first adult practice visit? Will it be sent virtually shortly after the last pediatric visit?*
        - *How will feedback results be kept confidential?*
        - *Will it be completed in a paper form? If yes, determine how often and who will collect the information and collate the results.*

Continued on next page

        - *If the feedback survey is being completed at the new adult practice, how will the feedback results be obtained? If the survey is completed in paper form, how will the survey results be sent to the pediatric office?*
        - *How will the results be incorporated into an improvement process for the pediatric practice's HCT process, if needed?*
        - *Will the HCT feedback survey be completed via an online survey (e.g., Survey Monkey)? Who will review the results? When will they review the results and present them to the pediatric practice team for review and action if needed?*
- *Once your HCT clinician feedback survey is ready for use, it is time to identify and test the process for completing it and how the results will be shared so changes can be made if needed. Below are some questions and ideas to think about.*
    - *Who will complete the survey: clinicians including office staff?*
    - *How will the results be kept confidential?*
    - *Test the questions with a few staff to be sure the questions are clear.*
    - *Who will collect the survey?*
    - *Who will collate the results?*
    - *How will the results be incorporated into an improvement process for the pediatric practice's HCT process, if needed?*
- *Create a written document to describe the practice/system process to obtain feedback on the HCT process. Have this document available for the staff in case there are staff changes.*
- *Offer education to all team members/staff about the practice's HCT feedback process.*

II. Quality Improvement Considerations, Tools, and Measurement

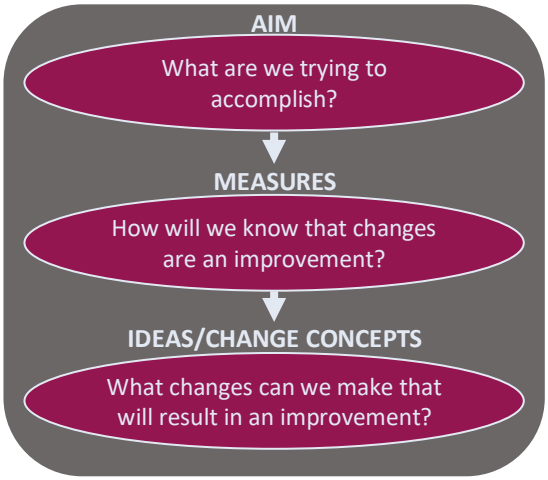
Quality Improvement Considerations

What should be thought about when forming a team? (See *Successful Teams* in the *QI Primer*)

- Include a representative from all areas of your practice
- Include a youth/parent/caregiver whenever possible
- Depending on what you are aiming to improve, consider any ad hoc members you might need (e.g., information services, lab, pharmacy, supply distribution, etc.)
- Schedule meetings or huddles

What is the Model for Improvement?

The Model for Improvement (see *Model for Improvement* in the *QI Primer*) is an approach to process improvement, developed by Associates in Process Improvement, which helps teams accelerate the adoption of proven and effective changes. The figure here illustrates the three questions that make up the Model for Improvement. This is a simple but robust model widely used for improvement in many industries, including health care.



Adapted from Langley GL, et al. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, 2nd ed. San Francisco: Jossey-Bass Publishers, 2009.

As you continue to work through this document and the Six Core Elements, you will find that the QI tools and other items below have been customized to each Element for each kind of practice. However, you will find the basic team considerations described above remain the same for most if not all of your QI work.

Quality Improvement Tools

The most important QI tools to guide a team's improvement work include ***Tools 1-5*** listed below. Using these tools in the following order will increase your chances of success, but teams can make modifications as needed. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

- ***Tool 1: An aim statement*** is a fundamental element of this model and answers the question of what you are trying to accomplish.
- ***Tool 2: Key driver diagrams*** allow teams to visualize the relationship between the project aim and contributing factors, helping them determine key actions necessary to meet this aim.
- ***Tool 3: Process flow maps*** can help you visualize the steps in your change process.
- ***Tool 4: The simplified failure mode and effects analysis*** form helps teams recognize what problems might arise in each step of the process and think of possible solutions.
- ***Tool 5: Plan-Do-Study-Act (PDSA) cycles*** allow teams to trial and learn from their process changes. Using Tools 1-4 before initiating a PDSA cycle helps teams assess root causes before jumping to solutions.

Tool 1: Aim Statement

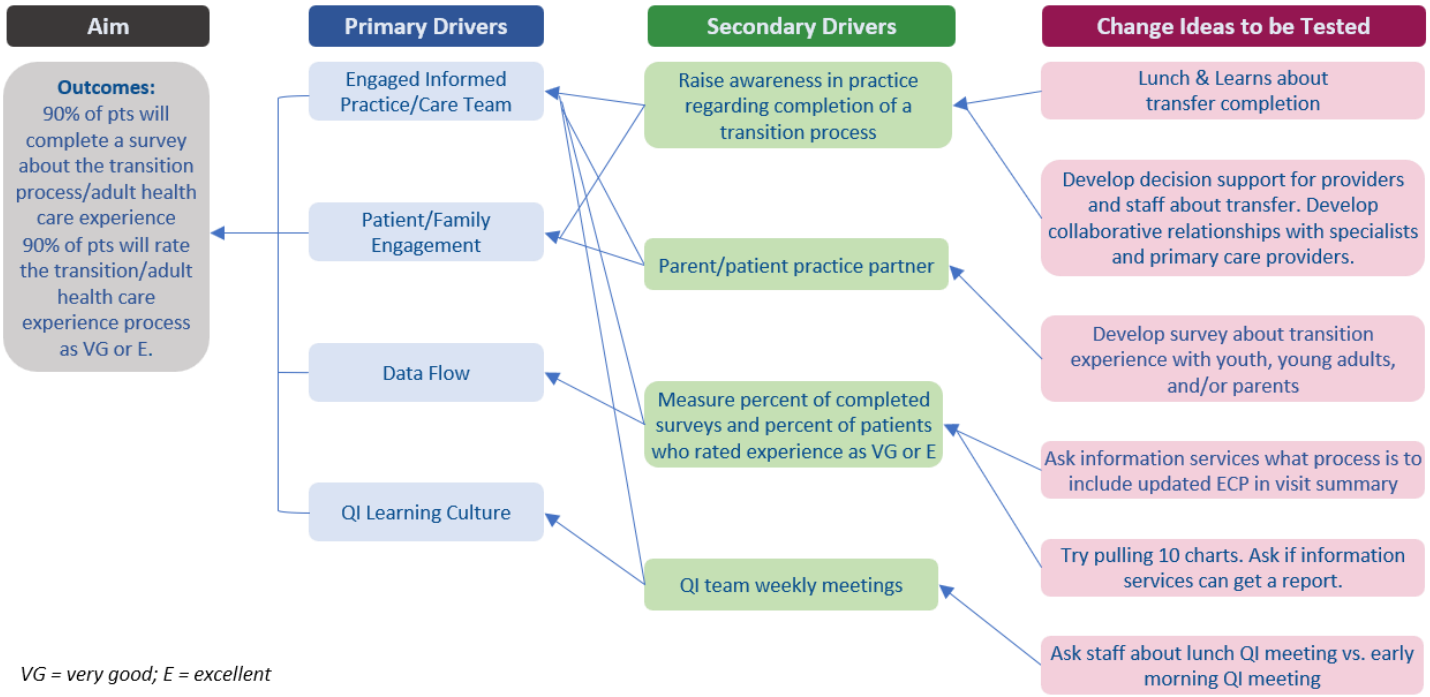
The aim statement is a written statement that describes the improvement effort and includes the rationale for doing the work, the target population, the time period of the work, and measurable numeric goals. For more information and examples, see *Model for Improvement* in the *QI Primer*.

Example Aim Statement

We aim to improve care for teenagers with diabetes by ensuring completion of a patient-centered transfer of care. By [insert date], 85% of eligible teenagers will have completed their first adult visit and 90% of families will rate their transfer experience as excellent.

Tool 2: Key Driver Diagram

Key driver diagrams (KDDs) require teams to identify their theories or "key drivers" which lead to outcomes. They help teams see relationships and organize work, especially in complex systems. They are frequently used for analysis, organization, and communication to direct improvement work. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

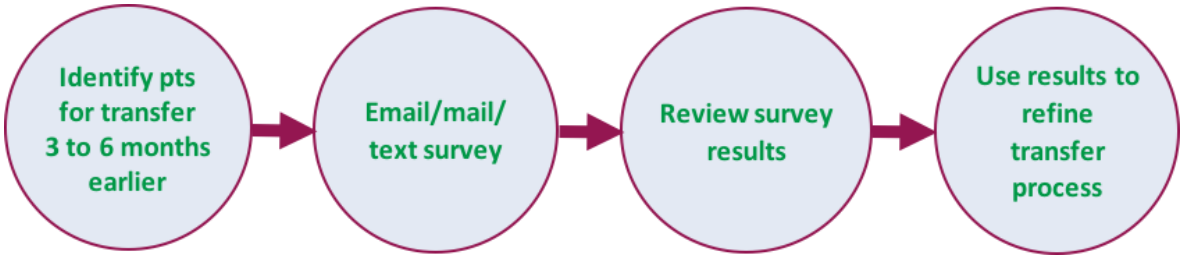


VG = very good; E = excellent

Adapted from ST3P UP, a collaborative sponsored by Patient Centered Outcomes Research Institute® (PCORI) Award MCSC-1608-35861 Titled A Comparative Effectiveness of Peer Mentoring Versus Structured Education Based Transition Programming For The Management Of Care Transitions In Emerging Adults With Sickle Cell Disease.

Tool 3: Process Flow Map

A flow map is a visual display of the separate steps in a process placed in sequential order. It is extremely helpful in documenting different views of the same process. It can show the sequence of actions, materials/inputs entering and leaving the process, decision points, and people involved. Flow maps can be used to document steps in the process of either how things are or how things could be. Posting the flow map gives staff an opportunity to clarify the steps in the process and can uncover conflicting understandings. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



Tool 4: Simplified Failure Mode and Effects Analysis (sFMEA)

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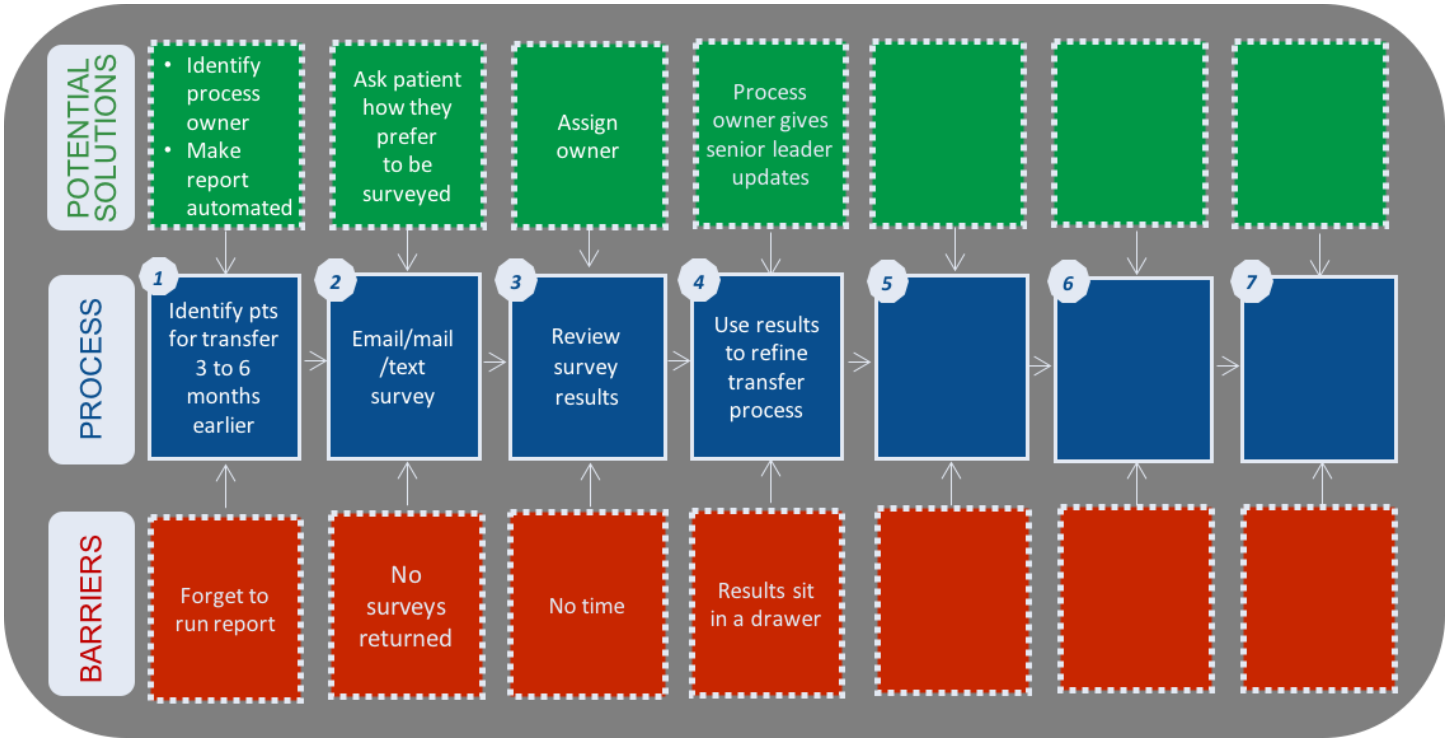

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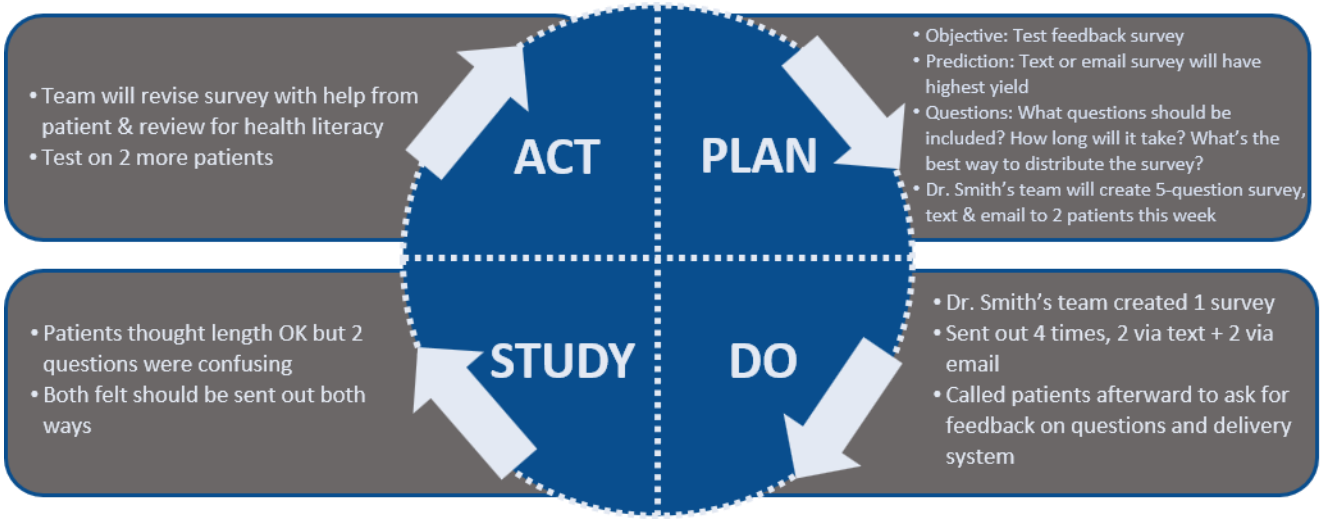
Tool 5: PDSA Cycles

PDSA cycles are a structured test of a process change. These are meant to be done rapidly, for example one patient, one afternoon, with one doctor. To accelerate learning and improvement, small tests with reflection allow for change ideas to be adapted, adopted, or abandoned easily within busy healthcare settings. Learning to do rapid cycle testing is key to keeping the momentum going; it is not necessary to schedule a full separate meeting, just a quick huddle allows teams to plan the next cycle. For more detailed explanation and a blank form, see *Model for Improvement* in the *QI Primer*. This effort includes:

- **Plan** the test: who, what, where, when;
- **Do** try the change and observe what happens;
- **Study** reflect on what was learned from the test; and
- **Act** decide next steps based on the reflection.

Examples of Ideas to Test

- Test feedback survey on one teen and one parent
- Test process for contacting teen/parent 3 months after transfer
- Test survey for adult providers on satisfaction with transfer process



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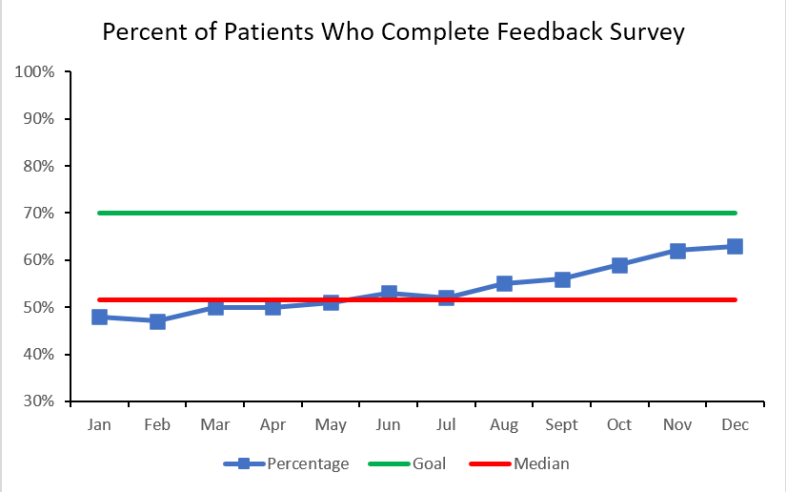
Example Data Collection Check Sheet

- ☐ Track the number of surveys sent.
- ☐ Track number of returned surveys.
- ☐ Assess themes from the surveys.
- ☐ Share feedback from the surveys with the team.

	Mon	Tues	Wed	Thurs	Fri
# surveys sent	||	||||	|||	|	||
# surveys returned	|	||	|		|

Data display is important for teams to assess the impact of the changes they are making. In QI, run charts are most often used. Run charts are a dynamic display of data over time. They require no statistical calculations and should be easily understood. Use a clear title. Data points are plotted around a median line. When possible, adding annotations to the chart to explain when certain changes were introduced can make the chart more informative and robust.



Sustain & Spread

For strategies on how to sustain and spread your work, please see Steps 6 and 7 in *How to Implement the Six Core Elements of Health Care Transition*.

III. Sample Health Care Transition Feedback Surveys

Sample Health Care Transition Feedback Surveys from Six Core Elements of HCT™

- Sample feedback survey for youth/young adults from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*
- Sample feedback survey for parents/caregivers from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*
- Sample feedback survey for clinicians from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

IV. Additional Resources

- Health Care Transition Timeline for Youth and Young Adults *(click here)*
- Health Care Transition Timeline for Parents/Caregivers *(click here)*
- Setting up the “Medical ID” Feature on Apple's Health App and on Android Phones *(click here)*

Suggested Citation: White P, Schmidt A, Ilango S, Shorr J, Beck D, McManus M. *Six Core Elements of Health Care Transition™ 3.0: An Implementation Guide.* Washington, DC: Got Transition, The National Alliance to Advance Adolescent Health, July 2020.

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