Strengthening Healthcare through Patient and Family Engagement in Quality Improvement and Research

A User's Guide for Patient and Family Advisors and Their Learning Healthcare Systems

Penn
University of Pennsylvania
Center for Patient Partnerships
University of Wisconsin-Madison
The Hastings Center

"It's certainly a priority for us to have patients and community members in every aspect of our work... there has to be a system in place to balance power, give them voice, and to make sure that they have an opportunity to provide input, and also evaluate the process."

Head of Research

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Background

We are a team of researchers and patient advocates. For three years, we explored how healthcare systems learn to improve their care, how they share what they have learned with other systems, and how patients and family members partner in this work. We have interviewed almost 100 healthcare system leaders and patient and family leaders from 16 learning healthcare systems, and have conducted focus groups with 77 patients, parents, and other family members, as part of this work.

This guide is primarily intended for patient and family members, acting on their own or within Patient and Family Advisory Councils (PFAC) or other committees, who seek to partner with their healthcare systems to improve care through quality improvement and research.

This guide can also be used by learning healthcare system personnel who seek to partner with patients and families to improve care.

What this guide covers

1. A definition of a learning healthcare system.
2. An exercise for assessing how your healthcare system functions as a learning healthcare system.
3. A description of the types of activities that learning healthcare systems may undertake to improve care.
4. Worksheets and exercises that will help you to:
    - Consider the types of learning activities your healthcare system engages in
    - Think about why specific issues or concerns are chosen for improvement
    - Evaluate how patients and families are engaged in those activities
    - Reflect on activities you would like to see your healthcare system commit to
    - Increase patient and family partnership with system leaders, quality improvement professionals, and researchers to advance learning and improve care
5. Ideas for expanding your role and influence in your healthcare system's learning mission.

What is a learning healthcare system? How does it learn?

The National Academy of Medicine (formerly the Institute of Medicine) first defined learning healthcare systems (LHS) in the early 2000s.

A learning healthcare system:

- Involves patients and families throughout the learning process
- Carefully studies how it cares for patients, and then uses what it learns to improve care
- Shares what it learns as widely as possible
- Is infused with a culture of learning

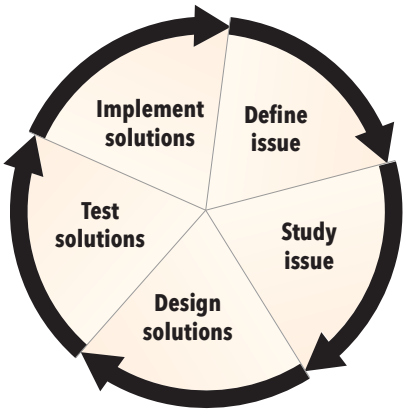
A learning healthcare system continuously improves patient care and the work environment of the people providing that care. As a result, patients benefit from consistently higher quality care that is safer, more efficient, cost-effective, and patient- and family-centered. The National Academy of Medicine, among others, believes that learning healthcare systems are an important way forward for American healthcare.

We discovered from our interviews that many learning healthcare systems wish to increase patient and family participation in the care improvement process. We also learned that including patients and family as advisors and partners is a long-term goal, one that few healthcare systems have yet to fully achieve.

"Learning healthcare system means that you use information and data from day-to-day care operations in a continuous cycle of improvement... that can be from research activities, it can be from quality improvement, it can be from even safety events, or any sort of patient experience that gets fed back into the system and then acted upon. That's how the learning health system should work."

Director, Quality Improvement

How healthcare systems learn



Want to know more?

Characteristics of a Continuously Learning Healthcare System – National Academy of Science
http://www.nationalacademies.org/hmd/Reports/2012/Best-Care-at-Lower-Cost-The-Path-to-Continuously-Learning-Health-Care-in-America/Table.aspx

Learning Healthcare Project – The Learning Healthcare Project
http://www.learninghealthcareproject.org/section/background/learning-healthcare-system

Learning Health Systems – Agency for Healthcare Research and Quality
https://www.ahrq.gov/learning-health-systems/index.html

Learning Health Systems – Wikipedia
https://en.wikipedia.org/wiki/Learning_health_systems

Ethical Oversight of Learning Healthcare Systems – Hastings Center Report Special Issue
https://onlinelibrary.wiley.com/toc/1552146x/2013/43/s1

A learning healthcare system partners with patients and families throughout the learning process

Learning healthcare systems recognize that partnerships with patients, families, and the community will ultimately lead to better care. In our study, we learned about a number of ways patients and family members can engage or partner with their healthcare systems, including:

- Completion of surveys and exit interviews
- Participation in town hall meetings
- Membership on Patient and Family Advisory Committees
- Service with healthcare system staff on committees; for example, hospital or health system health and safety committees, quality improvement teams or committees, and departmental committees like Cardiology or Pediatrics
- Participation as patient and family faculty and partners in research
- Service on hospital or healthcare system boards
- Partnership with doctors, nurses, and researchers to help lead quality improvement and research projects

"I think that we're deeply respected. I think we're esteemed. I think our voice is heard... I don't think it's unreasonable to also believe that we do have power and that our ideas—as rough around the edges as they may be... can be presented and used by the institution... can be heard and well-used and formulated for the betterment of both the population of patients and families and also for the staff."

Patient/Family Leader

In recent years, much work has been done to promote partnership between healthcare systems and patients and family members. There are many guides to building and strengthening these relationships. However, much patient and family engagement work has focused on the broad realm of improving communication and patient experience; there has been less emphasis on integrating patients and family members into the learning and care improvement process. There is growing awareness that patient and family advisors should be involved, from start to finish, in quality improvement and research activities.

The Head of Research at one of the learning healthcare systems interviewed for this project provided a good example of how this partnership around quality improvement and research can work:

Question: *Could you talk a little bit about how the learning healthcare program makes sure that these [quality improvement and research activities] are designed?*

Head of Research: *Oh, my goodness. We spend probably the largest amount of our time in the meetings talking about study design, so there are methodologists on the team, biostatisticians, clinical trialists. There are implementation scientists. There are researchers from all different disciplines who are on the team and review the protocols and have input into these before and after they're approved.*

Question: *How does the patient member participate in those kinds of discussions?*

Head of Research: *He is also present for those. He gets the proposals at the same time everyone else does. He has the same veto voting power as everybody else on the committee... he has the opportunity to ask questions and specifically how patients and families will be involved and how the information will be shared with them.*

For more information on patient and family engagement:

Patient Advisor Guide 1: Orientation for Patient Advisory Committees – Health Innovation Program
https://hip.wisc.edu/blog/patient-advisor-toolkit-1-orientation-patient-advisory-committees-pat-1-now-available

Guide to Patient and Family Engagement in Hospital Quality and Safety – AHRQ
https://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/index.html

Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit – IPFCC
https://www.ipfcc.org/resources/Patient-Safety-Toolkit-04.pdf

Patient Engagement in Redesigning Care – HipX
https://www.hipxchange.org/PatientEngagement

Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices – IPFCC
https://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf

A Toolbox for Creating Sustainable Partnerships with Patients and Families in Research – IPFCC
https://www.ipfcc.org/bestpractices/sustainable-partnerships/index.html

Strengthening the Diversity of Research Partnerships – IPFCC
https://www.ipfcc.org/bestpractices/strengthening-diversity/index.html

A learning healthcare system carefully studies how it cares for patients and uses what it learns to improve care

Learning healthcare systems study what happens within their systems to identify areas for improvement. They collect information about the issue, design quality improvement activities or research projects to study how best to improve care, put their findings into practice, and evaluate whether or not the changes implemented are successful in improving care. Learning healthcare systems collect data in a number of different ways.

"[Our system] is amazingly transparent with our families, which I know is a challenge sometimes. From what I gather, I think we have probably one of the most transparent hospitals and most innovative in patient family engagement. But I truly believe the philosophy of the hospital is that if we don't engage our families in these discussions or we're [not] transparent about it, our risk is greater. And the mission of our hospital is always to do what's best and to continue to improve our quality in the best way we can."

Patient / Family Leader

Some possible data sources are:

- Medical information contained in electronic health records
- Feedback from patients and families
- Feedback from healthcare system personnel
- Input from community groups

A learning healthcare system shares what it learns as widely as possible

The learning process can be expensive and time consuming, so learning healthcare systems share new knowledge and information about how to improve care as widely as possible. They share it both within their own organization and with other health systems. Mechanisms by which learning is shared include meetings, presentations, and publications.

A culture of learning infuses learning healthcare systems

The people we interviewed recognized that the process of becoming a learning healthcare system works best when system leaders are firmly committed to continuous improvement, and the idea of ongoing learning is embedded in the culture of the organization. Many also mentioned the need for transparency with patients, families, and the community.

"We give away everything we know."

Chief Executive Officer

"I think [our system] has done a very good job of taking those lessons learned and shared it with the national and international world."

Director, Quality Improvement

Signs that a healthcare system is a *learning* healthcare system

Most healthcare systems are still in the process of becoming fully evolved learning healthcare systems. And, as the name suggests, a learning healthcare system is always learning; its learning mission is never finished. But there are some ways to figure out to what extent a healthcare system is a learning system.

Signs to look for include:

Learning Healthcare System	Signs

Partners with patients and families throughout the learning process.
The inclusion of patients and families in the learning process is actively encouraged and supported. Patients' and families' perspectives, insights, priorities, and needs help ground the system.
	• Patient and Family Advisory Committees (PFACs) are actively engaged as partners in quality improvement and research efforts.
	• Patients and family members are involved in healthcare system committees as full members.
	  o Patients and family members are involved in committees relevant to their experience and interest.
	  o Any committee with patient and family members has at least two patient or family advisors on it.
	• Systems are in place to recruit, train, support, and recognize patient and family members interested in contributing to their healthcare system.
	• Systems are in place to solicit and use input from patients and families who are not serving on PFACs or committees. Examples might include surveys, focus groups, and community meetings.
	• The system shares accurate data with patient and family advisors. This information shows the system's strengths as well as areas that need improvement.
	• The system informs patients and families how their involvement and recommendations have been used and what changes resulted from their input.

Carefully studies how it cares for patients and uses what it learns to improve care. Electronic health records and other methods are used to gather and store information about care. That information is studied to improve patient care. Information about whether changes are properly and consistently implemented is also studied.	• The system has a fully functioning electronic health record. • The system invests in data analysts and other personnel so that it can collect and analyze information for quality improvement and research projects. • The system invests in technology and personnel to support implementation of quality improvement and research findings and to study the effects of changes that it implements.

Learning Healthcare System	Signs
Shares what it learns as widely as possible. Knowledge and information about how to improve care are shared within the organization and with other health systems	• The system publishes information about quality improvement and research activities on its website and in other materials in ways that are understandable to patients, families, and communities. • Staff, clinicians, and patient and family advisors present on the process and findings of projects and studies at public and professional meetings and conferences and publish in scholarly journals.
Nurtures a culture of learning. Leadership is committed to continuous learning, collaboration, and adaptability. Transparency is an important component of this culture.	• Mission and value statements explicitly mention learning, improving, and commitment to high quality, patient- and family-centered care. These statements are prominently displayed on posters, websites, computer screen savers, and in other informational materials for patients, families, staff, clinicians, administrative leaders, the governing board, and the community. • The system communicates its commitment to learning *with* as well as to learning *from* patients and families. • Leadership is visible. Leaders may round on wards and clinics or attend meetings of the Patient and Family Advisory Committee. • The system is transparent and willing to "own its errors."

I think of a healthcare system that's trying to always improve. I think about healthcare systems that are transparent because... there's a tight link between transparency... and the... willingness or desire to improve. We could always do better. We are by no means perfect.

Chief Experience Officer

EXERCISE: To what extent is my healthcare system a *learning* healthcare system?

Think about which of the following things your healthcare system does. It is likely that you won't know the answers to many of these questions; the purpose of this exercise is to help you identify areas that you may want to learn more about. If you don't know whether or not your system does something, think about who you might be able to ask.

By asking healthcare system leaders and employees about whether or not the healthcare system does some of the things on this list, you can encourage increased learning and improved patient and family engagement.

As you work through this exercise, remember that few learning healthcare systems do all of these things all of the time. Remember also that many systems may do some of these things in some places but not in others.

A learning healthcare system partners with patients as it learns.

Patient and Family Advisory Committees (PFACs) are actively engaged as partners in quality improvement and research efforts.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system partners with patients as it learns.

Patients and family members are involved in healthcare system committees as full members.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)
Systems are in place to recruit, train, support, and recognize patient and family members interested in contributing to their healthcare system.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system partners with patients as it learns.

Systems are in place to solicit and use input from patients and families who are not serving on PFACs or committees. Examples include surveys, focus groups, and community meetings		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)
The system shares accurate data about its strengths and weaknesses with patient and family advisors.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system partners with patients as it learns.

The system "circles back" to patients and families to let them know how their input has been used.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system carefully studies how it cares for patients and uses what it learns to improve care.

The system has a fully functioning electronic health record.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system carefully studies how it cares for patients and uses what it learns to improve care.

The system has invested in data analysts and other personnel so that it can collect and analyze information for quality improvement and research projects.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)
The system has invested in technology and personnel to support implementation of quality improvement and research findings and to study the effects of changes that it implements.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system shares what it learns as widely as possible.

The system publishes information about quality improvement and research activities on its website and in other materials in ways that are understandable to patients, families, and communities.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)
Staff, clinicians, and patient and family advisors present on the process and findings of projects and studies at professional meetings and conferences and publish in scholarly journals.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system nurtures a culture of learning.

Mission and value statements explicitly mention learning, improving, and commitment to high quality, patient- and family-centered care.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)
The system communicates its commitment to learning *with* as well as to learning *from* patients and families.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

A learning healthcare system nurtures a culture of learning.

Leadership is visible. Leaders may round on wards and clinics or attend meetings of the Patient and Family Advisory Committees.		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)
The system is transparent and willing to "own its errors."		
Yes (Note what you have seen)	**No**	**Don't know** (Whom can I ask? What did they say?)

"People who have never done it before always have some resistance to bringing patients on. They're worried that they're gonna slow things down or not understand. But honestly, once we bring patients in, it's usually a very positive experience for all. They greatly enrich the process, they bring important insights to the project."

Research Director

Learning Activities

Learning healthcare systems engage in learning activities such as quality improvement and research to determine how best to improve. A learning activity is a formal effort to define a problem, study it, design and test solutions, and implement those that are found to work.

There are multiple steps to conducting a learning activity. They include:

1. Identifying issues or problems that can be addressed through a learning activity.
2. Prioritizing which of the identified issues or problems the healthcare system will focus on.
3. Determining the best way to study the issue and collect information or data about it.
4. Collecting and analyzing data and information.
5. Using the results to make changes.
6. Checking to see if the changes are having the desired impact.
7. Making adjustments if needed.
8. Sharing what has been learned with other healthcare systems so that they too can benefit from the learning.
9. Ensuring that patients' rights are protected at all stages of learning.

Learning Activity Examples

Following are a few examples of learning activities that a healthcare system might undertake. Note that patient and family involvement in these activities can vary tremendously. For example, sometimes patient and family advisors help by identifying problems or providing suggestions for change. Other times, patients and families are included as full partners in study design, analysis, and reporting. It is also possible for patients and families to take the lead on developing or implementing learning activities.

Please note: These learning activity examples are for illustration only. To our knowledge, these studies have not been conducted.

Example 1:
Using the electronic health record to understand and solve a problem

Wait Times at an Outpatient Clinic

A hospital Patient and Family Advisory Committee (PFAC) raises concerns that wait times at many of the system's primary care outpatient clinics are too long. Because the issue has a negative impact on patient experience and may cause some patients to delay seeking care, the healthcare system decides to look into this issue. Results from patient surveys and analysis of the electronic medical record confirm that wait times are excessive. Further investigation, using the electronic medical record, determines that wait times are at their worst on Friday afternoons and that these long wait times seem to be related to a high number of walk-in patients. The healthcare system decides to focus on reducing Friday afternoon wait times.

For several weeks, staff and trained patient volunteers conduct brief interviews with Friday afternoon walk-in patients at two of the healthcare system's outpatient clinics. The healthcare system learns that many people who walk in on Friday afternoons came because they fear they will get worse over the weekend and will have no place to go for treatment other than the emergency room.

Based on what it has learned, the healthcare system extends its outpatient hours for sick visits at the two clinics studied to include Saturday and Sunday mornings. The healthcare system continues to monitor outpatient wait times. It finds that in the six months after opening the weekend clinic, the number of Friday afternoon walk-ins dramatically declines, and Friday afternoon wait times have dropped. Based on these findings, the healthcare system implements Saturday and Sunday sick-patient clinic hours at all their outpatient primary care clinics. It studies the impact of this change across the system and finds that at all the primary care outpatient clinics, Friday afternoon walk-ins decrease and wait times decline.

The healthcare system sends a letter to all patients who use the primary care outpatient clinics to let them know that Saturday and Sunday hours for sick visits are now available system-wide. In the letter, it describes the quality improvement project and thanks the PFAC for bringing the issue to its attention. It also thanks the volunteers and staff who conducted interviews and the patients who participated in the study.

Example 2:
Using research methods to test a change in healthcare system practice

Taking Medication as Prescribed

Physicians note that many recently discharged hospital patients don't take the medications prescribed for them. This observation is confirmed through review of the medical records for individuals discharged system-wide. The healthcare system considers this a serious problem, one that may result in people getting sicker or being readmitted to the hospital, so system leaders make it a priority to investigate this issue.

The task of figuring out why this is happening and what can be done to address it is given to the health system's Research Institute. Institute personnel consult with the Patient and Family Advisory Committee (PFAC) and front-line hospital staff on how best to study this issue. Both have heard many explanations for why people might not take their medications once they leave the hospital. Institute staff work with both groups to develop a list of possible reasons. They decide that short interviews with recently discharged individuals may be the best way to get good information.

Because this study involves consulting the medical record to obtain the names and contact information for people who were recently discharged, the Institutional Review Board (IRB) is asked to review the study to evaluate any possible risks to those who will be contacted. Though the IRB recognizes that there is the potential risk of a loss of confidentiality, it agrees that strong safeguards are in place to prevent this, and it authorizes the study to go forward.

The interviews are designed and conducted by a team composed of Research Institute staff along with patient and family members who work with the Institute. They learn that after a hospital stay, many patients and families are too overwhelmed to get new prescriptions filled. In response, the healthcare system develops a process where, when discharged, patients are sent home with a one-month supply of any new medications.

As a follow-up, the research team reviews the medical records of those receiving the one-month supply. They learn that for patients who are over 75 years old, once the one-month supply is gone, many prescriptions still are not filled. A test is then set up to study how this issue might be addressed. Half the individuals in this high-risk group receive assistance setting up mail-order delivery of all medications. The other half of those over age 75 do not receive any assistance beyond what is provided to all discharged patients.

The research team monitors this trial procedure for six months and finds that those in the group receiving help with mail order medications are much more likely to fill and take their prescriptions. The new process is implemented across the system to assist those over age 75 with obtaining their medication.

Two patient and family members of the research team and a nurse give a presentation about this study at a regional meeting on improving hospital care. As a result, five other hospitals implement the process for ensuring that discharged patients have access to needed medications.

Example 3:
Monitoring a change in practice

Reducing Surgical Interventions

The three patient and family members of a healthcare system's Health and Safety Committee encourage the system to look closely at how often and why a common surgical procedure is performed. This procedure is financially advantageous to the system, but it is costly to patients and has significant risks. Research done elsewhere suggests that the procedure is performed more often than necessary at many systems nationwide.

The healthcare system agrees to look into this further. It studies the medical record, which has information about the medical status of patients receiving the procedure, and realizes that it may indeed be performing the procedure more often than is necessary. Working with physicians and other clinical staff, the Health and Safety Committee (which includes three patient/family members) develops new guidelines for assessing when the procedure is appropriate. After the guidelines are put in place, the committee continues to monitor the situation. They find that the number of procedures conducted has gone down by 20%. Patients who do not receive the procedure do not seem to suffer adverse consequences.

Physicians in this area of practice, along with patient and family members who helped create the new guidelines, report on their findings at a national meeting. The healthcare system includes information about the study and about why it is now performing fewer of these procedures on its website.

Example 4:

Establishing a partnership between the healthcare system and the community

Working Together to Address the Opioid Crisis

A rural healthcare system is the main provider of medical services to a community hit hard by the opioid epidemic. Over ten years, overdoses have increased dramatically, and emergency rooms, beds, and outpatient placements in the system's substance use disorder treatment facilities are increasingly occupied by patients with opioid addiction. In addition, a recent employee survey found that over 50% of the system's employees (including nurses and doctors) have had a relative or friend who has struggled with opioid addiction.

Within the healthcare system's service area, a grass-roots community group has sprung up to provide education and support about opioid addiction. Most members of the group have lost someone to addiction. The group is well informed, passionate, and members span multiple age, economic, educational and income groups. The healthcare system recognizes the group as a natural ally.

The healthcare system proposes supporting a healthcare researcher and a data analyst to collaborate with the community group to review existing health system data, consider additional interventions, test effectiveness, and get the word out to the broader community. The community group accepts the offer and the team begins its work. For the first few months, the researcher and data analyst collect information the community group has requested as well as information they think may be useful to the team. The information is pulled from the healthcare system's medical record with all identifiers removed so that confidentiality of patients is protected. After consideration of the data and much discussion, the team decides to focus on community response to overdose.

The team enlists the support of the healthcare system physicians. All patients will be asked, at every primary care visit, if they would like to receive a naloxone rescue kit and be trained in its use (naloxone is a drug that can prevent fatal opioid overdoses). Those interested will have the opportunity to watch a brief video, ask questions of a nurse, and receive the rescue kit before leaving the office. If they are not able to receive training at that time, they can schedule a time to return for the training. Additionally, the community group offers several drop-in times per week at several locations throughout the region where people can receive the training and kits.

The healthcare system sets up prompts in the electronic health record (EHR) so that doctors do not forget to ask their patients these new questions. Patients' responses, and whether they completed the training and received the rescue kit, are recorded. The community group keeps records of how many people access the training and kits, and shares it with the healthcare system representatives as part of the data collected for the project.

De-identified data from the EHR and data collected by the community groups are compiled. Everyone, but especially the healthcare system leadership, is surprised by the high percentage of patients who participate in the training and receive the kit.

Looking at the data, the community group and the healthcare system recognize that it is not possible to tell if or how many overdose deaths were prevented by the intervention; however, the uptick in the number of people receiving naloxone before the arrival of first responders and in the number of kits distributed suggest that the collaboration between the health system and the community is having a positive impact.

Since there is some evidence that the partnership intervention may have resulted in fewer overdose deaths, and since healthcare system leadership views community service as an important component of the system's mission, it decides to continue to support the healthcare researcher and data analyst as part of the community team as it works to identify additional responses to the crisis.

Dissecting a learning activity

The following sample exercise is illustrated using Example 2: Using research methods to test a change in healthcare system practice – Taking medication as prescribed.

Learning activity steps	Why or how was this step taken?	Ways patient and family might be involved
Identify an issue or problem that can be addressed through a learning activity.	Many recently discharged patients are not taking the medications prescribed for them.	Feedback from patients and family members helps to identify the issue. Feedback may be received through surveys, complaints, or at Patient and Family Advisory Committee meetings.
Prioritize which identified issues or problems the system will focus on. Why was this issue chosen?	Because people may get sicker or be readmitted to the hospital as a result of not taking their medication, this issue is prioritized.	Patients and family members might advocate for making this issue a healthcare system priority.
Determine the best way to study the issue and collect information or data about it.	The Research Institute, working as a team with patients and family partners, leads the study.	Work with the Research Institute to develop interview questions and a system for ensuring that many different types of people with different types of medical issues will be interviewed.
Collect data and information.	Patients recently discharged from the hospital are interviewed. Interviewers learn that the main reason prescriptions are not filled and medications are not taken is because people are overwhelmed when they get home.	Members of the Patient and Family Advisory Council might join healthcare system staff as they conduct some of the interviews.
Implement the new plan.	All discharged patients leave the hospital with a one-month supply of medications.	Patient and Family Advisory Council meetings might review data on how implementation is going.
Study to see if the changes are having the desired impact.	While most people are now refilling their prescriptions before the one-month supply runs out, many patients who are 75 and older are still having problems filling their prescriptions and taking their medications.	The team leading the learning activity might report to the Patient and Family Advisory Council on how the program is affecting whether patients fill their prescriptions.

Learning activity steps	Why or how was this step taken?	Ways patient and family might be involved
Make adjustments if needed.	Conduct a test to see if helping those over age 75 set up mail-order prescription service before leaving the hospital will address the issue. Half of those over 75 receive help and half continue to receive the one-month supply. Collect data for six months. Learn that those receiving mail-order prescription assistance are more likely to fill and take their prescriptions.	Work with Research Institute to design the test. Work with the Research Institute to interpret the data.
Ongoing monitoring.	Continue to track that the improvement in medication use endures over time.	Work with the Research Institute to review data.
Share what has been learned with other hospitals or health systems.	Two patients and family members and a nurse involved in the project present on this study at a regional meeting on improving hospital care. Five hospitals implement this process.	Present on findings at meetings.
Ensure that patients' rights are protected throughout the course of the activity.	The Institutional Review Board (IRB) is asked to review this study to evaluate any possible risks. The IRB determines that the study can go forward.	Assist in preparation of documents for IRB review. Serve as community member on IRB.

Learning activity exercise: Have you been engaged in one of your healthcare system's learning activities?

Instructions:

Think about a learning activity that you have been engaged in, or that the patient/family advisory group you work with has been engaged in. See how many parts of the table you are able to complete.

If there are sections of the table that you cannot complete, consider working with your contacts within the healthcare system to learn more.

- Were these steps conducted by the system and, if so, how?
- If they were skipped, why?

After completing this exercise, if you find it helpful, you can repeat it for other learning activities—either ones that have already been completed or ones you would like to see the healthcare system tackle in the future. Doing this exercise for several learning activities may help you to see what parts of learning your healthcare system is doing really well. Doing the exercise can also help you see where you and your group can most effectively promote sound learning practices and increased patient and family collaboration in the learning process.

Describing a healthcare system learning activity

Briefly describe the learning activity:	
How did this issue or problem come to the attention of your healthcare system?	
How were patients & families involved?	
How did your healthcare system decide to prioritize this issue? Why was it chosen for a learning activity?	
How were patients & families involved?	
How did your healthcare system decide on the best way to study the issue and identify ways to address it?	
How were patients & families involved?	

Describing a healthcare system learning activity

How did your healthcare system collect data and information related to this issue?	
How were patients & families involved?	
How did your healthcare system go about implementing the new plan?	
How were patients & families involved?	
How did your healthcare system go about studying how well the improvement plan worked?	
How were patients & families involved?	
How did your healthcare system share what it learned from this learning activity with other hospitals or health systems?	
How were patients & families involved?	
How did your healthcare system ensure that patients were protected throughout the course of the activity?	
How were patients & families involved?	

Expanding the role of the patient and the family members in the learning mission

We hope that this guide has provided you with useful information about how learning healthcare systems learn. We also hope it has provided ideas for how you, as well as the patient and family members whom you work with, can encourage your healthcare system to promote learning that improves care.

At this point in the evolution of learning healthcare systems, it is uncommon for patients and family members to be involved in every step of the learning process, though many systems are interested in changing this.

Ways that you can help promote collaboration with patients and families in a learning healthcare system include:

- Share and discuss this guide with other patient and family leaders.
- Identify who at your healthcare system is best positioned to support the engagement of patient and family members in learning and invite them to your Patient and Family Advisory Committee meetings or other meetings. Among the staff and leaders you might reach out to are:

  Chief Quality Improvement Officer

  Chief Medical Officer

  Chief Nursing Officer

  Chief Experience Officer

  Staff Liaison for the Patient and Family Advisory Council
- Discuss the desire of patient and family leaders to be more actively and integrally involved in quality improvement and research with leaders in your health system.
- Use the last worksheet, *Describing a healthcare system learning activity*, as a template for planning and conducting a learning activity, and working together with health system clinicians and staff to encourage further patient and family partnership in quality improvement and research.

Please let us know if this guide was helpful to you, or how we can improve it, by contacting Dr. Steven Joffe (joffes@upenn.edu) at the University of Pennsylvania Perelman School of Medicine.

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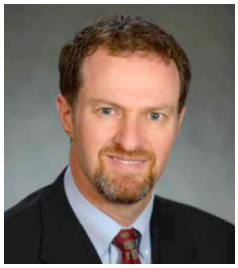
Research team



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