
Patient Engagement in Redesigning Care Toolkit



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The Patient Partners Welcome Packet and Patient Engagement Toolkit for Team Members follow the introductory information in this PDF, and are also available for download as separate files in Word format on <http://www.hipxchange.org/PatientEngagement>.

Use of the Toolkit



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This toolkit exists for the benefit of the health care community. These materials are available free of charge and can be used without permission; however, we ask that you register with HIPxChange prior to using the toolkit so that we may provide information on usage to our funders. It is acceptable to link to this Web site without express permission. If you decide to use these materials, we ask that you **please credit the Center for Patient Partnerships, UW Health, Primary Care Academics Transforming Healthcare, and the UW Health Innovation Program.**

Background

Engaging patients in healthcare quality improvement and system redesign has become increasingly recognized as a key component of redesigning the US health care system to support patient-centered, high-quality primary care due to the recognition that patients play an integral role in the improvement of quality and safety. This is evident in national guidelines and certification processes. For example, the medical home certification program through the National Committee for Quality Assurance and the final rule of the Centers for Medicare and Medicaid Services' Accountable Care Organization Shared Savings Program require that patients participate in governance and quality improvement activities.^{2, 3}

Definition of Patient Engagement

“An active process of ensuring that our patients’ experience, wisdom and insight are infused into individual care and the design and refinement of our care systems”¹

In a framework for patient engagement published by Kristin L. Carman and colleagues in *Health Affairs*,^{4, 5} patients are engaged at three levels: *direct care*, *organizational design and governance*, and *policy making*. In an innovative program to engage patients in large-scale primary care transformation at UW Health—a large, academic health system in Madison, Wisconsin—patients were actively engaged in a process to redesign care at the *team* level, which we defined as a small care unit consisting of a care team, their panel of patients, and the core processes that produced the patterns and norms of the unit.⁶ This effectively filled in the gap between the “direct care” and “organizational design & governance” levels in the patient engagement framework.

See the following article for details on the patient engagement process that we undertook and lessons that we learned.

Key Reference

Caplan W, Davis S, Kraft S, et al. “Engaging patients at the front lines of primary care redesign: Operational lessons for an effective program.” *Jt Comm J Qual Saf* 2014;40(12).

During this process, several materials were developed to help strengthen the role of patients in designing health care delivery and quality improvements.

What is in this toolkit?

This toolkit contains the following materials, which were developed as part of the patient engagement process described above.

Toolkit Contents

What is it?	Who is it for?	What is in it?
Patient Partners Welcome Packet	Patients who will be participating in quality improvement activities at your organization	Orientation information to help patients feel comfortable with participating in meetings and quality improvement activities, such as: <ul style="list-style-type: none"> • The value of being a patient partner • Patient engagement program philosophy • Goals of quality improvement • Examples of team-based quality improvement work • Tips for successful service • Other information and references
Patient Engagement Toolkit for Team Members	Employees in your organization who will be working with patients on quality improvement	Tools that team members will need to successfully engage patients, such as: <ul style="list-style-type: none"> • Definitions and principles of patient engagement • How to successfully identify, recruit, invite, and match patients to jobs within the project • Creating a welcoming environment • Celebrating successes • Capturing lessons learned

These materials are intended to serve as a starting point for customization by your organization to match your goals, processes, and patient engagement strategies.

Who should use this toolkit?

This toolkit is intended for hospital and clinic directors, managers, clinicians, and researchers who are interested in the framework and tools for engaging patients as partners in health system quality improvement and change initiatives.

The importance of customizing this toolkit

The toolkit materials are designed to be customized for your organization. Places within the toolkit that are meant to be customized are indicated in **[highlighted brackets]**. To this end, while the materials are included in this PDF file for your reference, they are also available for download as editable Word files on the HIPxChange website (www.hipxchange.org/PatientEngagement).

Customization by your organization is essential to match your goals, processes, and patient engagement strategies, and to authentically value your patients' contributions. Each

organization and initiative may have a unique vision about why and how patients are being engaged. Standardization in health care has shown significant value in improving quality and safety when applied in strategic ways.^{7, 8} Relational activities, however, such as engaging patients in a process to ensure that their insights and values contribute to quality and safety, must be implemented in a tailored and nimble way for maximum effect.^{9, 10}

Toolkit efficacy

The Patient Engagement Program for which these tools were originally developed was evaluated using an outcomes-oriented approach,¹¹ with mixed methods in a longitudinal design.

The results from this program evaluation demonstrated that program participants learned how to engage patients, gained confidence in the task, and believed in the value patients bring to quality improvement.

In addition, despite initial skepticism, over time, team member attitudes about patient engagement improved. Teams that engaged patients utilized their input to change processes, communications, and physical layouts.

A portion of this data was presented at a workshop at the 2013 Wisconsin Health Improvement and Research Partnerships Forum (September 12-13, 2013, Madison, Wisconsin), and a publication with these results is forthcoming.

Consulting services available upon request

The toolkit provided here was part of a comprehensive training program created for the Patient Engagement Program, which included training on multiple levels with system leaders, quality improvement coaches, participants in the primary care transformation effort, and individual teams.

In addition to those materials provided in this toolkit, the Patient Engagement Program also developed additional materials, including a Resource Guide resulting from an extensive process to develop healthcare system policies & procedures related to patient engagement. The table on the beginning of the next page describes these materials.

If you are interested in a consult for your organization or have any questions, comments, or suggestions regarding the Patient Engagement in Redesigning Care Toolkit, please contact Sarah Davis at sarah.davis@wisc.edu.

Additional Materials Created for the Patient Engagement Program

What is it?	Who is it for?	What is in it?
Patient Partner Quality Improvement Packet: For the Truly “QI Curious”	Patients who will be participating in quality improvement activities at your organization	Extensive detail about QI tools and methods for patients engaged as team members. It includes explanations regarding industrial engineering tools such as the Plan-Do-Check-Act cycle, process mapping, and fishbone diagramming.
Engaging Patient Partners for Better Care: Getting Started & Vital Resources Guide	Employees in your organization who will be working with patients on quality improvement	Internal information designed to help clinic managers, coaches, and team members understand regulatory and confidentiality issues, internal policies and procedures, internal resources, and opportunities/authorizations for marketing related to the project.
Patient Engagement Toolkit for Coaches	QI coaches in your organization who will be working with team members and patients	Similar content as the Patient Engagement Toolkit for Team Members included in this toolkit, but more comprehensive and aimed towards coaches who will be leading teams.

Development of this toolkit

This toolkit was developed by Sarah Davis, JD, MPA and Martha E. Gaines, JD, LL.M, both of whom are from Center for Patient Partnerships and the University of Wisconsin – Madison Law School. This was developed in collaboration with UW Health and made possible by funding from University of Wisconsin Medical Foundation. A participant engagement model was used for this program; as a result, some sample resources provided in this toolkit were created in collaboration with participating UW Health Microsystem team members.

Research on the efficacy of the Patient Engagement Program was led by Nancy Pandhi, MD, MPH, PhD from the University of Wisconsin Department of Family Medicine. The project was supported by the Community-Academic Partnerships core of the University of Wisconsin Institute for Clinical and Translational Research (UW ICTR) through the Clinical and Translational Science Award (CTSA) program, previously through the National Center for Research Resources (NCRR) grant 1UL1RR025011, and now by the National Center for Advancing Translational Sciences (NCATS), grant 9U54TR000021. Nancy Pandhi was supported by a National Institute on Aging Mentored Clinical Scientist Research Career Development Award, grant number 1 K08 AG029527. This project was also supported by the UW School of Medicine and Public Health from the Wisconsin Partnership Program, the University of Wisconsin Carbone Cancer Center (UWCCC) Support Grant from the National Cancer Institute, grant number P30 CA014520, and the Primary care Academics Transforming

Healthcare Writing Collaborative (PATH). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH or the United States government.

We would also like to acknowledge the contributions of the following people to this project: Marc Korobkin, JD; Stephanie Berkson, MPA; Susan Ertl, MSN, RN; Pratik Prajapati, MHA; Celeste Demitrios; Lauren Fiedler, MS; Pamela Kittleson, RPh; William Caplan, MD; Sally Kraft, MD MPH; William Schwab, MD; Zaher Karp; members of PATH; and the UW Health Microsystem team members, coaches, and patients who participated in the program.

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Patient Partner Welcome Packet

Quality improvement volunteering at
[Insert Name of Organization] for the
[XXX] Team

*[To be modified by each team to match
each specific engagement context]*



Credits: University of Washington Medical Center Patient and Family Centered Care “Volunteering as a Patient Advisor” Brochure, National Information Center for Children and Youth with Disabilities, A Parent’s Guide: Serving on Boards and Committees, October 1998; Langley et. al. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, 2nd Ed. Wiley, 2009; Microsystem Cliff Notes, September 2009, available at: http://dms.dartmouth.edu/cms/toolkits/getting_started/cliff_notes_booklet.pdf or www.clinicalmicrosystem.org; QI Example graphics used with permission from The Advisory Board Company.



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ADD A PICTURE OF YOUR TEAM HERE

Caption for the photo here



Welcome!

Welcome from [insert organization name]
Health Leader(s)

Every day at [insert name of organization], we have the privilege of caring for **thousands** of patients and families. Our goal is to provide the highest quality care in a compassionate, patient- and family- centered environment.

We are so fortunate to have your help.

You offer a valuable perspective: the patient's point of view. Your input helps us provide the best care possible – it's as simple as that.

Thank you for your service.

[Name(s) and title(s)]

Welcome from [insert name of Team, and members]

Thank you so much for volunteering to be a Patient Partner!

Your efforts to improve healthcare will help providers as well as your fellow patients.

This booklet contains guiding tips from other Partners to help you get started on your new journey. You will find helpful stories as well as background information about quality improvement in health care, the [insert name of organization and title of Initiative] Initiative, and your role.

We are delighted to have you join us as we help [insert name of organization] provide the highest quality healthcare!

[Insert contact information]

Thanks again,

[Name(s) and title(s)]



Value of Being a Patient Partner

Patients experience health care differently from providers and administrators so we can offer valuable experience, wisdom and insight to improve how care is delivered and received. Patient Partners share our valuable perspectives to support **[insert name of Organization]**, through this process.

Different patients want different things from a health care visit. Some care about getting in and out quickly, others want to have all tests and labs complete before the visit, still others care most about being able to schedule their visit at a convenient time.

Still, we all want quality care.

A Patient Partner strives to represent the diversity of patient voices as effectively as possible. The goal is to share a broad patient perspective with providers, to help them see through the patient's eyes.

Here is what other Patient Partners say about their volunteer work:

"Insert quote from member in your organization or patients engaged in other initiatives]"
- **[name and title]**

"Insert quote from member in your organization or patients engaged in other initiatives]"
- **[name and title]**

"Insert quote from member in your organization or patients engaged in other initiatives]"
- **[name and title]**



The Partnering with Patients Philosophy

Partnering with patients is integral to [insert name of Organization]'s mission.

[insert name of Organization] is committed to **Patient- and Family-Centered Care**, which means to:

- Regard patients and their loved ones as partners on the health care team
- Respect patients' values and their cultural and personal preferences
- Explain its teaching mission and honor patient and family wishes
- Seek to build long-term partnerships with patients and families at every phase of life, and
- Actively partner with patients, families, employees, learners and volunteers, to achieve service excellence.

[ADD QUOTE about commitment to Engaging Patients from strategic plan or other document]

“Patients help us get it right”

- Team physician

REPLACE THE ABOVE QUOTE WITH
A QUOTE FROM YOUR TEAM
PHYSICIAN

Patient- and Family-Centered Care is an approach to health care that:

- Promotes communication, choices, respect, and building on our individual and collective strengths.
- Leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction.

Patient Partners share their valuable perspectives and ideas at the organizational level to improve the quality of care for all.

[Add another team/clinic/patient photo here]



[Insert name of Organization and title of Initiative]

Initiative

[This section of the Patient Welcome Packet provides a broad summary of the Initiative Patients will be participating in for context. Below is how we characterized the UW Health Primary Care Redesign Initiative]

You have been asked to be a Patient Partner for the Primary Care Redesign Initiative. You will be working with a specific care team or clinic in the improvement work they have identified as important to them and their patients.

Broad Initiative Goals

A Vision Statement and Key Principles guide the Primary Care quality improvement work (see the Resources section at the end of this packet for a copy of the vision statement).

The Vision emphasizes “patient driven improvements,” fully empowering patients, ensuring the satisfaction and value of all members of the health care team, and quality.

Key principles touch upon responding to the individuality of all patients, emphasizing team-based care, and utilizing emerging technology.

Our Philosophy & Team Aims

The Primary Care Redesign Initiative is organized around specific care teams, namely the folks you see when you come in for a clinic visit. The philosophy behind quality improvement at the care delivery level is that improvement ideas must be “under the control of the team.” The focus is primarily on what they can improve themselves. The next section provides an example of a team’s quality improvement aim and activities.

It will be helpful to know about the specific improvement work of your team or clinic. Ask them to share background information about their Theme, Global Aim, and current Specific Aims.

A team usually includes:

- A doctor
- A nurse practitioner (NP)
- Registered nurse(s) (RN)
- Medical Assistants (MAs) or Licensed Practical Nurses (LPNs)
- A receptionist



Questions to Ask My Team

What is my team's Theme & Global Aim?

What Specific Aims is my team working on now?

Who is my team contact person if I have questions?

Other questions I have for the team:



Quality Improvement (“QI”) Example

[This section of the Patient Welcome Packet provides an overview of a Quality Improvement Process, as depicted on the next page. Share an example that your organization engages in and in which patients would participate.]





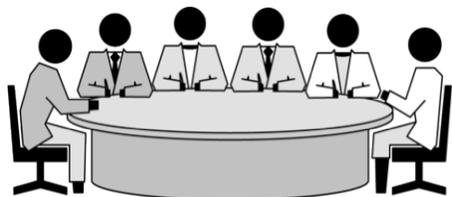
1: Problem Assessment

Having listened to their patients, team members knew, and their patient representative confirmed, that wait times were a problem. They decided to focus on delays caused by waiting for immunizations.

Example: Timing of Immunizations

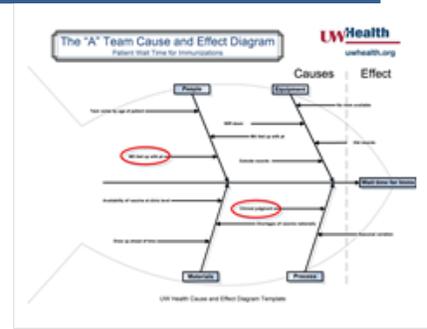
To give you a better feel for what teams do, here is an example of one team's experience with QI.

With help from the patient member, a team identified that they and their patients were most frustrated by two inter-related issues: the doctor being behind and patients having to wait. They then identified the current immunization process as a major reason for delays. Next the team determined the causes of the wait time. Focusing on two major causes, (1) the need for clinical judgment to determine whether immunizations should be given, and (2) the unavailability of the doctor to provide that judgment in a timely fashion, they came up with a process and tool to address the problem. By asking patients to try the new process, the team pilot tested the use of an Immunization Safety Screen that allows some immunizations to be given by the medical assistant before the doctor meets with the patient. Lastly, they presented the successful tool and process to the UW Health Immunization Taskforce, with the plan to then share it with other teams at UW Health.



5: Recommendations Shared

The team, including their patient representative, presents their findings to the UW Health Immunization Taskforce and then shares it with other teams.



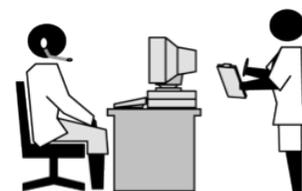
2: Determining Causes

The team used a fishbone diagram to determine the causes of the wait time and identified (1) clinical judgment, and (2) MDs' unavailability as major causes.



3: Ideas for Change

The team brainstorms solutions – identifying a process for early immunizations and a tool (Immunization Safety Screen) to address the issue.



4: Pilot Test

Patients complete the Immunization Safety Screen, the team tracks whether immunizations are given early, and surveys patient satisfaction.



Tips for Successful Service

Being a Patient “Representative”

At first it might make you uncomfortable to be expected to represent other patients. You may be asking: *“How can I possibly know what many other patients are thinking or feeling?”*

The first thing to keep in mind is that representing (or advocating) for a class of patients is not that different from advocating for one patient.

Second, you and your team will find ways to include other patients’ views in the process. Your team may decide to have a focus group, or survey a group of patients – so don’t worry about it all being on your shoulders. There are universal concerns and issues you will raise that are shared by most patients.

You may find it helpful at some point to talk with other patients, or gather information from relevant advocacy groups. For example, if you are providing insights about diabetes care: Is there a diabetes support group in your community or online that you could learn from?

Tips to Maximize Effectiveness

The list to the right offers some qualities of an effective Patient Partner. Generally, people are more open to suggestions if they are shared in a thoughtful and compassionate manner. It may help others receive your suggestions if they see that you understand the challenges facing providers, as they try to change well-established practices.

Other tips to increase your effectiveness:

- Be curious and learn about your team members
 - If possible, arrive a few minutes early and stay a few minutes late to talk with folks informally
 - People like to talk about what they know – ask questions and listen attentively
- Listen for details about what matters to each member
- Use your “new eyes”

Qualities of an Effective Patient Partner

- The passion to improve the health care experience for all – patients and providers
- Willingness to share insights and experience
- Ability to see beyond personal experience and seek other patients’ insights
- Respect for diverse opinions
- Good listener
- Works well with others
- An interest in health care from the providers’ perspective

-
- The team you are joining consists of co-workers who work together frequently and may have been working together for years. Whatever their history together might be, a key value of your presence is your “new eyes” – you see things in new ways and help your teammates see them too.
 - Seek common ground
 - We all share the value of quality care. Everyone on the team wants to improve the health care experience at [insert name of Organization]. Improvement work helps to re-energize team members and find renewed joy in their work and improve the healthcare experience for all.
 - Be yourself and share your opinions
 - This team invited you because they want to learn from you!

Committing to the Effort

[insert name of Organization] invited you because they value and need patient input. Take a moment to think about why you agreed to volunteer, what is important to you, and why you are committed to this effort.

Why did I say “YES!”?

What do I have to offer?

What is important to me about the [insert name of Organization] healthcare experience?

Resources

Vision Statement

[If patients will be engaged in a specific initiative, share the vision statement for that initiative]

Primary Care Redesign Initiative Vision Statement

UW Health will provide easy and timely access to health care that is culturally sensitive, quality-driven and maximizes use of educational and community resources based on patient needs. Our primary care delivery model will emphasize a sustainable and professionally satisfying environment that supports excellence at all levels. Such patient driven improvements to primary care will be achievable, flexible and affordable and will also focus on clinician wellness and satisfaction. A culture of respect and trust will be the basis for a primary care team that fully empowers patients; that values all members of the health care team; and that makes full use of existing and emergent technologies.

KEY PRINCIPLES

- We will have a healthcare environment that is uniquely tailored to each individual patient's needs and accommodates their cultural background. Patients will always feel welcomed, safe and respected. Their voice will always be heard.
- Wellness and health promotion will be key to the overall patient experience.
- A new model of care that aligns infrastructure, compensation and professional recognition will be necessary in order to sustain a primary care environment that attracts and retains physicians and staff.
- Total team care that fully uses the skills of each member of the healthcare team will be an integral part of the patient care experience from day one.
- Referrals and communication between primary care and specialty physicians will be closely coordinated with priority given to the patient's needs.
- Every effort will be made to bring healthcare to the patient, not the patient to healthcare using existing and virtual technology, personal contact, community resources and thoughtful team planning.
- A primary care system, though optimized IT technology, will anticipate the patient's needs and offer proactive care. Patients will be equipped with the knowledge and opportunity to make informed choices on provider selection and their preferred mode for receiving information, communicating with their provider and receiving care.
- There will be built-in efficiencies of time and cost for all primary care initiatives.
- There will be convenient access for the patient with the focus on the patient's needs and preferences.



Health Care Terms and Acronym List and Resources

[Think about the common health care terms and acronyms that your initiative will use – e.g. ACO, PPACA, ACA, Medical Home - and define them for your Patient Partners. You and our colleagues probably don't even realize how much short hand we use every day. The following resources can help get you thinking about terms you may need to define for Patient Partners:]

- *The Center for Medicare and Medicaid Services Acronym List and Glossary found at:*
<https://www.cms.gov/apps/acronyms/>
<https://www.cms.gov/apps/glossary/>
- *Kaiser Health News: <http://www.kaiserhealthnews.org/glossary.aspx>*
- *Wikipedia: http://en.wikipedia.org/wiki/Acronyms_in_healthcare/*

Health care, like many industries, often uses short hand to convey complex information. Here are a few terms and acronyms that may be used at meetings during your service. If you do not know the jargon that is being used, ask, as you are probably not the only person in the room who is not clear, and your service will be enhanced if you fully understand the context of what is going on. There are resources at the bottom of the page for additional definitions.

AHS/AHC	An academic health system or center is an accredited, degree-granting institution consisting of a medical school, an additional health professional school (e.g. Nursing, Pharmacy, Public Health), and a relationship with a hospital.
Charting	The act of recording important facts about a patient in a paper or electronic record (or “chart”). The patient's chart most often contains a medical history, a nursing history, results of physical examinations, laboratory reports, results of special diagnostic tests, and the observations of the nursing and medical staff.
NP	A nurse practitioner. A registered nurse (RN) who has completed an advanced training program in a medical specialty such as pediatrics or internal medicine. An NP may function as a primary direct provider of health care and prescribe medications.
MA	A Medical Assistant. MAs help physicians with administrative duties and basic clinical tasks. Some assistants do patient and laboratory work exclusively, while others are responsible for medical records, bookkeeping, and answering phones.
Rooming	The process of escorting patients to a clinic room and gathering basic health information and vitals (e.g. weight, temperature, blood pressure). Rooming is done by a MA.

The Centers for Medicare and Medicaid Services offers an Acronym List and Glossary found at:

- <https://www.cms.gov/apps/acronyms/>
- <https://www.cms.gov/apps/glossary/>

Kaiser Health News offers a glossary culled from many non-profit and government sources:

<http://www.kaiserhealthnews.org/glossary.aspx>



Commitment and Confidentiality Agreement

[insert name of Organization] PATIENT PARTNER COMMITMENT AND CONFIDENTIALITY AGREEMENT

Commitment:

- I am committed to help [insert name of Organization] in its efforts at constant improvement
- My services are donated to [insert name of Organization] without contemplation of compensation or future employment, and given with humanitarian and charitable reasons.
- I will ask questions when I need clarity or help to improve my ability to serve.
- I will strive to provide valuable input and be a voice for the voiceless.
- I will attempt to resolve any problems related to my volunteer service with my team, and if unsuccessful, attempt to resolve any such problems with the Clinic Manager.
- I will make my best effort to fulfill my commitment to [insert name of Organization] by completing all assignments that I accept.
- I will at all times uphold the Mission, Vision, Values and Code of Conduct of [insert name of Organization].

Confidentiality:

- As a patient, I understand the importance of respecting other patients' privacy and confidentiality
- I will hold as absolutely confidential all information that I may obtain concerning patients, medical staff, and [insert name of Organization] business practices. I will not share such information outside my work as a Patient Partner.
- I will only seek to obtain confidential information from patients, medical staff, or others that is highly relevant to my volunteer work as a Patient Partner.

Limitations and Completion of Service:

- I understand that I am free to end my service at any time. If I choose to do so, I will provide my team with as much notice as possible.
- I understand that [insert name of Organization] may terminate my volunteer status for just cause, such as: a) failure to comply with [insert name of Organization] policies, rules and regulations; b) inability to serve; c) unsatisfactory attitude, work or appearance; or d) any other circumstances which, in the judgment of the Clinic manager would make my continued services as a volunteer contrary to the best interests of [insert name of Organization].

Name (please print) _____

Signature: _____ Date: _____

Notes and Parking Lot

*What you leave behind is not what is engraved in stone monuments,
but what is woven into the lives of others - Pericles*

Notes:

Parking lot: A place to record important points and feedback to be shared at a different time



Patient Engagement Toolkit

For Team Members

*[To be modified by each team to match each specific engagement
context]*



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Using this Patient Engagement Toolkit

For the most part, engaging patients should be fun. We hope it will foster joy in your work.

The first section is the **Background section**. We encourage you to skim this section and make sure you get the feel for Patient Engagement, and the different levels.

The meat of the toolkit is the **Worksheet**. This provides a step-by-step process to engaging patients in a way that works for your team.

The last section provides **Resources**. These resources support your work engaging patients – and many were created by folks on the front line of providing care.

Happy engaging!

We use “Patient” as an encompassing term

For the purposes of consistency and to reduce confusion, this toolkit uses the term “patient” throughout to include: patients, consumers, users, families, carers, clients and the public.

Our intent is to strengthen collaboration and partnership between all people involved in care.



Patient Engagement: A Definition and Context

Engagement is: an active process of ensuring that our patients' experience, wisdom and insight are infused into individual care and the design and refinement of our care systems.

Patient Engagement is fundamental to [insert name of Health System/Organization]:

[ADD QUOTE from strategic plan or other document]

This toolkit begins with the premise that patient input will add tremendous value to quality improvement work at our organization. Our patients may not be experts in the business of health care, but they are expert consumers of care in our organization – and crucial members of our team.

Engaging patients in quality improvement work may be new to you, but it is not new to [insert name of Health System/Organization], and it is not new at leading health care entities in the United States, and around the world.

[insert name of Health System/Organization]: [Share any work your organization has done – on any level. Patient and Family Advisory Councils are good examples.]

Across the United States: National guidelines and certification processes such as the medical home certification program through the National Committee for Quality Assurance and the final rule of the Centers for Medicare and Medicaid Services' Accountable Care Organization Shared Savings Program require that patients participate in governance and quality improvement activities.^{4,5} **At Dana Farber**, advisory council members serve on more than 80 committees and project planning groups. **At Medical College of Georgia (MCG)**,⁶ partnering with patients and families is a core tenet of their patient- and family-centered care (PFCC) philosophy. MCG cultivates a robust volunteer patient advisor program with approximately 250 active patient advisors. Patient advisors sit on every committee in the adult hospital, children's hospital, and ambulatory clinics.⁷

“[ADD QUOTE from PFAC member in your organization or CEO statement supporting Patient Engagement]”

- [name and title]

Principles of Engagement

The Five Principles That Ground Our Patient Engagement Work

- (1) Patients offer Experience, Wisdom and New Perspectives
- (2) Engage Early and Often
- (3) Discern and Prepare
- (4) Communicate
- (5) Just DO IT!

1) PATIENTS OFFER EXPERIENCE, WISDOM AND NEW PERSPECTIVES

Start by assuming patient input will add tremendous value – then discern *what* input would be most valuable and *how* best to get it. Patients may not be experts in the business of health care, but they are expert consumers of care in our organization. They can also offer other beneficial personal and professional expertise. The artist, mother, industrial engineer, construction worker, lawyer, teenager, and factory manager bring new perspectives to our challenges. Diversifying a group adds new perspectives, awareness of a wider array of resources, and a rich catalog of experience in reforming systems.

Patients can also help leverage past internal “political barriers;” if our customers are asking for something reasonable, it probably makes sense to deliver. Patients can also help us see past our “professional blinders.” Sometimes we do something a certain way because “we have always done it that way” not because it necessarily makes the most sense anymore. And while we are all patients ourselves, as providers and administrators we have a different “insider perspective” that makes it hard to see with new eyes.

2) ENGAGE EARLY AND OFTEN

Patients are key stakeholders in health care. It is vital to tap their expertise *from the very start*: to help us identify the challenges to address, determine how to gather and interpret data, more clearly understand and describe the problems we encounter, identify valuable community resources, design targeted interventions, evaluate our efficacy, and communicate our efforts and successes to others.

3) DISCERN AND PREPARE

It is crucial to take the time to discover your group’s enthusiasm for engaging patients as well as to address any concerns expressed. Because health care organizations have not historically engaged patients in organizational quality efforts, early barriers range from an inability to imagine

how patient input could be valuable to deep fears about working with transparency or “airing dirty laundry.” This initial process is vital to help inspire interest, address fears, and ground teams to welcome patients alongside them.

When there is consensus to engage patients, the group can turn to considering when and how to engage them. Engagement can happen in several ways simultaneously, as explained below. Most important is to ensure that both patients’ and team members’ time is honored and well spent.

4) COMMUNICATE

Shared expectations are key, so it is important to communicate clearly with patients about what the collaboration will entail.

Teams will benefit from preparing a “job description” for patients that describes the effort, the desired time commitment, the team’s sense of the value of their contribution, how their input will be used, a projected end date for the engagement, and coverage of any nominal expenses (e.g.: parking, child care) offered.

Prospective patients may suggest changes to the “job description” that would help them contribute more effectively.

Beginning with a straightforward, respectful conversation helps everyone feel at ease.

5) JUST DO IT!

Don’t let perfection be the enemy of the good. Assume we won’t engage patients perfectly the first time. There’s always the next time, and the one after that. Rapid cycle improvement even in engaging patients!

The big secret is that patients are, well, just like us. So if we treat them with the consideration and respect we would want, any misunderstandings or confusions are likely to evaporate quickly.

Basic evaluation techniques (surveys, midstream and exit interviews) can help us improve the value of engaging patients to the organizations and our patients.

Benefits of Patient Engagement¹⁻³

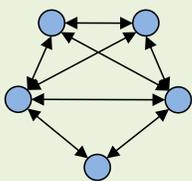
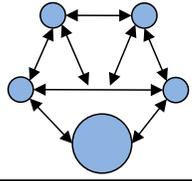
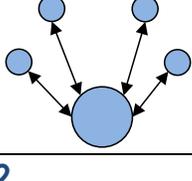
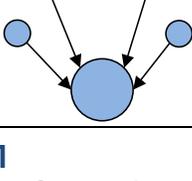
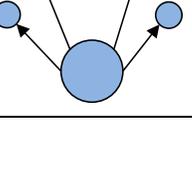
- Improved bottom line
- Revitalized organizational culture
- Enhanced mission focus
- Increased satisfaction of patients and providers
- Increased communication
- Enhanced community reputation
- Increased patient loyalty
- Reduced malpractice claims
- Increased staff retention
- Improved efficiency
- Improved quality

Levels and Methods of Engagement

OVERVIEW & DEFINITIONS

Multiple levels of engagement are useful for innovation work such as in the Primary Care Redesign: (1) Inform/Educate, (2) Gather Information, (3) Discuss, (4) Involve, (5) Partner.⁸ These levels progress from a low level of involvement and interaction between patients and the organization to a high degree of interactivity and influence. Consistent with aspirations, here we present them from the highest level to the lowest. (See: *Expanded Table in Resources section*).

Table 1: Levels and Methods of Engagement⁹

Engagement Levels		Definition and Methods
PARTNER	5 	<p>An ongoing joint venture, involving patients in every aspect of decision-making – from the early stages of defining the problems to developing and selecting the most promising solutions.</p> <p><i>Examples include members of a team, governance boards, and improvement initiative work groups.</i></p>
INVOLVE	4 	<p>Patients play a important role in innovation/quality improvement efforts, but are still viewed as “advisory,” with no role in decision-making.</p> <p><i>Examples include: ongoing Patient Feedback Panels, Patient Advisory Councils, and non-voting participation in patient safety rounds.</i></p>
DISCUSS	3 	<p>Providing information so that patients can respond with their viewpoint. The team commits to consider the input, not to incorporate patients’ perspectives into ultimate decisions and strategies.</p> <p><i>Examples include focus group or interviews.</i></p>
GATHER	2 	<p>Collecting information from patients and listening to their insights.</p> <p><i>Examples include surveys, cycle time, and suggestion boxes.</i></p>
INFORM/ EDUCATE	1 	<p>Communicating to your patients, and educating them about innovation efforts.</p> <p><i>Examples include brochures, health information posters, and electronic health records.</i></p>



CHOOSING METHODS OF ENGAGEMENT

Each team must decide what methods of engagement are right for:

- (1) The overall team effort (**global aim**), and
- (2) Each **specific aim** within that effort.

The engagement level for the *overall team effort* is reflected by the engagement methods you choose to shape your overall improvement goals and select individual aims.

The engagement levels for the *specific aim* are reflected by the engagement methods you select to gather insights to support that improvement work.

Global aim

For example, a team **invites a patient representative** to be a member of the team. The team's patient representative helps them define the problems, decide how to gather data, choice specific aims, and implement them. Having a patient on a team represents the highest level of engagement – a partnership.

Specific aim

With the help of the patient representative, the team selects an aim to improve the scheduling process. To support this aim, the team engages additional patients in various ways:

- **Gather level:** Gathering input about what works (and does not) from a cross-section of patients through a **penless survey** available in the waiting room,
- **Discuss level:** Holding a **one-time focus group** with a targeted group to gather more detailed information, including how best to educate patients about changes in the scheduling process, and
- **Inform level:** Informing patients about changes in the scheduling process by **hanging a poster** in the waiting room.

All engagement is valuable. Different levels meet different needs. The higher the level, however, the richer the experience for everyone and the more comprehensive the input patients can provide.

See the Key Engagement Methods Resource for concrete examples.

Engagement Essentials – The “How To” Worksheet

Now that you know the “what” and “why” of engagement, it’s time to turn to the “how.”

Engaging patients is unfamiliar at first, but it’s worth it. Ancient Chinese philosophers observed in the I-Ching that we know we’re onto something rich and valuable if we encounter “*Difficulty at the Beginning.*”

GETTING STARTED: A PROCESS OF DISCERNMENT

The key to success of any patient engagement effort is to have a shared understanding of how patients can add value. Make sure your team is on the same page and ready to engage.

1) Do not rush the process to prepare to engage

At this stage, your team should come to a common understanding of how you will engage patients.

Start by reaching a shared understanding of Patient Engagement. This step is about ensuring that you’re all talking about the same thing, using a common language – not that you all see engaging patients in the same way.

How does your group define Patient Engagement?

Review some common Myths about Engagement, available in the Resources section.

Do any sound familiar to your team? Are you ready to “move beyond” the Myths?

Discover your beliefs – is there variety in your views? If you are all confident and highly motivated to engage – GREAT! – go forth. If, however, your team differs in beliefs about the value of engaging patients, be sure to talk it through and find your common ground. Your team may find it valuable to review the *Concerns and Actions table* in the Resources section.

How interested in Engagement are team members? How confident? Is there wide belief in the value of patients' contributions?

2) Explore the Specific Value of Including Patients in Our Work

Ideally, teams will include patients as early as possible in the beginning stages of redesign/quality improvement work.

Here are some questions to help explore the value of patients' contributions through various stages of improvement work. You may find it helpful to think about some specific patients you know as you consider these questions:

- **Discovery:** How can patients help us discover and define the right problems to address?
- **Problem exploration:** How can patients help us find out more about a problem? (e.g., *data gathering relating to causes, nature, depth & breath of the problem, its connection to related community issues*)
- **Data & Design:** How can patients help us identify the necessary data and interpret it, and design promising interventions?

“To feel that we have contributed to change, rather than evaluating once it has happened, is important.”

- Parent involved with a Youth Health Network¹⁵

-
- **Implementation:** How can patients help us implement interventions and communicate with other patients about our work?
 - **Evaluation:** How can patients help us evaluate outcomes and understand successes and disappointments? (*e.g., insights, strategies, barriers*)

MATCHING THE ENGAGEMENT METHOD WITH YOUR PROJECT

Design your tailored engagement strategy. Decide what methods of engagement are right for:

- (1) The overall team effort, and
- (2) Each individual intervention within that effort.

Overall Team Effort (Global Aim)

How will you engage patients in your broad improvement strategy?

Should a patient(s) join your team?

Would a patient feedback panel make sense?

Is a one-time focus group more beneficial or manageable?

See Resources section for descriptions of Key Engagement Methods.

Individual Interventions (Specific Aims)

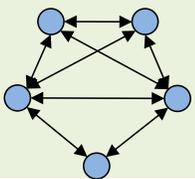
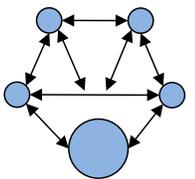
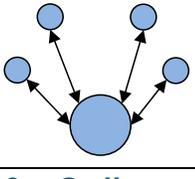
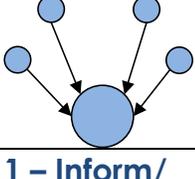
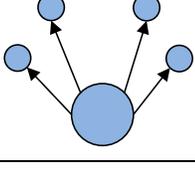
What input is helpful for each specific aim?

Do we need input from a hard-to-reach patient population, so capturing their feedback when they are in clinic is best?

Or do we need more complex information, where a focus group would work better?

Use the table on the next page to map out the engagement strategy for your overall team effort and for each specific aim.

Table 2. Identifying patient engagement strategies for overall team effort and specific aims

Engagement Level	Initiative Examples	Methods – Which shall you use? (Circle)	Which aim(s) would benefit from this level of engagement?
5 – Partner 	<ul style="list-style-type: none"> • Include patients as full members of teams, work groups and redesign management committees • Patients fully engaged from the start 	<ul style="list-style-type: none"> • Patients participate fully with teams: help plan meetings and agendas identify aims, craft interventions and as liaisons with other patients 	ALL AIMS <i>– Patients help pick Aims and choose additional engagement methods</i>
4 – Involve 	<ul style="list-style-type: none"> • Patients engaged throughout redesign process as <i>advisors</i> when their input is deemed valuable • Patients provided enough info about primary care challenges to help propose and weigh solutions 	<ul style="list-style-type: none"> • On-going patient feedback panels • Patients are occasional invitees to team meetings 	
3 – Discuss 	<ul style="list-style-type: none"> • Talk with patients about care processes, seek clarification of feedback • Solicit and share improvement aim ideas 	<ul style="list-style-type: none"> • Targeted meetings to clarify patient input • One-time focus grp • 1:1 interviews (by phone or in person) • Informal waiting room discussions 	
2 – Gather 	<ul style="list-style-type: none"> • Gathering information from patients to inform decisions 	<ul style="list-style-type: none"> • Face-to-face • Questionnaires • Cycle time • Penless surveys • Suggestion boxes • Patient E-record 	
1 – Inform/Educate 	<ul style="list-style-type: none"> • Sharing information about a specific improvement effort • Explaining new care processes to patients 	<ul style="list-style-type: none"> • Face-to-face • Visibility wall • Newsletter • Website • Brochure • Patient E-record • Mail/Email • Posters in clinics 	

DEFINING THE JOB

Once you have selected your engagement method(s), you can define the job and write a job description. Whether the job description is shared with the patient depends on your needs and the type of engagement.

Consider the following elements for the description:

- Type of health care experience desired
- Interaction with your clinic (e.g., frequency of visits, missing appointments)
- Participation expected
 - Type, time, frequency, duration
- Will the patient share their own individual experience or be expected to act as a representative for a class of patients?
- Coverage of any nominal expenses (e.g., parking, child care)
- What the job is not (that it is not a forum to talk about individual health issues or comment on other issues/challenges for the organization)
- Outcome sharing methods – how will they learn how they helped
- Service recognition – in newsletter, clinic bulletin board

See *Sample Job Descriptions* in *Resources* section.

Consider an engagement opportunity for a patient – begin to sketch out elements of the job description

IDENTIFYING AND RECRUITING THE BEST PATIENTS FOR THE JOB

Once you have a job description, you can begin to recruit patients. Each of you knows patients who would offer valuable insights.

Cast a wide net. Expect only approximately 10-25% of those you ask to respond³ – so if you need 5 patients for a focus group, plan to ask 25-50!

Don't be “too picky” now. Think of this stage as selling your engagement efforts as much as recruiting patients – you are letting your patients know that you care about what they think.

Traits to consider as you invite patients

- Patients with a **challenging but important healthcare experience**
- Patients with **valuable personal experience** (e.g., multiple kids as patients in your clinic, cultural background that creates barriers to good care, seen multiple providers in one clinic)

Patients you know who would be great potential volunteers for this effort:

Recruitment strategies you will try:

Some strategies for recruiting patients¹⁰

- Word of mouth
 - Make use of your contacts and colleagues
 - Once patients are involved in your projects they can also be great resources for recruiting others
- Letters to clinics and units—nursing leaders, physicians, social workers, etc.
- Direct invitation (verbal or written) to your patients and others

- Newsletters/brochures
- Flyers on bulletin boards
- Letting Volunteer Services know
- Posting on our organization's website
- Presentations to specific interest groups
- Link with activities in target community

INVITING PATIENTS: OBTAINING A MUTUALLY BENEFICIAL MATCH

Once you identify some patients, inquire about their interest and share the job description. Describe how their input will be valued and used. Be clear about the time commitment & other “details.” (See *Sample Phone Script and Invitation Letters in Resources Section.*)

Questions to consider

- Where is the patient in his/her health care experience?
- Availability for volunteer commitment
- Comfort-level and experience with meeting/committee work

At this stage, for ongoing engagement efforts such as having a patient on your team or a patient feedback panel, you want to determine if you have a “mutually beneficial match.”¹⁰

It may make sense to interview potential volunteers. For patients who may be joining your team, you may decide to invite interested patients to attend your team meetings on a “pilot” basis for 2-3 meetings with the understanding that you will both have an opportunity to opt out at any time during that period.

CREATING A WELCOMING ENVIRONMENT

Once you have patients to engage, it's time to make sure it is a positive experience for everyone. Think of how you would like to be treated, and what would put you most at ease.

Make participation easy – find out what your volunteers need and provide it whenever possible (e.g., free and convenient parking, day care or child care reimbursement, refreshments).

Consider a critical mass – Having more than one patient on a team can put them at ease and foster participation.

If patients are joining your team, adapt your meetings to welcome a new member -

- Meet at a convenient time.
- Modify your meetings to take more time to get to know your new members, and bring them up to speed.

“Take time to get to know each other: Tell stories and share information that break the ice, and help people develop real connections with each other.”

- Essential Allies: Families as Advisors. Institute for Patient and Family-Centered Care

- Provide sufficient background materials for relevant agenda items¹⁰
- Use common shared language (avoid jargon and acronyms)¹⁰
- Check in with patients throughout the meeting to make sure they are following the discussion.

Patient Partner Welcome Packet

We have created a Patient Partner Welcome Packet for patients. Please share it with volunteers who join your team, or your Patient Feedback Panel.

Including patients in your meeting is new for everyone. It is natural to have some hesitation, and equally possible to address concerns together as a group. (See *Concerns and Actions about Patient Engagement tables in Resources Section.*) This presents an opportunity to learn together and grow as a team.

Patient Partners Value:¹¹

- Having a clear role
- Having a purpose and direction
- Feeling invited into the conversation
- Feeling as if they are contributing and making a difference



How will you welcome patients?

CELEBRATING ENGAGEMENT SUCCESSES

After you have had some initial engagement successes, make sure you celebrate them.

Highlight how patient engagement improved the process and the outcome.

Internally, along with your successes talk about challenges – and how they were overcome.

Tell the stories; these have the power to inspire others.

Capture your experience along the way and share your story

- Take photos at meetings
- Capture notable quotes
- Ask patients to share a reflection of their experience
- Write a piece for your organization's newsletter or website
- Hang a poster in your clinic

How will you celebrate your engagement successes?

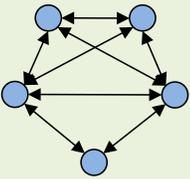
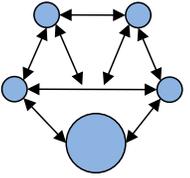
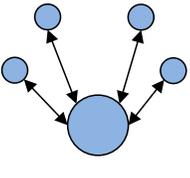
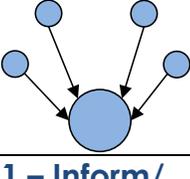
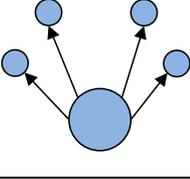
CAPTURING LESSONS

Through the process of engaging your patients, you will learn as you go. Consider the following questions:

- What about engaging patients was comfortable for me? For our patients?
- What insights/perspectives have patients shared that we would not have known about?
- What would we do differently next time?
- Has engaging patients increased the joy factor in redesign work? Why or why not?

Resources

LEVELS AND METHODS OF PATIENT ENGAGEMENT

Engagement Level	Definition	Individual Care	Organization Design and Improvement	Engagement Methods
5 – Partner 	<ul style="list-style-type: none"> Patients have significant voice and influence in their own care and improvement interventions Full participation like other team/committee members 	<ul style="list-style-type: none"> Empower patients to engage in complex medical decision-making Activate patients to make healthy choices and design own care management plans. 	<ul style="list-style-type: none"> Include patients as full members of teams, work groups and redesign management committees Patients participate fully with teams to identify aims, craft interventions and as liaisons w/ other patients 	<ul style="list-style-type: none"> Patients design own chronic illness management plans Patients on teams Patients help plan meetings, agendas
4 – Involve 	<ul style="list-style-type: none"> Patients and providers are committed to meaningful, ongoing relationships Patients play an <i>advisory</i> role in quality improvement efforts 	<ul style="list-style-type: none"> Patients co-create their illness management plans Patients view their own health as their responsibility Providers support patients in health maintenance Patients use health care resources wisely 	<ul style="list-style-type: none"> Patients are engaged throughout the redesign process when their input is deemed valuable Patients are provided enough info about primary care challenges to help propose and weigh solutions 	<ul style="list-style-type: none"> Medical homes Patients help shape chronic illness care plan for their communities On-going patient feedback panel Patients attend some team/committee mtgs
3 – Discuss 	<ul style="list-style-type: none"> Two-way communication to gather information and learn from each other 	<ul style="list-style-type: none"> Discuss valuable prevention strategies Share and evaluate treatment options Co-create treatment plan 	<ul style="list-style-type: none"> Talk with patients about care processes, seek clarification of feedback Solicit and share improvement aim ideas 	<ul style="list-style-type: none"> Medical consultations Targeted meetings to clarify input One-time focus grp 1:1 interviews (by phone or in person) Informal waiting room discussions
2 – Gather 	<ul style="list-style-type: none"> Collecting information from patients Listening to patients 	<ul style="list-style-type: none"> Intake and assessment Medication review Medical history 	<ul style="list-style-type: none"> Gathering information from patients to inform decisions 	<ul style="list-style-type: none"> Face-to-face Questionnaires Cycle time Penless surveys Suggestion boxes Patient E-record
1 – Inform/Educate 	<ul style="list-style-type: none"> Communicating information to patients Educating Notifying of quality and safety initiatives 	<ul style="list-style-type: none"> Informing patients of treatment options Counseling about second opinions, treatment options Health Education campaigns 	<ul style="list-style-type: none"> Sharing information about a specific improvement effort Explaining new care processes to patients 	<ul style="list-style-type: none"> Face-to-face Visibility wall Newsletter Website, Patient E-record Brochure Mail/Email Posters in clinics

ENGAGEMENT MYTHS (AND FACTS)

Myth: We have to do what patients want

Fact: Patients ideas should be considered on their merits

Patients provide an important perspective, but not the only perspective. Patients are experts in their patient experience, and may provide other useful wisdom. When engaging patients, it is important to share the purpose of the engagement and let patients know how their insights will be used.

Engagement exists on a continuum. Information gathered from a survey will be considered on its merits. Information provided from a patient representative on a committee may have more influence, as that patient has been afforded extensive opportunity to learn about the complexities of the problem facing the health care entity.

When patients are knowledgeable about the complexity of health care delivery and allocation, they can support policy positions seemingly counter to their own individual interests that offer broader beneficial public health implications.

The takeaway: take the time to provide patients sufficient education so they can provide valuable feedback. Prepare to be surprised by how thoughtfully patients respond to the complexities of our challenges.

Myth: We will look bad if we make mistakes in front of patients

Fact: Sharing with patients the complexity of modern health care increases understanding

“Pay no attention to the man behind the curtain” is not a sustainable strategy for health care organizations. Engaged patients understand that health care is a complex business and will appreciate the chance to help address the issues.

Creating a culture of transparency is also an enormous relief to everyone involved in the partnership for quality care. We all make mistakes; the measure of our worth is in how honestly and effectively we deal with them.

Myth: HIPAA makes it hard to engage

Fact: HIPAA and Patient Engagement share many objectives

HIPAA was enacted to ensure that information sharing maximizes patients’ health care while protecting patients’ privacy; it should not be a barrier to patient-centered care or patient engagement. Engaging patients in innovation work does not require the disclosure of Personal Health Information (PHI) by a health system or provider, so HIPAA is not a bar.

If the concern is that volunteers may see PHI as they walk through care areas to reach a conference room, brainstorm how to shield nurses stations, or store charts in a manner that

protects PHI. If for some reason that is not possible, consider meeting in a different location. A nearby library, school or other public space will likely have a conference room you can use.

Consider also neighboring businesses; you might be surprised how willing folks are to share an available conference room.

The main point is not to see HIPAA as a barrier to gaining the valuable insights patients have to offer. The law was designed to enhance patient care, not inhibit innovation¹².

Myth: Patients don't know enough about the business of health care to add value

Fact: Patients know about the experience of being a patient and hold other insights

Patients may not be experts in the business of health care, but they are expert consumers of care in our organization, and can offer other beneficial personal and professional expertise also.

The artist, mother, industrial engineer, construction worker, lawyer, teenager and factory manager bring new perspectives to our challenges. Sometimes the best solutions come from different disciplines or dimensions. Diversifying a group adds new perspectives, awareness of a wider array of resources, and a rich catalog of experience in reforming systems.

Myth: Chosen Patient Representatives are not Representative

Fact: It is important to seek the input of patients – as vital stakeholders

Another perceived barrier to patient engagement is concern that those chosen will not be “representative” of all patients. The truth is that a small number of patient representatives cannot possibly represent all legitimate views held by patients. “However, the same can be said of the ability of a small number of clinicians or health care managers to represent the complexities of their constituencies’ views, much less the views of the public [or patients.] Focusing on representation misframes the issue. What is important is not that those individuals represent all sectors of their communities, but that a diverse group of fair-minded individuals from relevant constituencies come to the table, participate in deliberations and articulate a range of diverse and relevant values.”¹³

Myth: Patients won't be interested in our organizational improvement work

Fact: Many patients want to improve the experience for themselves and others

Many patients find pleasure in helping to solve challenges and improve care systems for selfish and selfless reasons.

An invitation allows each patient to decide whether and how they would like to contribute. No harm can come from asking, and even those patients who decline to participate will appreciate the request. It is vital, however, that we engage patients thoughtfully so as to maximize the value of their time and input.

ENGAGEMENT CONCERNS AND ACTIONS¹⁴

Potential Patient Barriers to Successful Engagement Efforts

Potential Patient Barriers	Possible Actions
Concerns about damaging their relationships with health care providers if their comments are negative.	<ul style="list-style-type: none"> Initially, select Patient Partners who have trusting relationships with one or more provider representatives or team members. Ensure ground rules define respectful listening. Clearly identify and provide access to the Engagement consultants. Thank patients for their candor when they share suggestions for improvement
Concerns that their opinion may not be valued or respected	<ul style="list-style-type: none"> Share goals and objectives with Patient Partners individually and at meetings. Explain that the primary goal is the inclusion of patients in the process but not all patient (or provider/other team member) recommendations will necessarily be incorporated into final decisions. Demonstrate commitment by incorporating a patient recommendation early in the project. Hold regular, frequent meetings, especially at the beginning of the project, to build trust in the process.
Unfamiliarity with health care systems and the medical world; belief that they do not have enough medical knowledge to participate constructively.	<ul style="list-style-type: none"> Explain that the expertise you seek from them is grounded in their experiences as patients Provide educational materials, such as articles and presentations, on relevant information for the project. Conduct all meetings using nonmedical terminology or jargon. Appreciate their input, especially when their fresh perspective reveals something valuable
Logistical complications limiting their availability to participate in meetings.	<ul style="list-style-type: none"> Ask patients what they need Select a meeting time and location to meet the needs of Patient Partners. Provide support, such as transportation, childcare and translator services, if necessary and possible.
Concerns about being active participants and contributors.	<ul style="list-style-type: none"> Invite patients' input from the start Assign patients' reasonable amounts of homework and responsibilities to actively engage them.

Potential Provider Barriers to Successful Engagement Efforts

Potential Provider Barriers	Possible Actions
Concerns about revealing problems and mistakes in the system with their patients.	<ul style="list-style-type: none"> Review literature and examples from other organizations that have engaged patients – many report this fear was allayed once they began engaging. Obtain confidentiality statements from Patient Partners. If necessary, limit the scope of the project. Remember that patient volunteers may already be aware of the concerns.
Concerns that patients will use their service as an opportunity to vent unrelated complaints.	<ul style="list-style-type: none"> Select and vet appropriate Patient Partners. Utilize strong meeting facilitation skills to keep meetings on track. Offer patients another opportunity or venue to share their concerns

Concerns that a small number of patients will not be representative of all patients, including their own.	<ul style="list-style-type: none"> Recognize the limitations of all representatives on the team. Highlight the current lack of any patient perspective without their involvement. Propose to expand patient number if initial project is beneficial, and/or use various forms of engagement to confirm input (e.g. have a patient on the team and do a survey).
Inexperience with patient engagement models.	<ul style="list-style-type: none"> Learn – read this toolkit. Share that “newness” of the venture with everyone and plan to learn together Ask for help
Concerns about negative repercussions—legal or otherwise—on the staff and organization.	<ul style="list-style-type: none"> Share stories from other organizations that demonstrate positive repercussions without negative impact. Review the [Internal Resources guide] and run concerns by your clinic manager. Identify how partnering with patients is part of cultural transformation toward patient-centered care.

KEY ENGAGEMENT METHODS

There are many methods to engage patients. Here we provide descriptions of, and information for several key methods. Feel free to adapt any method to suit your team’s specific needs, but make sure to maximize the benefit by thoughtfully preparing patients for their role.

General advice for all methods³

- Clarify topic, purpose, objectives, and outcomes before recruiting patients.
- Check with participants ahead of time to provide any additional support (*regarding reading, hearing, seeing, language interpretation, or unique physical access*).
- Hold gatherings in a comfortable, accessible venue.
- If possible, and where applicable, use a “neutral” facilitator/interviewer who knows enough about the topic but is not directly connected to the project or clinic. A few representatives with “skin in the game” should attend and listen closely to patients’ insights.¹⁵
- Provide water for gatherings; whenever possible, for meetings/groups of longer than an hour provide healthy refreshments.
- Provide a thank you and specific feedback about the value of their input to participants afterwards.

(1) Patients Joining Your Team

Having patients join your team involves selecting one or more patients to serve as “patient representatives” to be full members of your team. They will attend as many meetings as you and they agree will be valuable.

For example, you may decide that it is best to focus on specific issues you need patient input in two meetings each month. If you decide not to include patients in all meetings, make sure you are thoughtful “excluding” them from some meetings for valid reasons for the team and the patients.

If it makes sense, they may share the “rights and responsibilities” of being a team member; e.g., rotate facilitation and other meeting roles.

When to use

- When you need ongoing feedback to support improvement work
- When there is value in “investing” in 1 or more patients who will support your work so you can maximize feedback value.
- *In addition to using a patient feedback panel* – when there is benefit in having a few “patient representatives” learn a lot about your team and patient population.

Advice

- Follow the general advice for all methods
- Welcome patients as your peers; work hard to make them feel like full contributing members to the team
- To maximize patients’ contribution and feelings of belonging, make sure you establish regular communication and if necessary, bring the patient(s) up to speed at the beginning of meetings. Remember, they will not benefit from the daily informal communication that happens at the clinic.
- Select a person act as a go to person for your Patient Partner.

(2) Patient Feedback Panel

A patient feedback panel is a group of patients tapped – either in person, electronically, by phone, or mail – as needed over time to provide general insights about improvement work or specific help with individual improvement initiatives. The group usually averages between 8 and 15 members.

The make-up of the group will reflect the needs of the team, ranging from a cross-section of patients to a very specific sub-population. It is beneficial to have a panel meet periodically in face-to-face group meetings – at least 2-3x year, but additional feedback can easily be solicited through other means.

When to use

- When you have the need for ongoing feedback over a period of at least 6 to 18 months to support improvement work, whether to gather general information about what patients feel should be improved or specific information about individual aims
- When there is value in “investing” in a group of patients who will support your work so you can maximize the depth of the feedback you receive.

- *In addition to having patient(s) join your team* – when you want to gain insights from a broader group of patients and maximize flexibility of how to gain input. (Often, future “patient team members” emerge from patient feedback panels.)

Advice

- Follow the general advice for all methods
- To maximize patients’ contribution and connection over time, it is essential to provide regular updates on your team’s work between input sessions
- Take time to build relationships in the group. Utilize “ice breakers” at several of the first face-to-face gatherings.

(3) Focus groups³

A focus group is a one-time gathering of a small group (5-10 people) who generally share common health experiences or characteristics. For example, they could use the same clinic, have the same disease, or even follow the same treatment plan.

Group make-up should aim for a good mix of participants, with considerations made for all the components that constitute diversity in the target community and in the relevant clinic population. The facilitated focus group usually lasts one to two hours.

The purpose of the group is to gather insights from your patients, their families and caregivers. It will be important to share enough information about the goals of the group so that patients can know what is relevant. Also plan to share how you will use the information and any plans for follow-up.

When to use

- When you have a specific need for feedback to support improvement work – whether general information about what patients feel should be improved or specific information about individual aims.
- To gather a wide-range of input from a diversity of your patient population
- When you have the time to organize and attend a meeting that will likely occur on evenings or weekends.
- *Versus individual interviews* – when you think the group process will bring richer insights and deeper consideration of an issue.

Advice

- Follow the general advice for all methods
- Plan ahead - be clear about your goals and plan your questions ahead of time (see guidelines for questions below under “advice for interviews.”)
- Try to limit your questions to no more than 5-6. It is much better to get in-depth information on a few key topics, than surface information on more.

- Consider sending information about the topic, including some initial questions, in advance to the group.
- Assign all the roles for the focus group: a neutral group moderator, scribe to take notes, and a separate logistics manager to troubleshoot.
- Share ground rules with the participants, especially those ensuring everyone's participation.
- Use a Round Robin method to encourage participation among quieter participants and be ready with some techniques to re-direct those who tend to dominate conversations.
- Record the conversation with a reliable recorder (check the power source), and verify it is working throughout the session.
- Consider combining a focus group and a survey tool to maximize input. Leave 10 minutes towards the end of the group, after folks are comfortable and have sufficient background information, to have individuals complete a short survey.
- After the focus group, immediately debrief to capture any immediate impressions/observations, including any surprises. Then organize the notes into themes, and organize your written report around those themes.

(4) One-on-one Interviews

Interviews allow you to gather information from patients individually. Unlike a survey, they allow you to follow-up on answers. They are a quick way to gather data, and they can be done at the convenience of the interviewee and interviewer, and “slotted in” during a work day.

Depending on the number of questions, a useful interview can take as few as 5-15 minutes. Occasionally, it can be beneficial to do more in-depth, lengthier interviews. Interviews can be done over the phone, or in person – perhaps before or after an appointment.

When to use

- When you would like feedback quickly
- When you want to weave improvement work into your daily schedule
- To gather a wide-range of input from your patient population
- *Versus focus group* – when you think that patients will provide more authentic responses if they do not hear what other patients have to say about the topic.
- *Versus a survey* – when you will benefit from asking follow-up questions and learning from a patient's tone of voice or body language.

Advice

- Follow the general advice for all methods
- To maximize contribution, send patients information about the topic – including some initial questions – before the interview.

- Confirm at the beginning of the call/meeting that the patient has sufficient time available.
- Plan your questions ahead of time:
 - Make wording open-ended, so respondents can choose their own terms when answering questions
 - Be as clear, accessible as possible.
 - Choose neutral words. Avoid wording that might influence answers; e.g., evocative, judgmental wording.
 - Ask questions one at a time.
- Encourage responses with occasional nods of the head or "uh huhs"

SAMPLE ENGAGEMENT TOOLS

Sample Patient Surveys - Engagement Interest

Dear Patient,

We want to create a Patient Feedback Panel, a group of patients who will help us continually improve our services. The group will meet in person once or twice a year and provide occasional additional feedback in email surveys. We need your help to make the clinic the very best it can be!

Please help us get started by completing the survey on the next page.

Sincerely,

[Insert Name] Care Teams

Please make a one inch tear through the answer that best matches how you feel about each question.

YES	
-----	--

Do you think that setting up a 'patient feedback panel' is a good idea?

Would you be interested in being part of the 'patient feedback panel'?

	YES
--	-----

NO	
----	--

	NO
--	----

If you would like to participate in the Patient Feedback Panel, please fill in the spaces below.

Name

Regular Provider

Contact Phone:

Please return this survey to any Clinic staff member before you leave today.

Sample Job Description

Job Description for Patient Feedback Panel for Diabetes Initiative

Aim: Improve diabetes care for adolescents. Specifically pilot group visit model.

Patient's/Caregiver's role:

Patients on this project will help us:

- Learn about patients' and caregivers' experiences with diabetes care at [insert name of organization]
- Select the most promising challenges to address,
- Gather and understand key data to help us define the challenges accurately,
- Identify a wider variety of potential resources,
- Design and refine a pilot intervention, and
- Communicate essential aspects of our redesign efforts to our patients.

Patient's/Caregiver's responsibilities:

- Available to attend 6 evening meetings over 3 months [decide which meetings/how often]
- Share wisdom, knowledge, experience and advice
- Help us choose and prioritize challenge(s), design solutions, and
- Communicate effectively with our patients

Patient/Caregiver desirable experience:

- Have diabetes yourself or be a caregiver for someone with diabetes
- Experience attending diabetes related medical appointments [at a certain type of clinic?]
- Appreciate the challenges of learning about effective diabetes control
- Familiarity with the struggle to control A1C or blood sugar levels
- Experience with the struggle to care for one's diabetes – regular lab tests, clinic visits, exercise, eating a healthy diet
- Familiar with group processes or eager to learn

The Team will provide:

- A commitment to engage patients, not just include them,
- A warm welcome to the group,
- Information, context, and history about diabetes care at our organization,

- Training on relevant substantive topics and organizational process issues,
- Adaptation of meeting processes (eg: agendas, meeting times, facilitation format) as necessary to ensure full value of patient input,
- Information to patients about how their input will be put to best use,
- Reimbursement for any nominal costs of participation including parking, child care, etc.
- Recognition of volunteer service in our newsletter and website.

Sample Phone Script – Focus Group

“Hi, this is **[insert name]** from **[insert clinic]**. Is this a good time to talk?”

“My staff and I are working on ways to improve **[insert aim]** scheduling at **[insert clinic name]**. We strongly value our patients’ perspective in the services we provide, and are looking for volunteers to attend a one-time focus group. If you might be interested, I would like to briefly tell you more about it.”

[If no interest – “Thank you for choosing **[insert name of organization]** and for your time today.”]

“The focus group will be held from **[insert date, time and place]**. **[Provide information about the focus group]** The discussion will be very informal. The care team will be there, which consists of me, the nurse **(insert name)**, the medical assistant **(insert name)**, and the receptionist **(insert name)**, Our quality improvement support person, **(insert name)**, will be there too. We expect about 5 patients.”

“We would like to talk with you about ways to improve our scheduling process. As someone who attends our clinic, you can offer important insights.”

“Please know that children of any age are most welcome. We will arrange the conference room so that there will be plenty of room for the children to sit, crawl, color and play. Parking is free at our clinic and we will have refreshments at the meeting. **[Consider what accommodations would be helpful for the patients you are inviting – in this case it is parents of young children.]**”

“If you are interested and available, we will send you more information before the meeting. Might you be willing to help us?”

Sample Invitation Letter – Focus Group

Dear **[insert patient's name]**,

My staff and I are working on ways to improve **[insert aim]** scheduling at **[insert clinic name]**. We strongly value our patients' perspective in the services we provide, and we want to ensure that what we are working on meets the needs of our patients. Thank you, in advance, for being willing to attend our care team meeting and provide your insights.

The meeting will be held from **[insert date, time and place]**. One of the care team members will meet you at the clinic entrance in the morning and help you find the room.

[Provide information about the focus group] The discussion will be very informal. The care team will be there, which consists of me, the nurse (**insert name**), the medical assistant (**insert name**), and the receptionist (**insert name**). Our quality improvement support person, (**insert name**), will be there too. We have invited two other patients to participate in the discussion. Children of any age are most welcome and we will arrange the conference room so that there will be plenty of room for them to sit, crawl, color and play. **[Consider what accommodations would be helpful for the patients you are inviting – in this case it is parents of young children]**

[Provide information to prepare the patient for their contribution.] We will begin by reviewing the steps in the current scheduling process, and we are interested in looking for opportunities for improvement. In order to give you a better idea of the discussion we'll be having, it might be helpful to think about the following questions:

1. What are some positive experiences that you've had when you've tried to schedule an appointment at **[insert clinic name]**?
2. What could be improved in the scheduling process?
3. What is most important to you when you schedule an appointment?
4. If you could change one thing in the scheduling process, what would it be?

Again, we cannot thank you enough for taking time out of your busy schedule to provide your invaluable input on our scheduling process.

We strive to be patient- and family-centered in the care we provide, and your input makes this possible. If you have any questions, please do not hesitate to contact me at **[(phone) or (email)]**.

Sincerely,

[Your name, or names of all team members]

Sample Invitation Letter – Patient Feedback Panel

Juan D. Patient
1234 Strong Heart Rd.
Madison, WI 53700

Dear: *'Patient Name'*

Please help us improve care at your clinic.

We at the **[insert name]** Clinic write to invite you to participate in an exciting effort to improve patient care. We desire your insights and thoughts in our Team Improvement Projects. The “Team” is your care team – the doctor, nurse, medical assistant, and receptionist who support your health care at the clinic.

We are excited to include you in our efforts. So far, we have **[give an example of improvement work that would resonate with your patients]** improved the process to refill prescriptions. Patients are reporting that this has saved them time.

We are now developing **[insert example of what you want help with]** a method for previsit planning to allow more timely and appropriate care of ongoing health problems. Would you be able to help us?

We ask that you be available to respond to occasional email inquires and meet in person with your Team and other patient volunteers a few times a year.

If this volunteer opportunity might interest you, please call **[receptionist]** at **[number]** and we will provide you with more details.

Thank you so much for your consideration.

Sincerely,

[Your name, or names of all team members]

Sample Invitation Letter – Join Team

Sarah Q. Patient
1234 Paradise Lane
Madison, WI 53700

Re: We want your help

Dear Ms. Patient:

We are grateful that you have chosen **[insert name of organization]** to serve your family's health care needs. We are always looking for ways to take better care of our patients and wonder if you would be interested in helping us improve **[insert type of care]** our diabetes care.

Your care provider, Dr. Jane Smart, believes your experience as **[insert relevant experience]** the mother of a teenage son with diabetes gives you a perspective that would be most valuable to our efforts. We are trying to find ways to **[insert specific aim]** better serve the needs of adolescents with diabetes and we know we need input from these patients, as well as their parents, teachers, coaches and other significant adults in their lives to be successful.

Would you consider partnering with us on our Improvement Team? We will call you next week to see if you are interested in talking more about this opportunity.

If you are able to join us, you will be one of several patient representatives to meet with us on a regular basis over the next year.

We are committed to making this a rich experience for you and for us.

Thank you for considering our request.

Sincerely,

[Your name, or names of all team members]

Sample Patient Partner Application

This application can be modified to suit your team's needs. For example, if you know you are recruiting only for a focus group, add "Focus Group" to the title, modify the introduction and remove the section "How would you like to help [insert name of organization] as a Patient Partner?"

If you know you want to interview folks because you are forming a Patient Feedback Panel, consider removing some of the questions and using them in an interview instead. *(In order to fit the Application in this Appendix, we do not leave sufficient room for questions.)*

2010 Patient Partner Application¹⁶⁻²⁰

Please complete this form if you are interested in volunteering as a Patient Partner at [insert name of organization].

There are lots of ways to help us improve and we welcome your interest. All information contained on this form is considered confidential and is intended for use by the Patient Partner program only.

Today's Date _____

Name *(Please Print)* _____

Home Address _____

City _____ State: _____ Zip: _____

Home Phone () _____ Cell Phone () _____

Work Phone () _____ Is it ok to call you at work? Yes No

Number to call first: home cell work

Email Address _____

_____ Your birthdate _____

Are you a Patient Family member Caregiver _____?

If you are not the patient, please provide

Patient's name(s): _____ birthdate(s): _____

How would you like to help [insert name of organization] as a Patient Partner? (Check all that apply.)

- Review items via email
 Attend regular meetings
 Attend occasional meetings
 Join a committee or team
 Attend a one-time focus group
 Respond to a survey
 Be interviewed
 Other: _____

Please list times when you are generally available to help: (Check and provide detail for all that apply)

- Daytime: _____
 Evening: _____
 Weekend: _____

Please write brief but *descriptive* answers to the following questions in the spaces provided.

1. Why are you interested in being a Patient Partner?

2. What types of experiences have you had with [insert name of organization]? (Check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Primary Care | <input type="checkbox"/> Inpatient: _____ |
| <input type="checkbox"/> Specialty Care: _____ | <input type="checkbox"/> Urgent care |
| <input type="checkbox"/> Occasional outpatient visits (therapies, clinic appointments, tests) | <input type="checkbox"/> Emergency Department |
| <input type="checkbox"/> Regular outpatient visits (therapies, clinic appointments, tests) | <input type="checkbox"/> Same-day Surgery |
| | <input type="checkbox"/> Psychiatry |

3. Is there anything you would like us to know about these experiences?

4. What are some specific things that health care professionals did or said that were most helpful to you and your family?

5. What are some specific things that you or your family would like health care professionals to do *differently* in order to be more helpful?

6. There are special and unique things about every individual and family. Please tell us whatever you want about yourself and your family.

If you want to serve on a committee/team or attend regular meetings, please answer the following:

1. If you have served as an advisor, been an active volunteer committee member, or done public speaking for other programs or organizations, tell us briefly about your experience.

2. When you are in a group, what role most suits you? Quite observer? Most outspoken? How do other group members usually respond to your input?

3. How would you feel about expressing an opinion in front of a group? How would you feel about hearing an opinion with which you disagree? Will it make a difference if you are one of a few patients in a meeting with lots of health care professionals and administrators?

Help us find other Patient Partners. If you know other individuals and/or families who have experienced care at [insert name of organization] who might be interested in serving as Patient Partners, please list their name(s) and phone number(s) and email address here or be sure to tell them about our search for volunteers:

I understand that:

- [insert name of organization] Patient Partner program will try to find an activity for me that is a good fit.
- There may not be an activity that is a good fit with my experiences or interests.
- I can say no when [insert name of organization] asks me to do an activity.
- My health or the health of the patient I care about will not be affected if I say no.
- I can tell the Patient Partner program not to contact me and/or to take my name off the list.

Signature

Date

Thank you for your interest in being a Patient Partner. We will contact you by phone or email to arrange a time to meet you, talk more about your interests, and discuss the opportunities to get involved.

Please return forms to:

[INSERT CLINIC CONTACT]

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