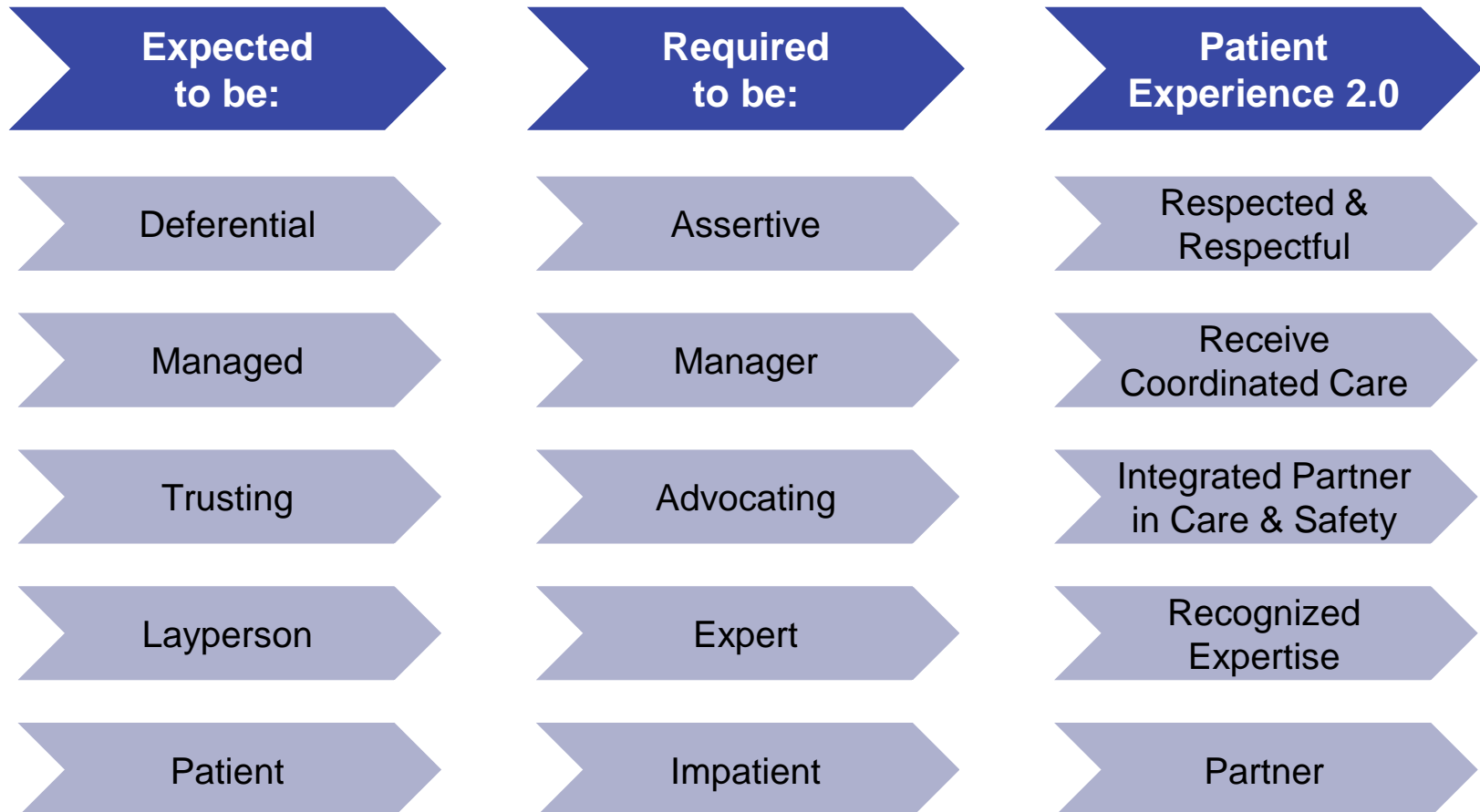Patient Experience

Building Health Literate Care Through Meaningful Patient Engagement

UHN

By the end of today's session, you will be able to:

- Describe the benefits of working together with patients to plan health literate care

- Identify methods for organizational patient engagement that can be applied across healthcare settings

- Plan how to use patient engagement strategies in your own work or organizations

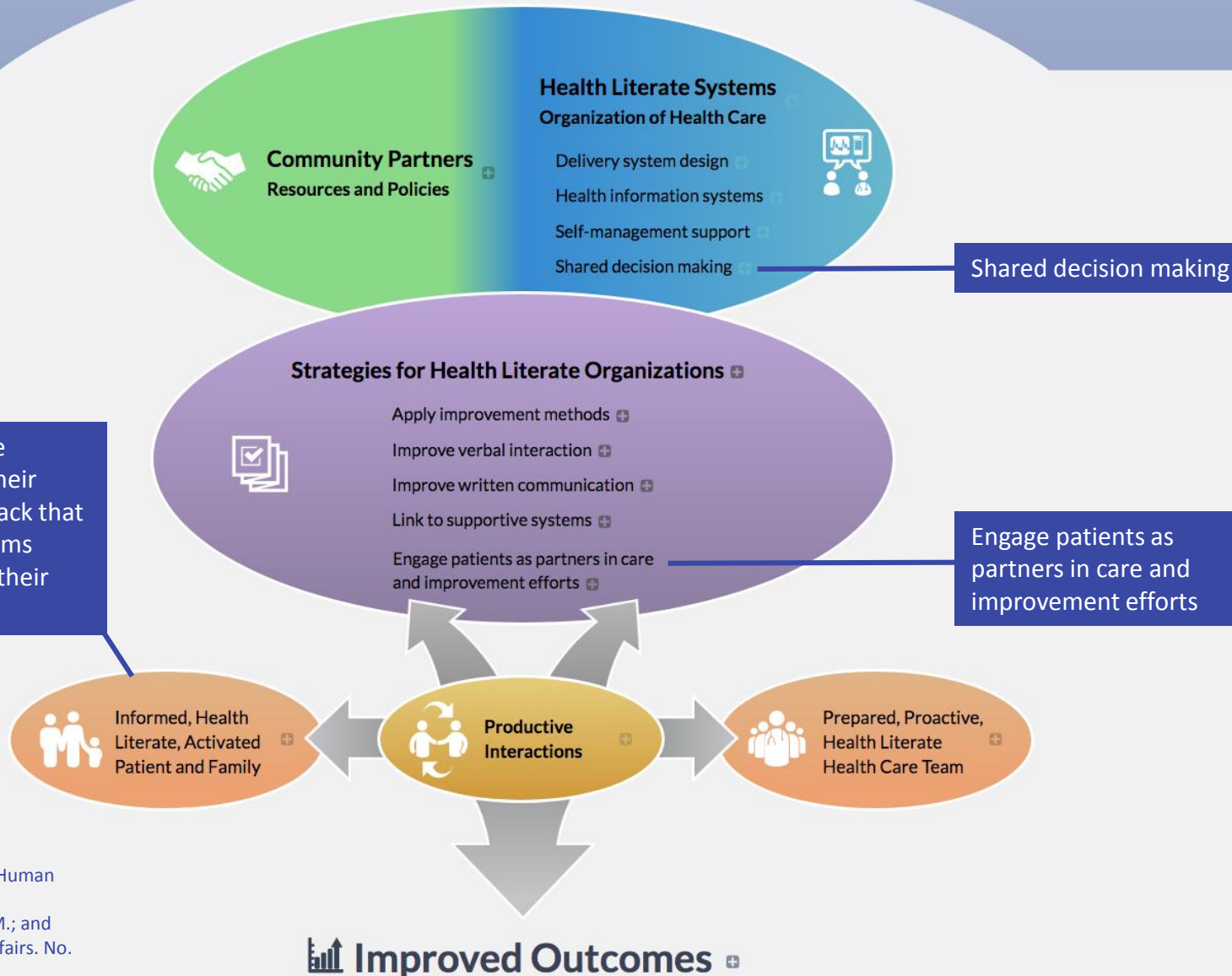**UHN**

Health Care: Cultural Transformation

Expected to be:	Required to be:	Patient Experience 2.0
Deferential	Assertive	Respected & Respectful
Managed	Manager	Receive Coordinated Care
Trusting	Advocating	Integrated Partner in Care & Safety
Layperson	Expert	Recognized Expertise
Patient	Impatient	Partner

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Health Literate Care Model

A Universal Precautions Approach

Share

Health Literate Systems
Organization of Health Care

Community Partners
Resources and Policies

Delivery system design

Health information systems

Self-management support

Shared decision making — Shared decision making

Strategies for Health Literate Organizations

In a health literate care system, patients and their families Provide feedback that helps health care systems respond effectively to their evolving needs

Apply improvement methods

Improve verbal interaction

Improve written communication

Link to supportive systems

Engage patients as partners in care and improvement efforts — Engage patients as partners in care and improvement efforts

Informed, Health Literate, Activated Patient and Family

Productive Interactions

Prepared, Proactive, Health Literate Health Care Team

Improved Outcomes

Patient-Centered Care Values

Dignity & Respect

- Health care practitioners listen to and honor patient and family perspectives and choices

- Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

Information Sharing

- Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful

- Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

Participation

- Patients and families are encouraged and supported in participating in care and decision-making at the level they choose

Collaboration

- Patients, families, health care practitioners, and health care leaders collaborate in policy and program development & implementation:
  - In research;
  - in facility design; and
  - in professional education,
  - in the delivery of care.

Resources: from Institute for Patient and Family Centred Care

Patient Engagement

- ## Engaging with patients in their own care
    - How we work with patients during their care
    - Partnering with patients in their care while supporting and understanding patients' needs, preferences and perspectives
    - Health professionals use the skills and tools to communicate and support patients

- ## Partnering with patients at the organizational level
    - Creates an environment where patients, staff and leaders work together as partners to improve the quality and safety of care

What are your thoughts?

- What opportunities do you see in partnering with patients/family caregivers in this project?

- What concerns or questions about working with patients/family caregivers do you have?

THOUGHTS

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Why Engage Patients and Families?
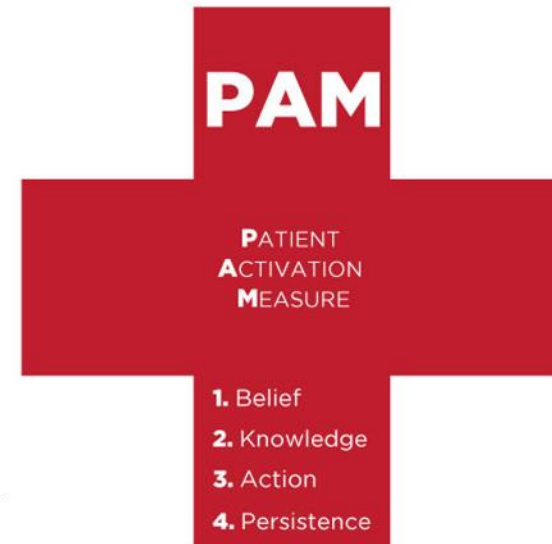
Make the Case for Engaging Patients in your Work

ACTIVITY

Create an elevator pitch or generate a story to make the case about engaging patients

OR

Tell us about a time when engaged others in your work and it made a difference. Or when not engaging made a difference.

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How to Engage Patients

A Framework for Patient Engagement
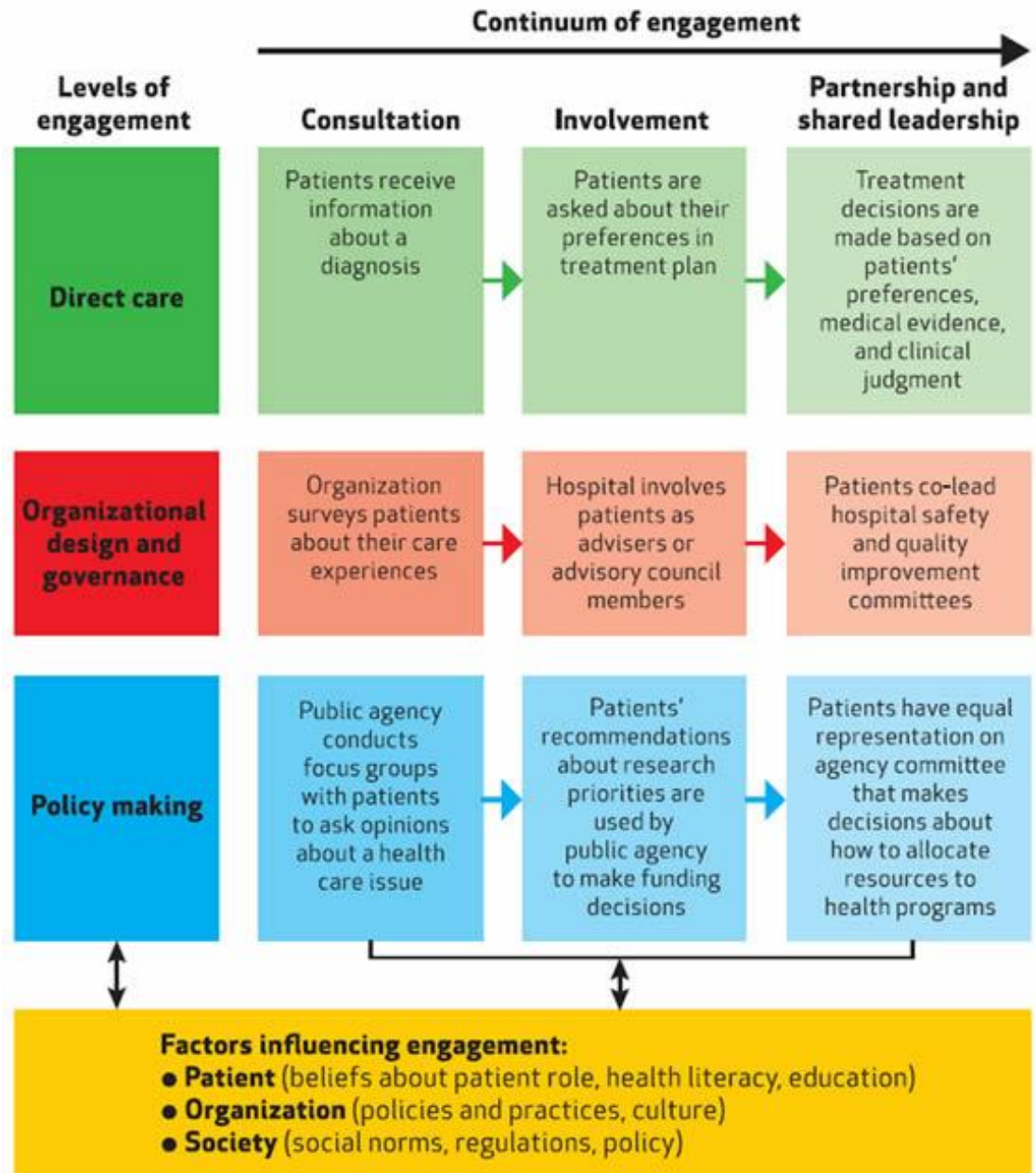
Source: Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K. Bechtel, C. & Sweeney, J. (2013). Patient and family engagement: A framework for understand the elements and developing intervention and policies Health Affairs, 32, 2, 223-231.

A Framework for Patient Engagement

IAP2'S PUBLIC PARTICIPATION SPECTRUM

iap2 international association for public participation

The IAP2 Federation has developed the Spectrum to help groups define the public's role in any public participation process. The IAP2 Spectrum is quickly becoming an international standard.

INCREASING IMPACT ON THE DECISION →

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

Reference: International Association of Public Participation; Government of B.C. Integrated Primary and Community Care Patient and Public Engagement Framework

Health Quality Ontario: Patient & Caregiver Engagement Framework

Patient Engagement at the Organizational Level

- An environment where patients, staff and leaders learn and work together as partners to improve the quality and safety of care

- Patient feedback, perspectives and needs are integrated into planning and decision-making

- There is a culture that enables collaboration:
  - Learning
  - Reflection
  - Transparency
  - Respect

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Preparing for an Effective Partnership: Our Top 10

1. Define a clear role for patient and family participation: Why are you inviting them to the table? Better yet: ask patients why, what, and how they should be involved.

2. Be clear about the level of engagement you are trying to achieve

3. Give information in advance about the purpose, goals, and intended outcomes of the effort

4. Clearly define expectations, including timelines, deadlines, and responsibilities

5. Have a follow-up process in place that informs patients of the outcome of the project

Adapted from: Agency for Healthcare Research and Quality (strategy 1, tool 11)

Preparing for an Effective Partnership: Our Top 10

6. Ask yourself and others: whose perspectives are we missing?

7. Identify the barriers to participation and look for ways to reduce or eliminate them.

8. Build partnerships in the community and look for ways to get outside the walls of your organization.

9. Develop staff: provide them with training and support on how to best partner with patients and families, including how to hold patient-friendly committee meetings.

10. Provide ongoing training and support for patients and families. Check-in and ask for feedback regularly!

Adapted from: Agency for Healthcare Research and Quality (strategy 1, tool 11)

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Methods of Engagement

An initiative, intervention or project can call for multiple methods of engagement which allows for validation & more voices and perspectives

Methods of Engagement

Method Of Engagement	When to Use	Notes
One on One (Interviews, story sharing, materials review, questionnaire)	• To identify priority areas for quality improvement • To explore a single issue or understand experience	• Can lead to opportunities and ideas for other methods of engagement in the future
Focus Groups	• To identify general approaches to a problem • To identify priority areas	• Duration and size of focus group is important • Have clear and defined question(s)
Committees / Working Groups	• To develop and implement a specific project in partnership/collaboration • To collaborate on driving the entire quality improvement process	• There are various preparatory steps to take for this longer duration engagement method (ongoing relationship)
Surveys	• To receive systematic feedback from a larger population • Opportunity to gain insight into a specific issue/question	• Real-time surveys • Virtual patient focus group • Can be used in conjunction with another method of engagement

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Preparing for a **Focus Group**

Preparatory Element	Notes
• Define a clear role for patient participation	• What will they be doing?
• Be clear about the level of engagement you are trying to achieve	• Consult, Deliberate, Collaborate • How will this tie into the engagement that occurs at the point of care?
• Identify a facilitator for the group • Identify a Staff Liaison	
• Give information about the purpose, goals, and intended outcomes of the focus group	• Part of the invite we send out • Part of the background given at the start of a focus group • Template slide deck available
• Have a follow-up process in place that informs patients of the outcome of the project	• How will they be updated after on the outcome of the work?

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Preparing for a **Working Group/Committee**

Preparatory Element	Notes
• Define a clear role for patient participation	• What will they be doing? What are you asking them to do?
• Be clear about the level of engagement you are trying to achieve	• Consult, Deliberate, Collaborate • How will this tie into the engagement that occurs at the point of care?
• Prepare the team before the engagement	• Staff education session
• Identify a Staff Liaison	• Someone connected to the work and part of the engagement (see role description)
• provide information about the purpose, goals, and intended outcomes • Clearly define expectations, including timelines, background information	• Site Orientation • Terms of reference • Goals for the group
• Have a follow-up process in place that informs patients of the outcome of the project	• How will they know the outcome of the work?

Adapted from: Agency for Healthcare Research and Quality (strategy 1, tool 11)

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Preparing for a **Survey**

Preparatory Element	Notes
• Be clear about the level of engagement you are trying to achieve	• Consult, Deliberate, Collaborate • How will this tie into the engagement that occurs at the point of care?
• Determine how the survey will be administered (online, real-time) • If online, develop the survey in an online format (e.g. survey monkey)	• Ensure there are clear instructions
• Give information about the purpose, goals, and intended outcomes	• As part of the preamble in the survey
• Have a follow-up process in place that informs patients of the outcome of the project	• Provide the results of the survey • Share with the survey participants how the information will be used/final decision made

Preparing for **one to one Engagements**

Preparatory Element	Notes
• Define a clear role for patient participation	• What is the theme, topic? • Provide high level questions ahead
• Be clear about the level of engagement you are trying to achieve	• Consult, Deliberate, Collaborate • How will this tie into the engagement that occurs at the point of care?
• Who will conduct the information gathering?	
• Give information about the purpose, goals, and intended outcomes	• Part of the invite we send out • Part of the background given at the start of a focus group
• Have a follow-up process in place that informs patients of the outcome of the project	• How will they be updated after on the outcome of the work?

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Engagement in Programming and Decision Making: Case study

How to Engage Patients

ACTIVITY

Barriers and opportunities

Barrier	Opportunity
Staff questioning representation	• Have more than one advisor per committee • Use more than one method of engagement
Fear of repercussion	• Anonymous feedback • Structure of questions and dialogue • Focus group setting/interviews • More than on advisor per committee
Language	• Interpretation & Translation Support Services • Community Engagement – get outside beyond your 4 walls
Unable to recruit or find patients	• Access formalized patient advisory committees or groups • Work with community partners • Ask at the point of care

Barriers and opportunities

Barrier	Opportunity
Culture	• Using engagement methods that fit into organizational norms instead of other cultural norms
Geography – Distance Accessibility	• Technology: teleconference, • Reimbursement for accessible taxi • Mindfulness re: timing of meetings
Assumptions about knowledge or lack of knowledge	• Fulsome interview and matching process
Not feeling heard/ valued/contributions not added to change/impact – do we listen to what is important from a cultural perspective	• Validation of what has been heard to confirm understanding • Patients are asked to provide input into the agenda and suggest topics • Close the loop

Why Patient Engagement is Important
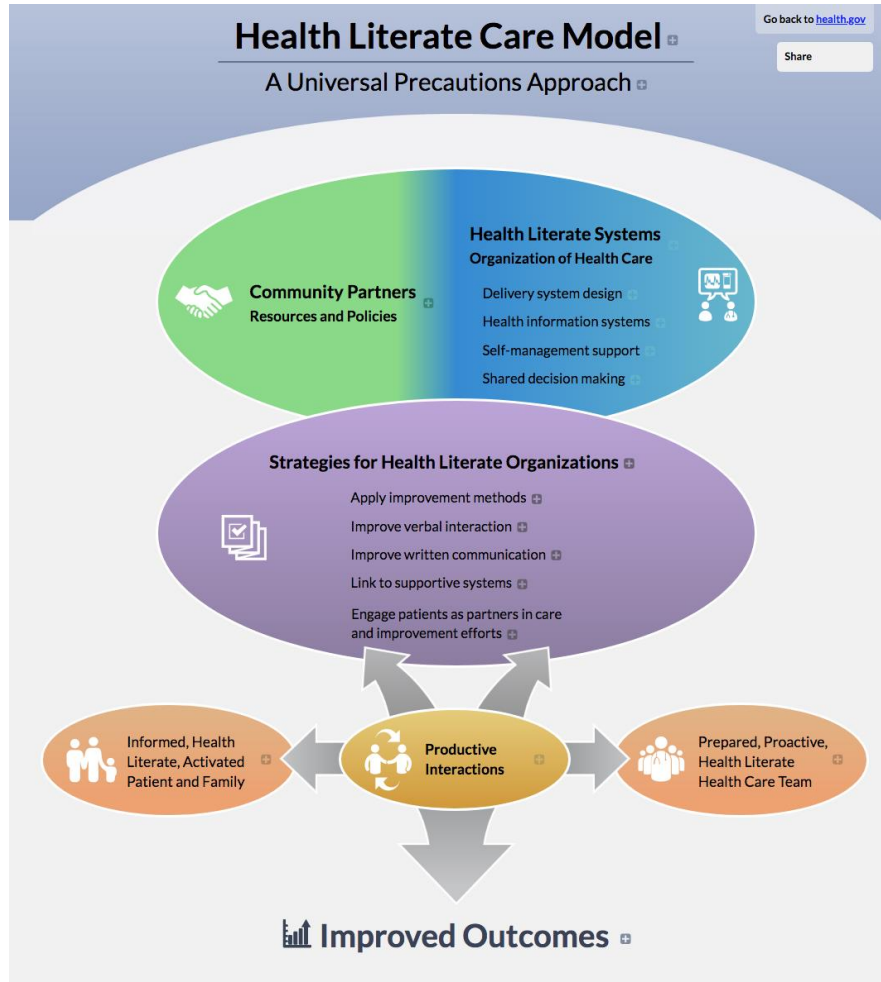
Health Care:
Cultural Transformation

Patient Experience 2.0

Patient Centred Care Values
- Dignity & Respect
- Information Sharing
- Participation
- Collaboration

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Final reflections

What is one thing you can take from this to bring back to your work?

Questions?