

# The POWER of PARTNERING with FAMILIES to TRANSFORM HEALTH

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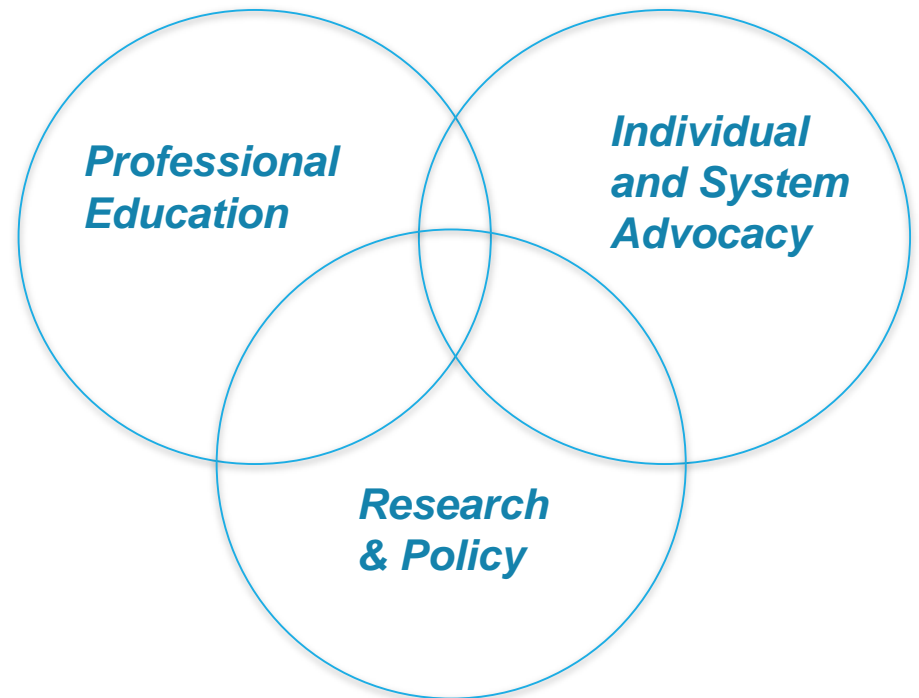


# OUR MISSION



To ensure that Patient (and Family) Experiences Inform Health Care Delivery, Receipt, and Action

*Through Partnerships with Patients (and Families), Providers, and Policymakers*



# AGENDA

1. Power of Partnering: Valuing Families' Contributions
2. Engagement Approach for Quality Improvement
3. Planning to Engage
4. Engaging!!
5. Addressing Barriers
6. Discussion

# WHAT IS PARTNERING?

“In high-functioning health care teams, **families are members of the team**; not simply objects of the team’s attention; **they are the reason the team exists and the drivers of all that happens.**”

# WHAT PARTNERING IS NOT

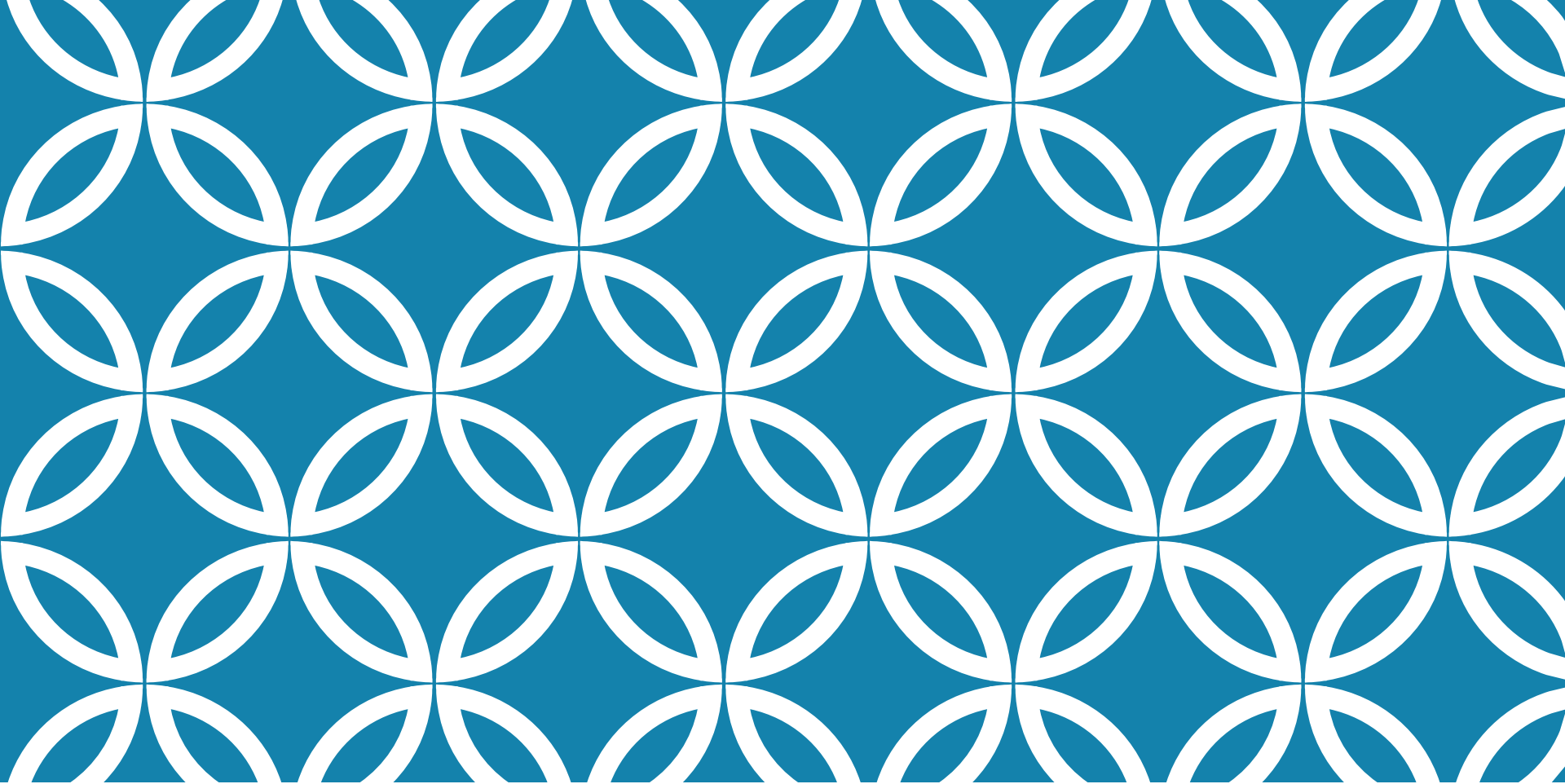


***“We want to include you in the decision without letting you affect it”***

# REFLECT AND SHARE

Think about “families as the drivers of all that happens”

What does (or could) this look like for your initiative?



# ENGAGEMENT APPROACH FOR QI

# DEFINITION AND CONTEXT

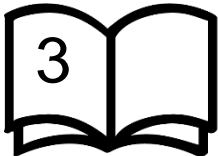
## Engagement for Quality Improvement

- An active, ongoing process
- Family knowledge and experience
- Inform improvements to care

## Patient & Family Engagement in Clinics

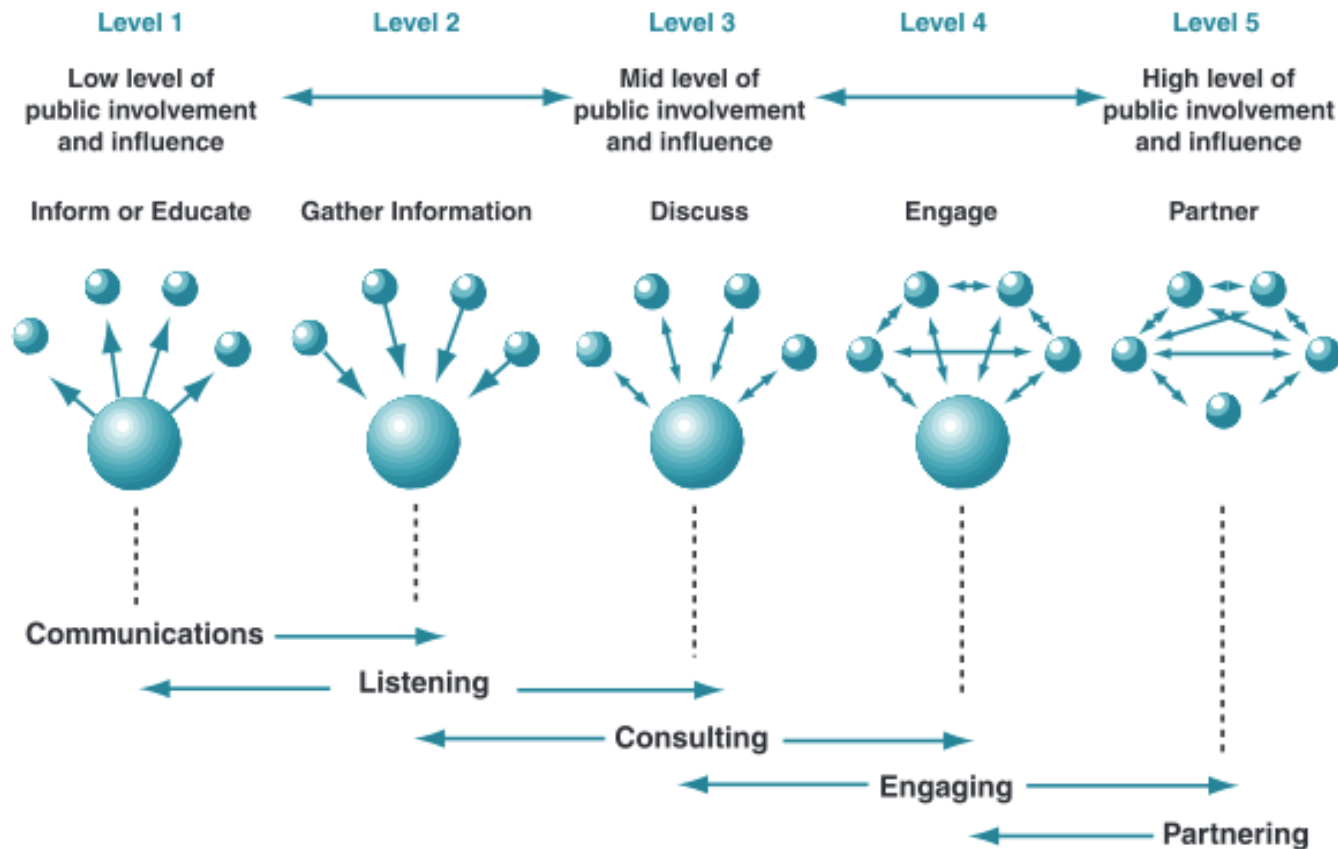
Level	Purpose	Type of Engagement
Direct Care – Individual Patient	Engagement in own care –	<ul style="list-style-type: none"><li>• Activation</li><li>• Shared decision making</li></ul>
<b>Care Team – Providers</b>	<b>Quality Improvement</b>	<b>Tools introduced in toolkit</b>
Clinic Management	Advising leadership	Patient and family advisory committees

Adapted from Carman K L et al. Health Aff 2013;32:223-231



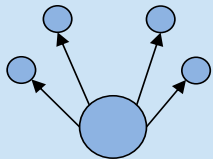
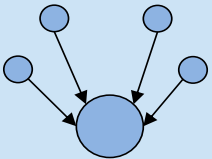
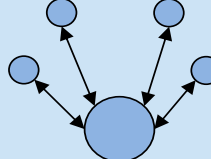
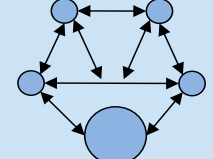
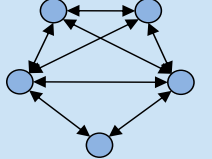


# PUBLIC INVOLVEMENT CONTINUUM

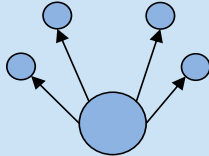
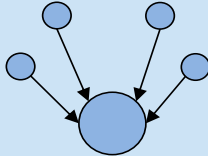
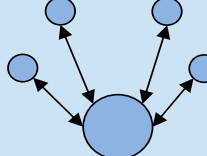
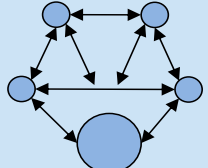
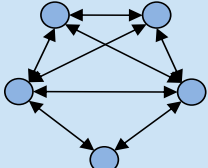


Adapted from Patterson Kirk Wallace

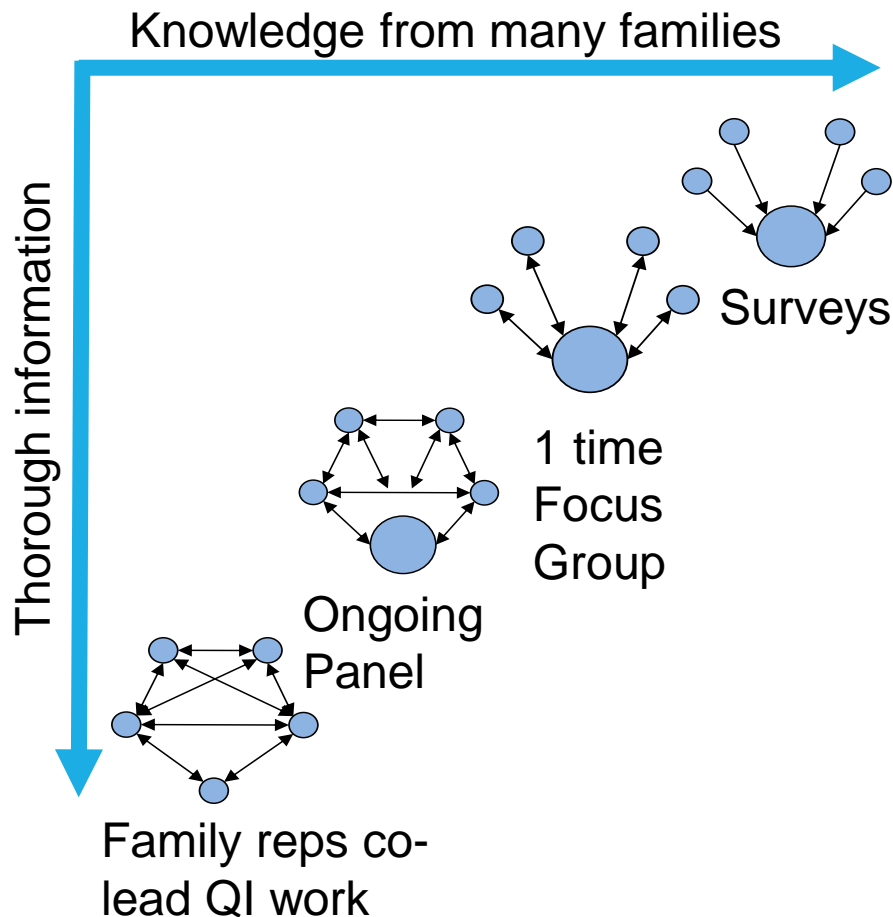
# FAMILY ENGAGEMENT CATEGORIES

CATEGORY	Inform/ Educate	Gather	Discuss	Involve	Partner
Visual					
Definition	Families receive education	Families inform based upon questions	Families and clinicians discuss	Families advise	Families fully participate in QI
QI Example	Explain to families the new SPoC process	Ask families what is not working about SPoC	Talk with families about QI ideas and ask for input	Families included in frank conversations to deeply understand the problem so they can help solve it	Families are included from the very beginning and in every stage

# FAMILY ENGAGEMENT METHODS

CATEGORY	Inform/ Educate	Gather	Discuss	Involve	Partner
Visual					
Methods: In person	<ul style="list-style-type: none"> <li>- Explain in person</li> <li>- Brochure</li> <li>- Newsletter</li> <li>- Visibility wall</li> </ul>	<ul style="list-style-type: none"> <li>- Ask questions during visit</li> <li>- Paper Surveys</li> <li>- Cycle time</li> </ul>	<ul style="list-style-type: none"> <li>- Conversations in waiting room</li> <li>- Focus group</li> </ul>	<ul style="list-style-type: none"> <li>- Ongoing patient panels</li> <li>- Town halls</li> </ul>	<ul style="list-style-type: none"> <li>- Family representatives learn QI methods and join QI efforts</li> </ul>
Methods: Technology	<ul style="list-style-type: none"> <li>- Website</li> <li>- Patient portal</li> <li>- Social Media</li> </ul>	<ul style="list-style-type: none"> <li>- Electronic survey</li> <li>- Phone interviews</li> <li>- Webinar w/ Q&amp;A</li> </ul>	<ul style="list-style-type: none"> <li>- Phone conversations</li> <li>- Online discussion forums</li> <li>- Video conference call</li> <li>- Collaborative documents</li> </ul>		

# GOAL IS COMPREHENSIVE ENGAGEMENT - BREADTH AND DEPTH

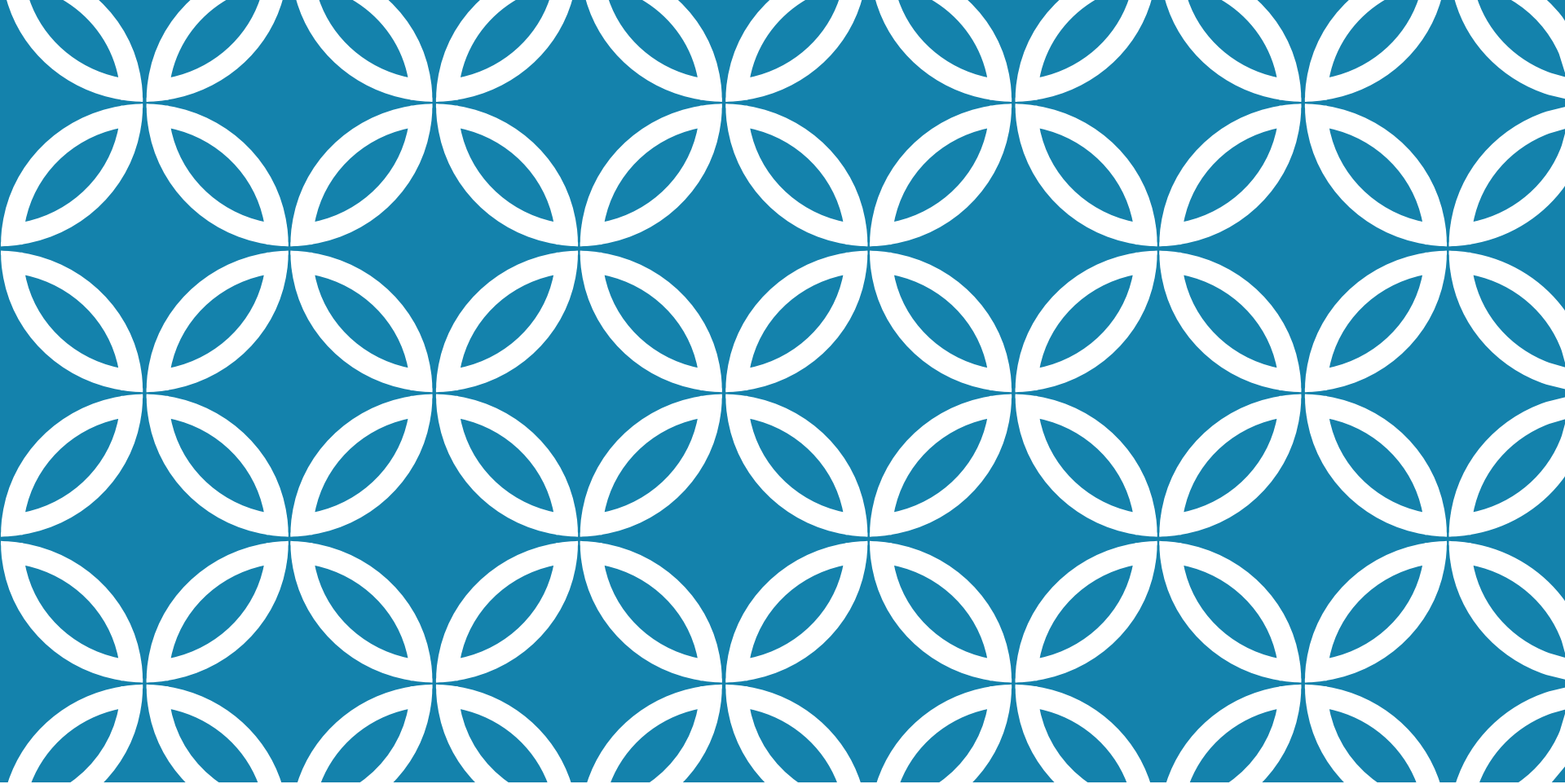


- Continuum
- All valuable
- Different methods meet different needs
- Mix and match methods

# REFLECT AND SHARE

Think about the various engagement methods.

Which method(s) have you used and could you imagine using? Why?



# PLANNING TO ENGAGE FAMILIES FOR QI



# PLANNING STEPS

1. **What** are you trying to improve?
2. **Why** will families be able to help – what insights might they offer?
3. **Who** will have insights – generally which kinds of families should be asked for their input?
4. **Which** engagement methods will provide those insights?
5. **When** should you use each of these methods?



# WHEN AND WHICH METHODS?

1. **FIND** a Process to Improve
2. **ORGANIZE** a Team
3. **CLARIFY** Current Knowledge
4. **UNDERSTAND** Root Causes
5. **SELECT** the Improvement



WHEN	WHY	WHICH
Our QI Stages	Our goals for patient engagement in this stage	Engagement methods to use in this stage



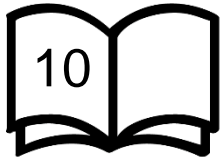




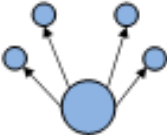

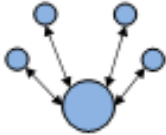
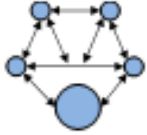
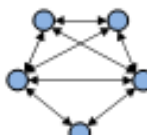
**ENGAGING!!!!** |

# ENGAGEMENT STEPS

1. Defining the Opportunities
2. Identify Families and Recruiting for Short-Term Opportunities
3. Inviting Families to Participate in On-Going Opportunities
4. Creating a Welcoming Environment
5. Engaging
6. Celebrating Engagement Successes and Capturing Lessons



# DEFINING THE OPPORTUNITIES

Engagement Category	<b>Inform/Educate</b> 	<b>Gather</b> 	<b>Discuss</b> 	<b>Involve</b> 	<b>Partner</b> 
	Patients are recipients of info & education	Patients are informers	Patients, clinicians, & staff discuss issues	Patients are advisors	Patients are full participants in QI
Job Description	<b>NO Job Description</b>	<b>Simple Explanation</b>	<b>Comprehensive Job Description</b>		

- Participation expectations
- Information you are seeking
- Coverage for nominal expenses
- How you will share results

# IDENTIFYING FAMILIES FOR ACTIVITIES

- Brainstorm specific families
- Be inclusive
- Cast a wide net



# RECRUITMENT STRATEGIES FOR SHORT-TERM OPPORTUNITIES

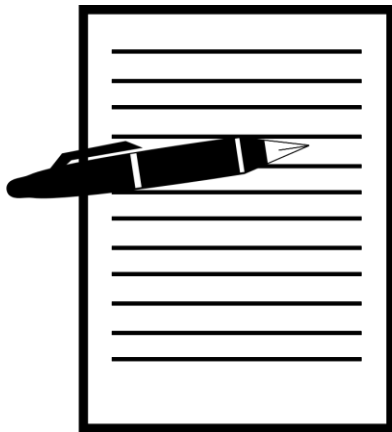


- Clinic-based surveys
- Newsletters
- Flyers
- Using volunteer services



Tool 1

# INVITING PATIENTS TO PARTICIPATE IN ON-GOING OPPORTUNITIES



- For ongoing efforts in the Involve and Partner categories
  - Patient feedback panels
  - Patients joining QI teams
- Pay more attention to personalized invitation
  - Direct invitation
  - Community leaders (champions)
- Be clear that either the patient or you can decide it was not the best fit



# CREATING A WELCOMING ENVIRONMENT

- Make participation easy
  - Convenient location & time
  - Free parking
  - Child care
  - Food and drink
- If patients are joining your team, ideally invite more than one so they have company
- Adapt your meetings
  - Language used
  - Facilitation



Resource: C/D

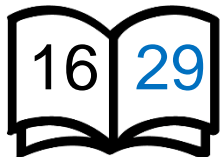
# ENGAGING!!

**QI Goal:** Increase colorectal screening rates for patients of average risk



Our QI Stages	Our goals for patient engagement in this stage	Engagement methods to use in this stage
<b>PLAN:</b> Problem Assessment	<ul style="list-style-type: none"><li>• <b>Gather information from relevant patients</b> about their reasoning for not being screened.</li><li>• Use <b>process assessment tools to determine workflow-related causes to low screening rates and brainstorm solutions to test.</b></li></ul>	<ul style="list-style-type: none"><li>• Electronic survey</li><li>• Cycle time</li><li>• 2 patients join QI team</li></ul>

Use the table you complete on page 9 of your toolkit!



Resource E



# CELEBRATING ENGAGEMENT SUCCESSES AND CAPTURING LESSONS

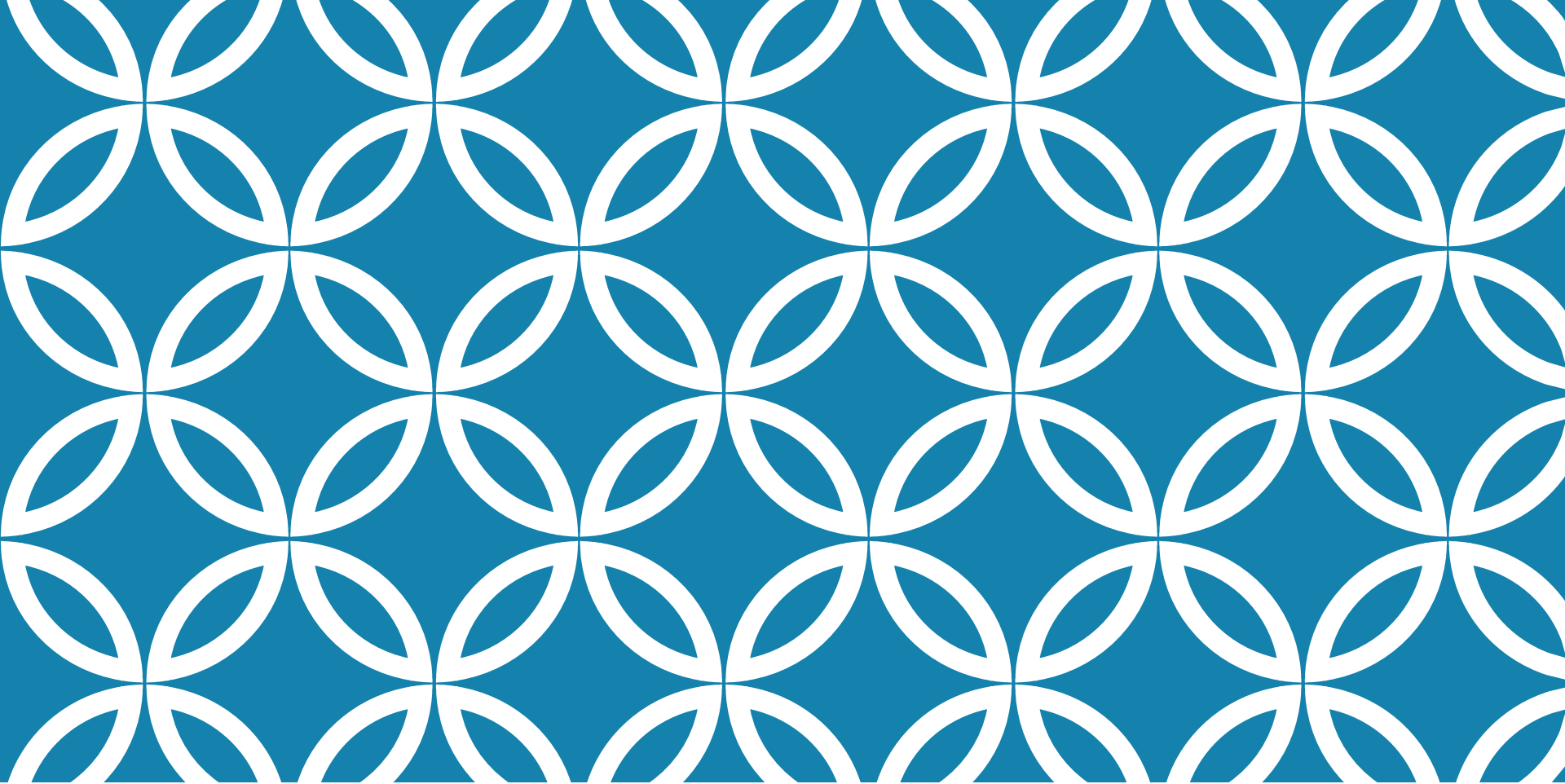
## CELEBRATING

- Make sure you thank patients along the way
- There are many ways to celebrate successes - privately and publically

## CAPTURING LESSONS

- Through out the process, ask:
  - What is going well?
  - What could use improvement?





# SOLUTIONS TO KEY BARRIERS |

# REFLECT AND SHARE

In your QI work, what are some reasons that engaging families does not happen enough?

What can YOU do to change that?

# MYTHS ABOUT ENGAGING FAMILIES

- We have to do what families want
- Families will see our mistakes and judge us
- HIPAA prohibits/limits family engagement
- Families don't know enough about the business of healthcare to add value
- Families will only vent about own experience
- Skepticism about their interest in QI details

# MYTH BUSTING

Myth	Truth
We have to do what families want	Trust is built on honesty. Explain to families that there are many factors to consider when designing a program, and you may not be able to address everything they think is important.

# MYTH BUSTING

Myth	Truth
Families will see our mistakes and judge us	Engaged families tend to respect the complexity of healthcare delivery and show empathy.

# MYTH BUSTING

Myth	Truth
HIPAA prohibits/limits family engagement	HIPAA is a patient protection law. Patients can waive confidentiality. Meet in non-clinical spaces.

# MYTH BUSTING

Myth	Truth
Families don't know enough about the business of healthcare to add value	Families know about the patient & family experience – and the realities of their daily lives – that is the expertise you desire from them.

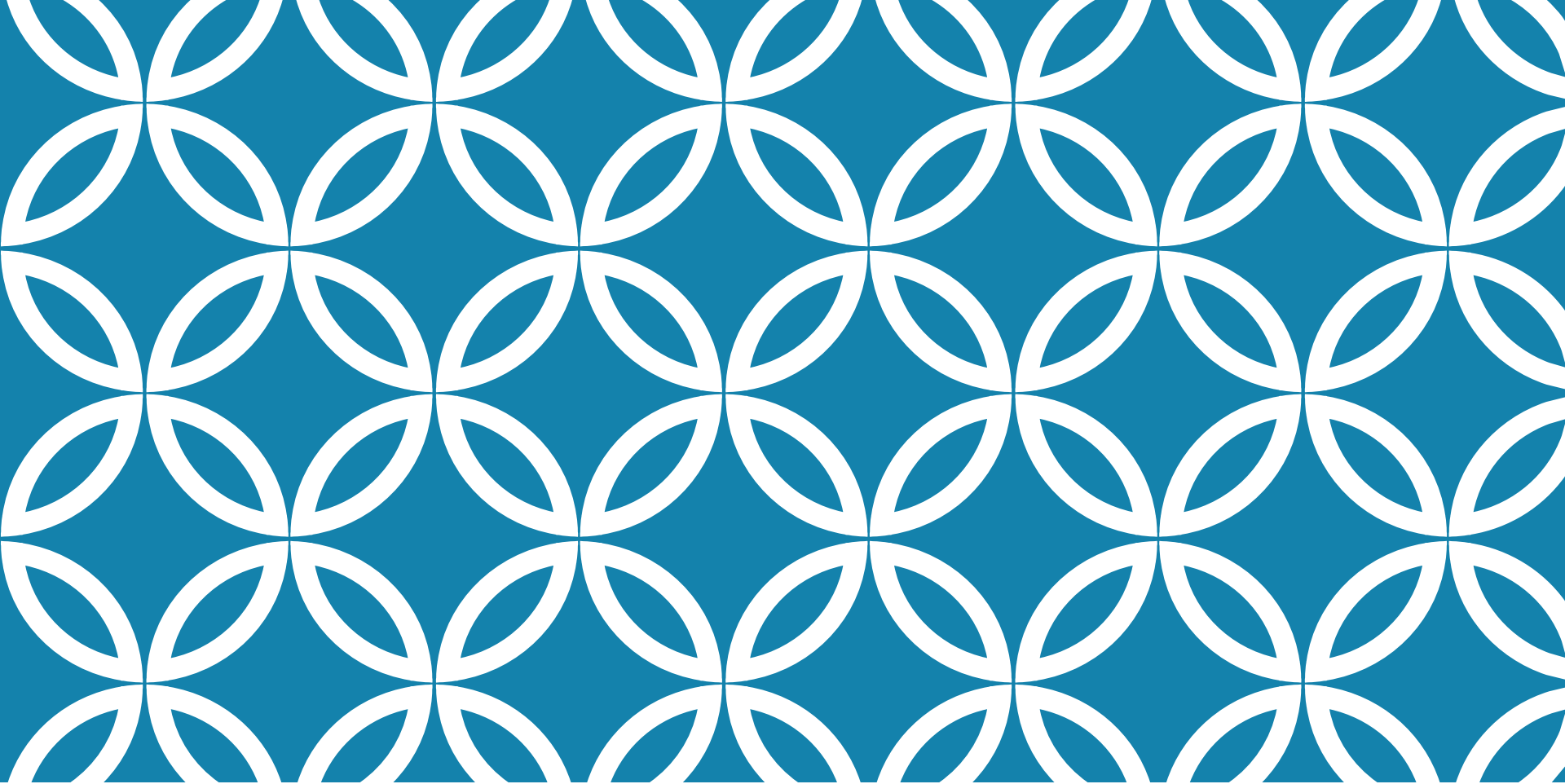


# MYTH BUSTING

Myth	Truth
Families will only vent about own experience	With appropriate guidance and facilitation, most families understand the role of a “representative”.

# MYTH BUSTING

Myth	Truth
Skepticism about their interest in QI details	Healthcare Reform has been well covered in the media. Many patients are curious and want to see the “inner workings” of improvement in health care.



**RESOURCES AND TOOLS** |

# RESOURCES

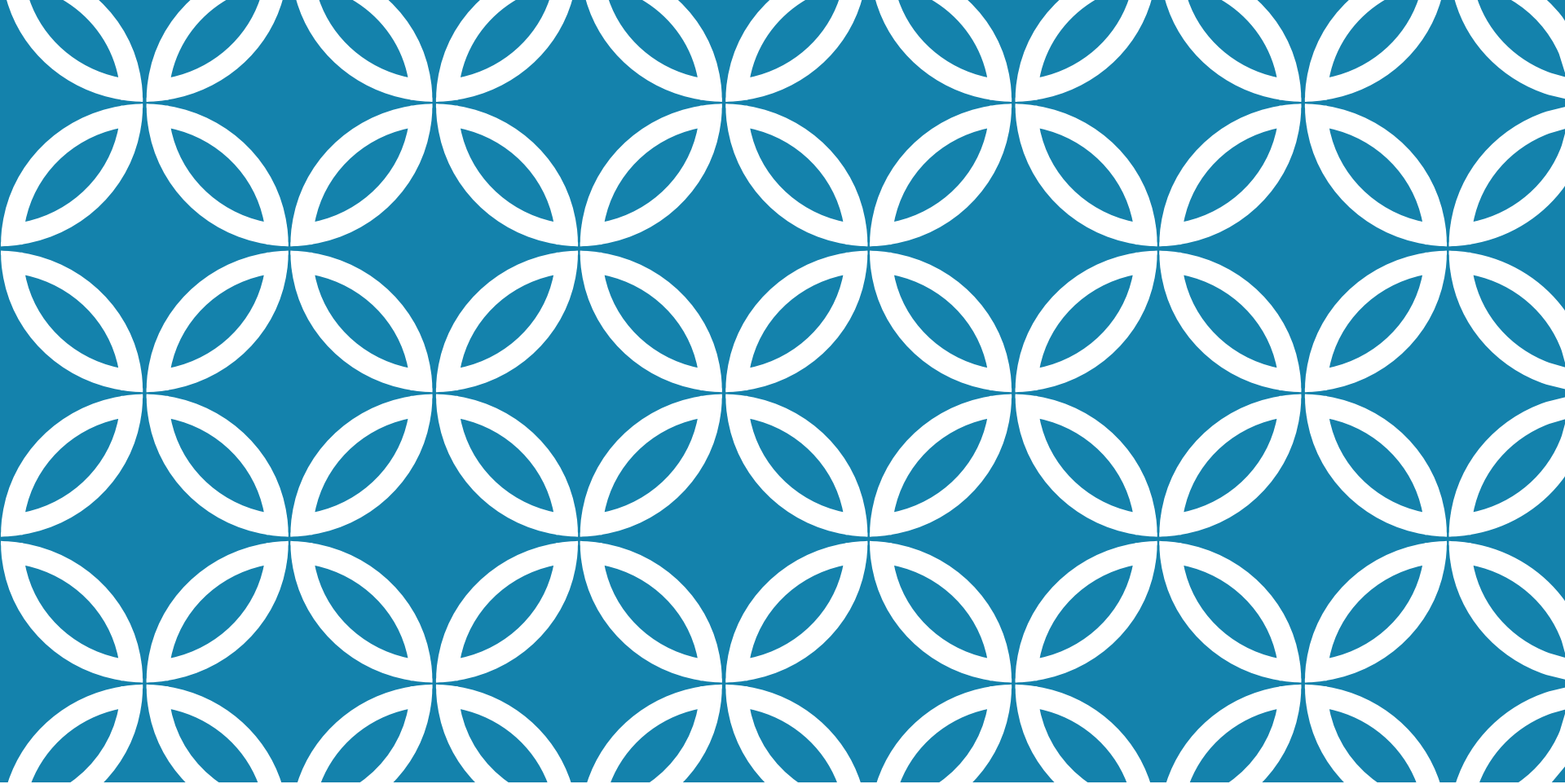
- **Resource A:** Engagement Readiness Assessment
- **Resource B:** Perceived Engagement Barriers (and Solutions)
- **Resource C:** Engagement Concerns and Actions
- **Resource D:** Budgeting for Engagement Costs
- **Resource E:** Sample Planning for Engagement Table
- **Resource F:** Key Engagement Methods



# SAMPLE TOOLS

- Patient Interest Survey
- Job Description
- Phone Script
- Invitation Letters
- Guidance for Ending Patient Partner Service
- Patient Partner Application





DISCUSSION |

# THANK YOU!



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**ICTR**

UW Institute for Clinical and Translational Research





# PUBLICATIONS & RESOURCES

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- Patient Engagement for QI Toolkit at: <http://hipxchange.org/PatientEngagement>
- Stakeholder Engagement for Research Toolkit at: <https://www.hipxchange.org/DeeplyEngagingPatients>
- Burns, K. K., Bellows, M., Eigenseher, C., & Gallivan, J. (2014). ‘Practical’ resources to support patient and family engagement in healthcare decisions: a scoping review. *BMC health services research*, 14(1)
- Lavalley, D. C., Wicks, P., Alfonso Cristancho, R., & Mullins, C. D. (2014). Stakeholder engagement in patient-centered outcomes research: high-touch or high-tech?. Expert review of pharmacoeconomics & outcomes research, 14(3), 335-344.