WORKSHOP ON ADVOCACY AND ENGAGEMENT TO IMPROVE HEALTH

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ENGAGEMENT "BARRIERS":

- We have to do what patients want

- Patients will see our mistakes and judge us

- HIPAA prohibits/limits patient engagement

- Patients don't know enough about the business of healthcare to add value

- Patients will only vent about own experience

- Skepticism about their interest in QI details

CLEARING BARRIERS: MYTH BUSTING

Myth	Truth
We have to do what patients want	Trust is built on honesty. Explain to patients that there are many factors to consider when designing a program, and you may not be able to address everything they think is important.
Patients will see our mistakes and judge us	Engaged patients tend to respect the complexity of healthcare delivery and show empathy
HIPAA prohibits/limits patient engagement	HIPAA is a patient protection law. Patients can waive confidentiality. Meet in non-clinical spaces.
Patients don't know enough about the business of healthcare to add value	Patients know about the patient experience – and the realities of their daily lives – that is the expertise you desire from them.
Patients will only vent about own experience	With appropriate guidance and facilitation, most patients understand the role of a "representative".
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.

STAKEHOLDER MAPPING

1. Identify potential stakeholders through brainstorming

2. Categorize possible stakeholders

3. Evaluate possible stakeholders to further determine the intensity of their involvement

4. Finalize potential stakeholder list and their level of involvement

❖Stakeholder Engagement for Research Toolkit at:
https://www.hipxchange.org/DeeplyEngagingPatients

POWER VS. INTEREST

SH=Stakeholder

Pandi-Perumal, S. R., Akhter, S., Zizi, F., Jean-Louis, G., Ramasubramanian, C., Freeman, R. E., & Narasimhan, M. (2015). Project Stakeholder Management in the Clinical Research Environment: How to Do it Right. Frontiers in psychiatry, 6.

	High-touch approach	High-tech approach
Recruitment	Ask patients during registration or in exam room to participate in improvement activities	Send emails or text message invites; Website announcement
Project kick-off	Best to be in person – bring people together at a joint meeting	X
Conduct of Activity	Team meetings Focus groups Shadow processes	Electronic surveys Telephone calls Occasional conference call meetings Google docs
Dissemination	Presentations Attend community events	Social media Hashtags Website content Live-streaming
Celebrate Successes and Honor Stakeholders	Host a party	Acknowledge in electronic Newsletter and on website

HARNESSING HIGH TECH

Lavallee, 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

PUBLICATIONS & RESOURCES

❖ Caplan, W., Davis, S., Kraft, S., Berkson, S., Gaines, M., Schwab, W., and Pandhi, N. "Engaging patients at the front lines of primary care redesign: Operational lessons for an effective program." *Jt Comm J Qual Saf* 2014;40(12).

❖ Davis, S., Berkson, S., Gaines, M. E., Prajapati, P., Schwab, W., Pandhi, N., & Edgman-Levitan, S. (2016). Implementation science workshop: engaging patients in team-based practice redesign—critical reflections on program design. *Journal of general internal medicine*, 31(6), 688-695.

❖ Patient Engagement for QI Toolkit at: http://hipxchange.org/PatientEngagement

❖ Stakeholder Engagement for Research Toolkit at: https://www.hipxchange.org/DeeplyEngagingPatients

❖ Lavallee, 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.

PUBLICATIONS CON'T

❖Gaines, M., Grob, R., Schlesinger, M., & Davis, S. (2014). Medical Professionalism from the Patient's Perspective: Is There an Advocate in the House?. In DeAngelis, C. Ed. Patient Care and Professionalism. Oxford University Press

❖Frampton S, Guastello S, Hoy L, Naylor M, Sheridan S, and Johnston-Fleece M. "Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care. *A National Academies of Medicine Discussion Paper*; January 31, 2017.

❖Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223-231.

❖Meyerson, Debra E. "Radical Change, the Quiet Way." Harvard Business Review 79, no. 9 (October 2001): 92–100.

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