

# Implementing High Impact Patient Family Engagement Practices

**Libby Hoy,**

Founder/CEO PFCCpartners



# Vision

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Reinvent the healthcare industry so that hospitals, healthcare organizations and stakeholders continuously partner with empowered patients and families as a resource in the co-design of programs, policies, and quality improvement activities.



# Definitions

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## Noun

- Person Family Centered Care

## Verb

- Patient Family Engagement

## Outcome

- Patient Safety
- Patient Experience
- High Quality Care



# Team Hoy

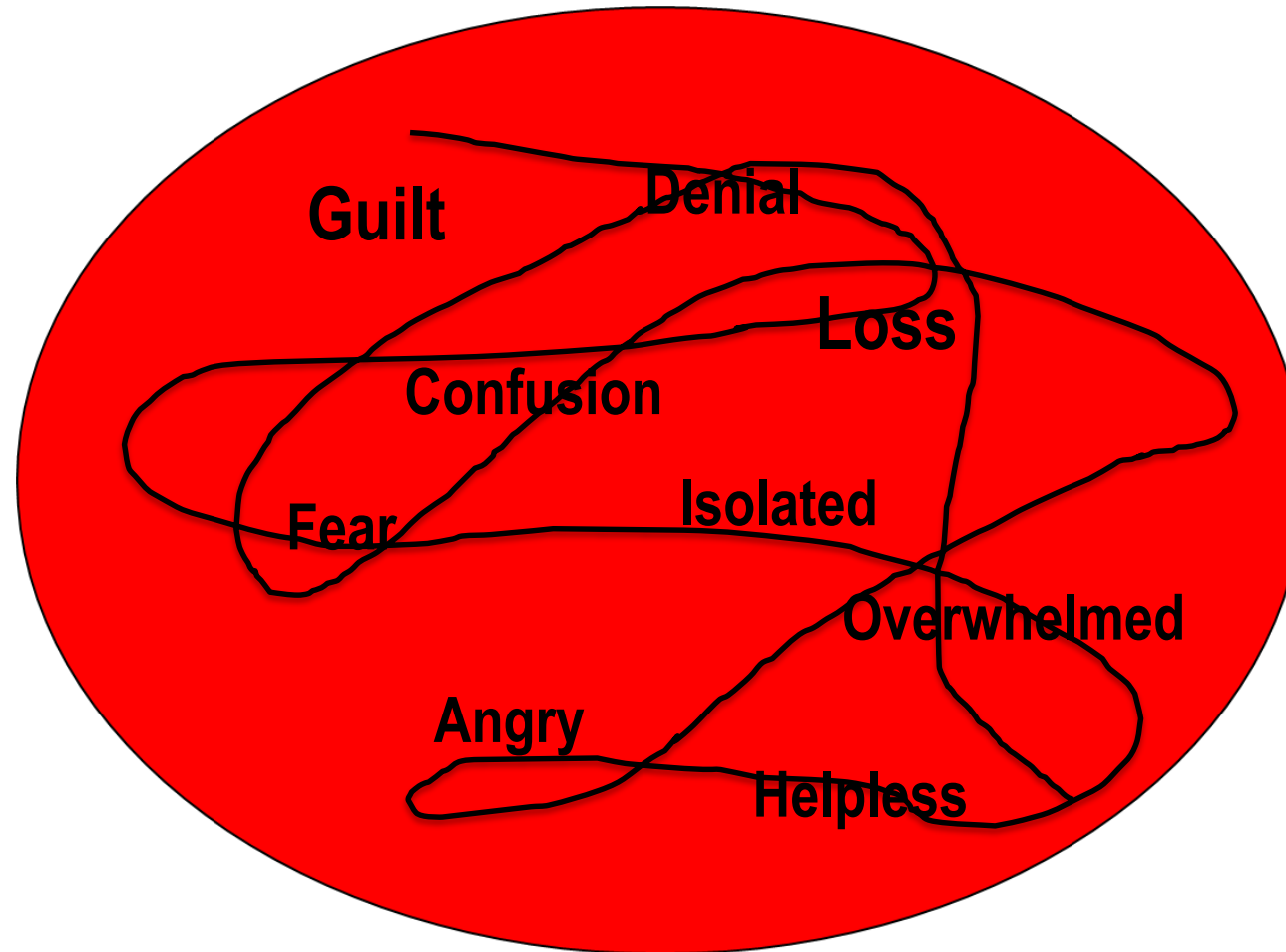
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A story of  
partnership  
impacting the  
health and well  
being of a family  
living with  
chronic illness



# Emotional Response

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# Ready for Engagement

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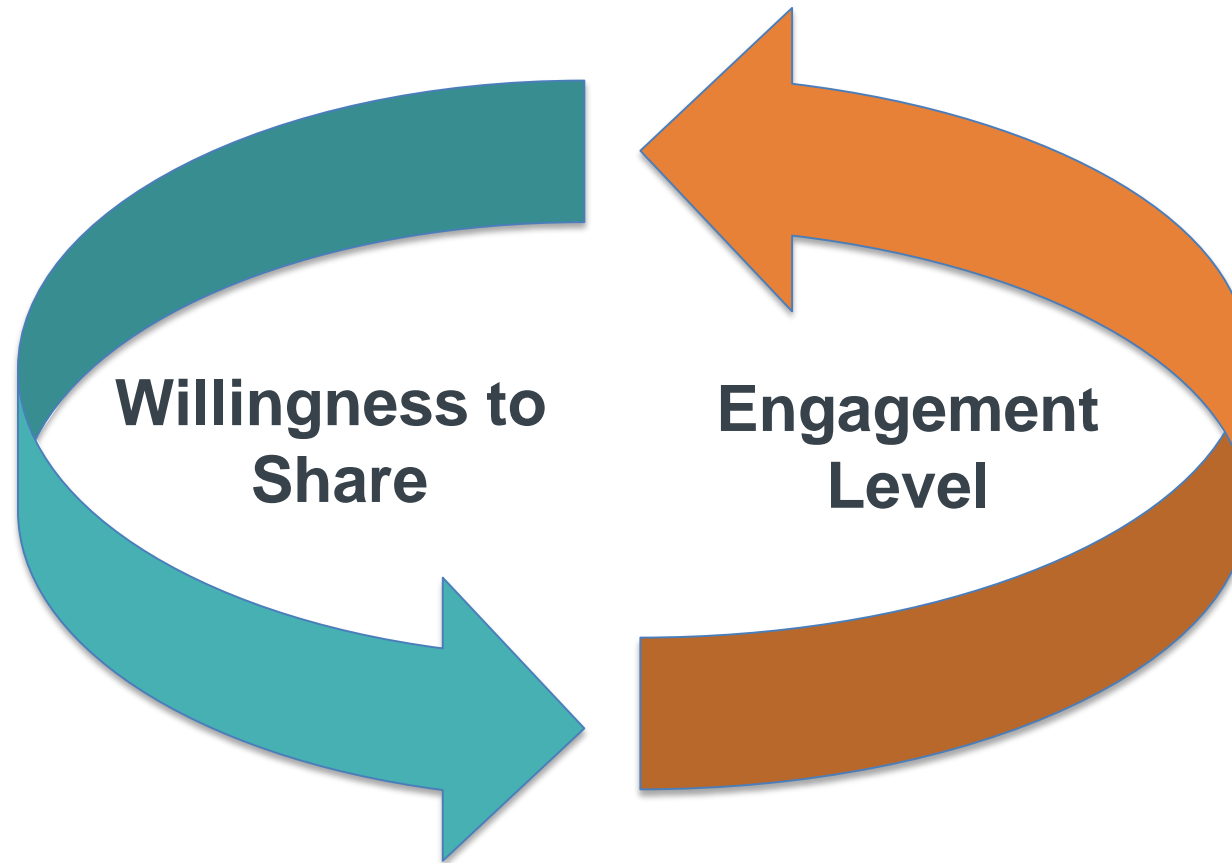
# Ingredients of Partnership

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# Reciprocity in Care

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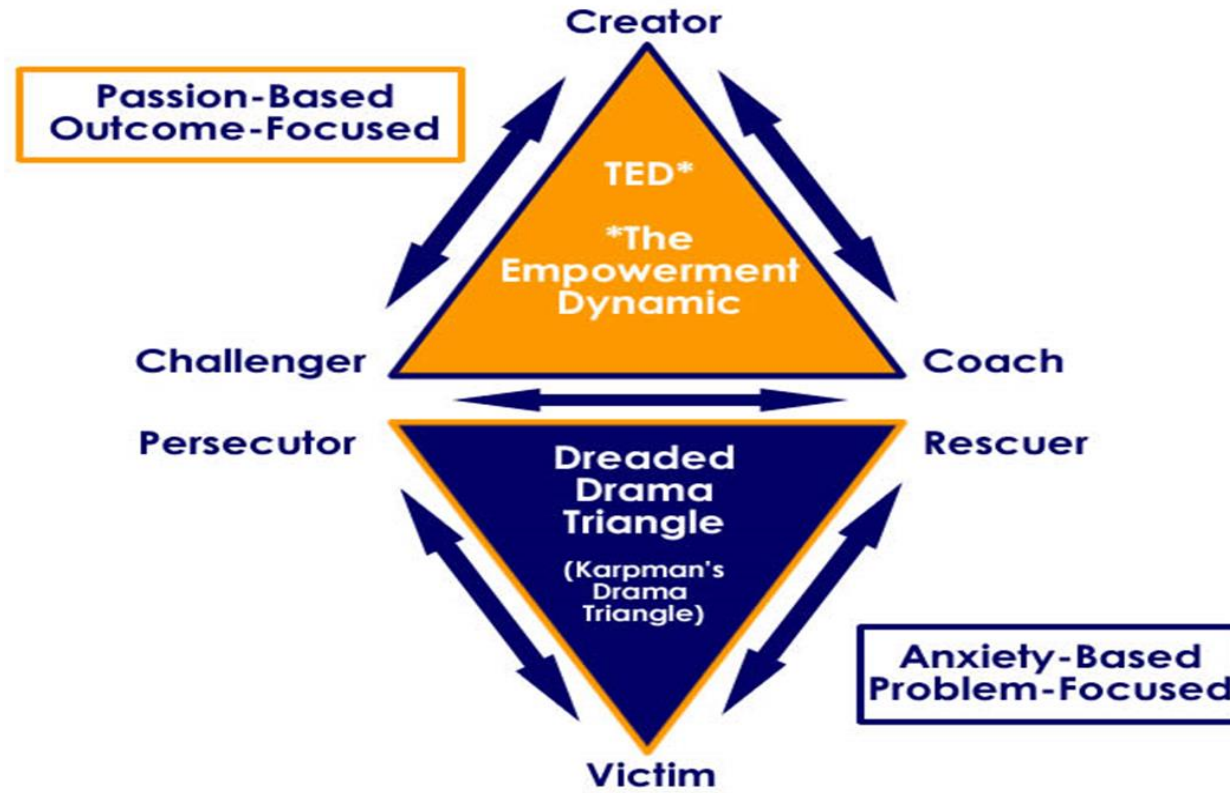
# Engagement **NOT** Entitlement

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# Engagement = Empowerment

David Emerald's TED\* (\*The Empowerment Dynamic) triangle provides an alternative to the Karpman Drama Triangle



# Outcomes in the making...

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# Jeopardy Question

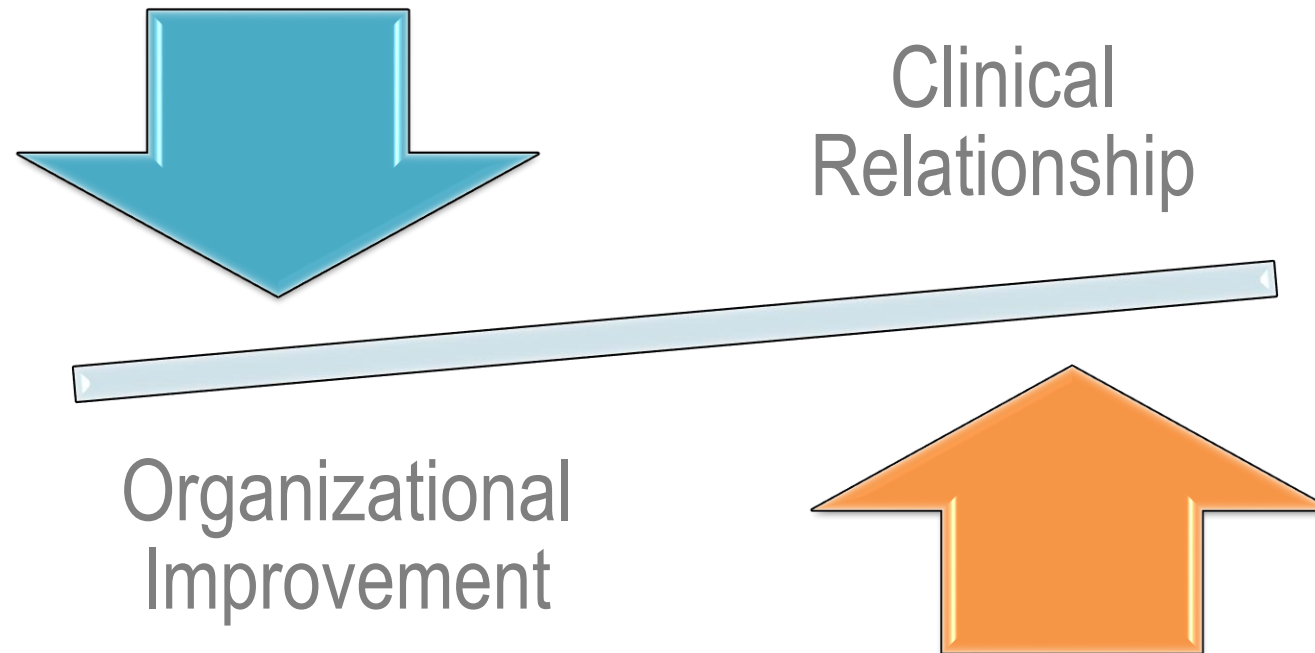
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What is the most underutilized resource in the healthcare environment for improvement?

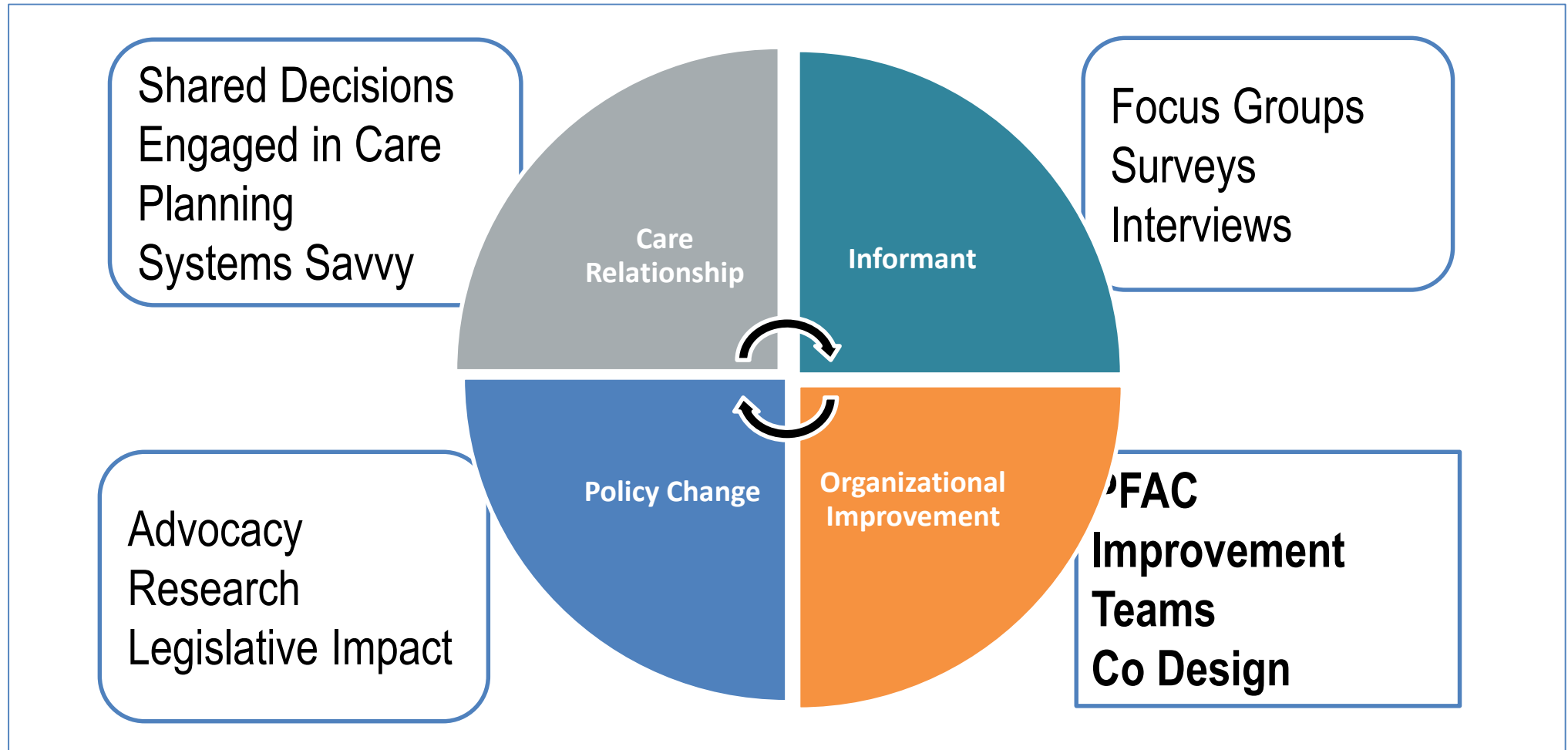


# Engaging Patients & Families

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# Patient Family Engagement Across the System



# Healthcare Goals

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# Shared Challenges

Challenge	Patient /Family	Staff
Space Restraints	X	X
HIPAA	X	X
Restricted Access	X	X
Fear of Harm	X	X
Guilt	X	X
Feeling in the Way	X	X
Families lack of Understanding	X	X
Competing Priorities	X	X
Unfamiliar Environment	X	X
Consistent Communication	X	X
Language Barriers	X	X







Method	Quality of Information	Benefit	Organizational Burden
Patient Satisfaction Surveys	Somewhat diluted from delayed & diffusion of experience – unilateral	Targeted information	Financial, Dissemination
Focus Groups	Broader range of information received on a specific topic – bilateral	Insights into patient family experience beyond what we might have assumed	Minimal effort for high return of information
Patient Family Advisory Councils	Highly informative on a continuous basis, dependant on relationship of trust & relevance to the organization Reciprocal	A resource hard wired into the hospital so that your patients and families continuously inform improvement	Moderate amount of staff time and financial resource required.
Project Improvement Teams (LEAN, A3, Quality, Safety Cmte)	Highly relevant – Patient Family Advisors continuously inform improvement efforts across the organization Dynamic	360 degree understanding of improvement needs of the organization	Moderate amount of staff time and financial resource

# Implementation

## Patient Family Advisory Councils

Integrated  
Approach to  
Improvement

Organizational  
Commitment

### Rapid Improvement Teams

Inter-  
disciplinary  
Teams

Area of  
Experience

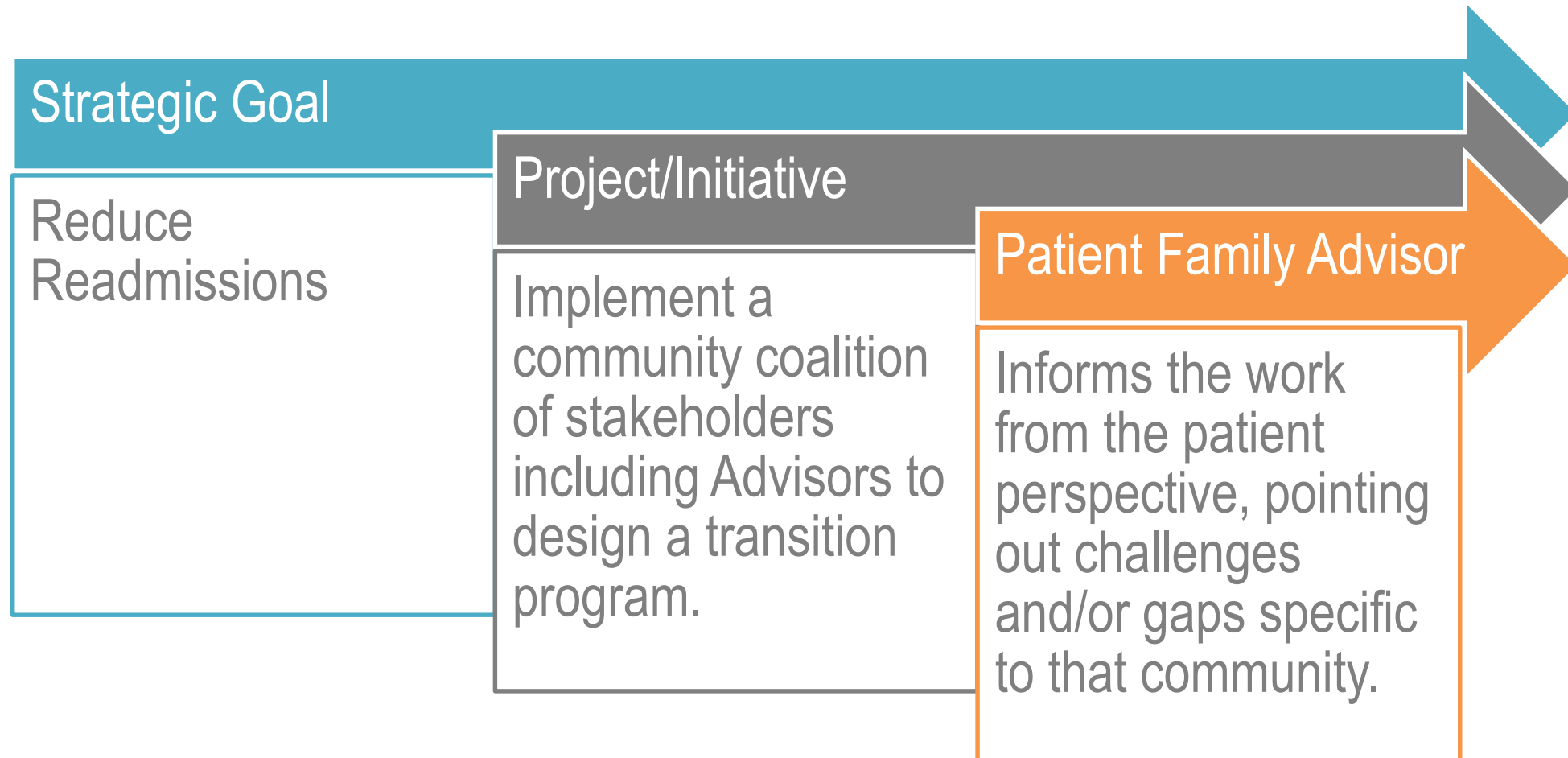
### Focus Groups

Single Focus

Starting point



# Advisors informing Improvement Goals



# Moving from Initiative to Culture

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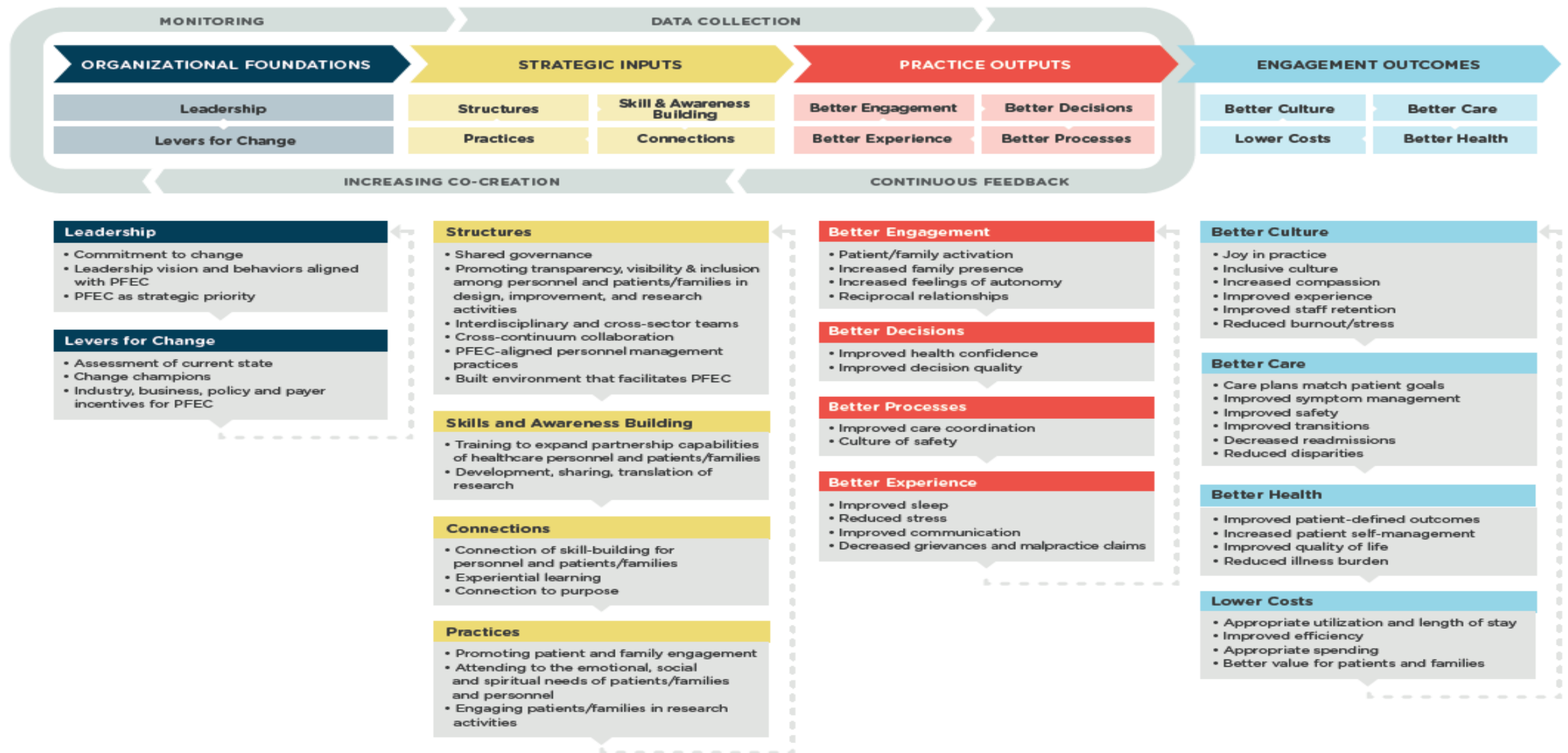
“...everyone in healthcare really has two jobs when they come to work every day: to do their work and to improve it.”

*What is “quality improvement” and how can it transform healthcare?*  
**Batalden,P; Davidoff.F** Qual Saf Health Care. 2007 February; 16(1): 2–3



# Patient and Family Engaged Care

## A Guiding Framework



NOTE: Linear placement of each bucket is not meant to suggest order or hierarchy

## DISCUSSION PAPER

**Susan B. Frampton, PhD**, Planetree; **Sara Guastello**, Planetree; **Libby Hoy**, PFCPartners; **Mary Naylor, PhD, FAAN, RN**, University of Pennsylvania School of Nursing; **Sue Sheridan, MBA, MIM, DHL**, Patient-Centered Outcomes Research Institute; **Michelle Johnston-Fleece, MPH**, National Academy of Medicine

**ABSTRACT | Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes explicit and partnered determination of goals and care options, and it requires ongoing assessment of the care match with patient goals.** This vision represents a shift in the traditional role patients and families have historically played in their own health care teams, as well as in ongoing quality improvement and care delivery efforts. PFEC also represents an important shift from focusing solely on care processes to aligning those processes to best address the health outcomes that matter to patients. In a culture of PFEC, patients are not merely subjects of their care; they are active participants whose voices are honored. Family and/or care partners are not kept an arm's length away as spectators, but participate as integral members of their loved one's care team. Individuals' (and their families') expertise about their bodies, lifestyles, and priorities is incorporated into care planning and their care experience is valued and incorporated into improvement efforts.

To address these barriers, the National Academy of Medicine's (NAM's) Leadership Consortium for a Value & Science-Driven Health System convened a Scientific Advisory Panel (SAP) to compile and disseminate important insights on culture change strategies. The SAP's focus was on evidence-based strategies that facilitate patient and family engagement and are tied to research findings revealing improved patient care

and outcomes. To achieve this goal, the SAP drew on both the scientific evidence and the lived experiences of patients, their care partners, practitioners, and leaders to develop a comprehensive framework that explicitly identifies specific high-impact elements necessary to create and sustain a culture of PFEC. Research in support of the various elements of the model was then compiled into a selected bibliography. This paper introduces the framework and associated evidence, along with practical examples of elements of the model applied in the "real world," with the goal of supporting action that will pave the way for PFEC to become the norm in health care.

Adams, J.R., Bivins, G., Légaré  
Archives of Internal Medicine  
Aljibawi, F., Dong, F., Moore,  
Communication. Health: health  
Afterburner D, Whelan R, Visio  
to improve hip and knee  
Abtoud KA, Slemmon SR, Ga  
7m Driving Transfection in  
Belgum, J. [2003]. From blan  
69-83.  
Balogun, I., et Johnson, G. [2  
523-549.  
Barrett B, Haynes MB, Muller  
CL Meditation or exercise for  
100 M, Vesselinov P, et al. [2  
perform prostate-specific a  
Bauer, B, Mitchell, C, Salmon  
Orthopedic Patients. A Patient  
Bauer, B, Mitchell, C, Salmon  
children, 2013]. [doi:10.1007/s126  
Béliveau, L. \[2013\]. Middle m  
1345-1362.  
Béliveau, L. \[2015\]. Model ba  
Conference in Boston, on Oct  
2015, March 2nd - 3rd  
children, 2008\]. Health Envir  
Boots, S., Bleedsoe, T., & Jenz  
Botick WJ, Bekora J, Chan Y, Vi  
patients with osteoarthritis of  
and Craig, C. \[2007\] 667-686.  
Brun, J.P., and Dugas, N. \[200  
Human Resource Management  
Burnes, B. and Jackson, P. \[2  
Management, 11\(2\), 135-143.  
Center for Researching Studie  
Choi, Y.-S., & Bosch, S.J. \[201  
Coleman EA, Ground KL, Ma  
Common J. Qual Patient Saf. 201  
Coleman EA, Min SJ, Patient  
2015;34\(3\):417-473.  
Coleman EA, Perry C, Chalmre  
25:1666171-1822-8.  
25:1666171-1822-8.  
Coleman EA, Roman SP, Hall  
Healthcare, 2015 Jan;10\(1\)  
Coleman EA, Roman SP, Pam  
Coleman EA. Extending self-m  
Coomont M, Roy C& Dumas  
management. Ergonomics, 32\(1\), 87-95.  
De Canale S, Louis, M.T. \[2008  
an empirical study of primary  
Eckman MH, Wise R, Leonard  
educational intervention in  
for patients. Podiatry Clin N  
discussions with patients wit  
Elwyn G, Frisch D, Thomson  
decision making: a model for  
Freeman, R.E. and Auister, E.I  
for patients. Public Health  
key obstacles to shared decis  
Frosch DL, Rincon D, Oscho S  
Geriatric Soc. 2010 Aug;58\(8\) :  
Gagliardi, P. \[1998\]. The crea  
of shared decision-making in  
\(Millwood\). 2015 Mar;34\(3\)](#)

Greer L, Fagan A, Co  
Clinical Outcomes M  
Guastello S, Frampt  
Settings." Journal of  
Raskind T, Devak  
Korah, S. [2005]. The  
Influences of individ  
Applied Psychology,  
Hawker GA, Wright  
role of clinical sever  
Balaguer, R. P. Liu, C.  
modest economic re  
Heilrich, C. D., Dol  
team-based care fun  
Kane, J. [2009]. The  
Care Management R  
Hibbard JR, Greene  
Health Aff (Millwood  
Higgins, M. C., Wein  
2013; 32(6):1066-107  
Hirschman KB, Shald  
Centennial Medical H  
Hojat M, Hosni DZ, Iv  
and, J. [2013]. The  
Ibrahim SA, Laoutis P  
children with knee o  
Jaibre P, Belhomme  
Naka, A, Isrta J, Belt  
systematic review of  
Carroll M., Printz, B.  
Health Environment  
Kelley JM, Kraft-Tod  
systems. Health Aff  
Kennedy AD, Heist  
affairs for menorigia  
Kern R, Shah SS, Sri  
Luan X, Debaradaran  
with charge to  
Kotter, J. P. (1995). I  
Krutzholz HM, Post-L  
Linn D, and Zimmer  
Wang, C. [2009], Lo  
Apr. 59(12):147-49.  
Lukas CV, Holmes SK  
organizational mode  
Luttk, M., Jaarsma  
relationships with heart  
McClelland, L. E. &  
McClelland, L. E., &  
patient perceptions?  
McClure, J. [2015 Jan  
Organization. [2015]  
Meyer, J. P. et al. [201  
Journal of Occupatio  
Meyers TA, Echhorn  
Am J Nurs. 2000 Feb  
21(5), 249-261.  
Spornoff, R. [2011]  
Stacy RD, Légaré F  
Decision aids for p  
Smith, G. D. One  
care conference at  
Stone S. "Outcomes"  
"Outcomes." Health

Quam, X., Joseph, A., & Ensign, J. C. [2021]. Impact of Imaging Room Environment: Staff Job Stress and Satisfaction, Patient Satisfaction, and Willingness to Recommend. Health Environments Research & Design Journal (EHDR) [vendome Group] 24(2), 61–79.

Raelin, J.D. et Cataldo, C. [2011]. Whether media management? Empowering interface and the failure of organizational change. Journal of Change Management, 11(4), 485-507.

Rask D, Barrett B, Zhang K, Hoeft TP, Grayson B, Marchand L, Scherer J. Perception of empathy in the therapeutic encounter: effects on the common cold. Patient Educ Couns. 2015 Dec;95(3):390-397.

Riehl H, Kelley JM, Bailey R, Konowitz PM, Chey ST. Improving empathy and relational skills in otolaryngology residents: a pilot study. Otolaryngol Head Neck Surg. 2011 Jan;144(1):120-2.

Riesch H, Kelley JM, Bailey RW, Dunn EJ, Phillips M. Empathy training for resident physicians: a randomized controlled trial of a neuroscience-informed curriculum. J Gen Intern Med. 2012 Oct;27(10):1280-6.

Riesch H. The Impact of Clinical Empathy on Patients and Clinicians: Understanding empathy's side effects. American journal of Bioethics Neuroscience, 2015;

Rippin AS, Zimring C, Samuels O, Denham ME. Finding a Middle Ground: Exploring the Impact of Patients- and Family-Centered Design on Nurse-Family Interactions in the NICU. HCER. 2015 Fall;9(1):89-98. doi:10.1177/1977887155895551. Epub 2015 Jul 17.

Ross, J. A. [2009]. The Impact of Two Models' Designs and Providers' Social Responsibility on Social Responsibility and Coping Factors for Children With Cancer and Their Families. Journal of Pediatric Oncology, 30(4), 340–353. [http://dx.doi.org/10.1007/s12089-009-9177-9](#)

Rosemond CA, Hanson LC, Ennett ST, Schenk AP, Weiner BL. Implementing patient-centered care in nursing homes. Health Care Manage Rev. 2012 Jul-Sep;37(3):257-66. doi:10.1097/HCM.0b0e13e8182be5617.

Rosland AM, Kleffer E, Spencer MS, Gross R, Palmigiano G, Valerio M, Nicklett E, Hesler M. Do pre-existing patient symptoms or depressive symptoms influence the effectiveness of patient education? BMC Public Health. 2015 Nov;15(1):1402.

Rosland AM, Piette JD, Choi H, Hesler M. Family and friend participation in primary care visits of patients with diabetes or heart failure: patient and physician determinants and experiences. Med Care. 2011 Jan;49(1):37-45.

Rosland AM, Piette JD. Emerging concepts for mobilizing family support for chronic disease management: a structured review. Chronic Illn. 2010 Mar;6(1):7-21.

Rosland AM, Piette JD, Lykes C, Parker M, Wolffet, H. H., Adler, N. E., . . . Karter, A. J. [2024]. Social support and lifestyle vs. medical diabetes self-management in the Diabetes Study of Northern California (DISTANCE). Annals of Behavior

Rosland, A.-M., Hesler, M., Janovic, M., Connell, C. M., Langs, K. M., Kerr, E. A., & Piette, J. D. [2013]. Current and potential support for chronic disease management in the United States: the perspective of family and friends of chronically ill adults.

Rosland, A.-M., Hesler, M., & Piette, J. D. [2012]. The impact of family behaviors and communication patterns on chronic illness outcomes: a systematic review. Journal of Behavioral Medicine, 35(2), 229–239. [https://doi.org/10.1007/s12689-012-9589-2](#)

Rosland, A.-M. [2009]. Sharing the Role of Family in Chronic Illness. California Health Care Foundation.

Rosland, A.-M., Hesler, M., Choi, H.-J., Silveira, M.J., & Piette, J. D. [2010]. Family influences on self-management among functionally independent adults with diabetes or heart failure: do family members hinder as much as they help? Chronic Illness, 6

Rosland, A.-M., Ne

Rosland, A.-M., Hesler, M., Elwyn G, Wilson CJ, Stultz C, Dillon EC, Lin M, Chang, L, Meelan A, Roth C. Enhancing Shared Decision Making Through Carefully Designed Interventions That Target Patient And Provider Behavior. Health Aff (Millwood). 2016 Apr 1;35(4):805-12.

Tarboton CK, Rendle KA, Halley MC, May SG, Lin AC, Pross DC. Implementation of Patient Decision Support Systems in Primary Care: The Role of Relational Communication. Med Decis Making. 2013 May;33(2):258-70.

Turnmers, L., Krueyen, P.M., Vijverberg D, and Voensket, T. [2015]. Connecting HRM and change management: the importance of proactivity and vitality. Journal of Organizational Change Management, 28(4), 627 – 640.

Verooff, J., Arias, A., Veenendaal DE. Enhanced support for shared decision making reduced costs of care for patients with preference-sensitive conditions. Health Aff (Millwood). 2013 Feb;32(2):288-93.

Vogel, T., & McClelland, L. E. [2016]. When the customer is the patient: Lessons from healthcare research on patient satisfaction and service quality. In: Handbook of Healthcare Service Quality, pp. 371-379.

Volandes AE, Pasche-O'Connor M, Mitchell SL, Beachwaj A, Davis AD, Barry MJ, Hartshorn K, Jackson VA, Gillick MR, Walker-Cookles ES, Chang Y, López L, Kennedy M, Bulone M, Kern M, Miras, P, Kawachi A, Abbo AD, Etchison AF, Epstein AI, Ayo, J., Levin TW, Glenn JS. Randomized evaluation of a patient decision support tool for cardiopulmonary resuscitation decision making in advanced cancer. J Clin Oncol. 2013 Jan 21;31(3):380-4.

Ulrich RS, Barby L, Quam X, Parfitt T. A conceptual framework for the domain of evidence-based design. Health. 2010 Fall;14(1):95-114.

Urban, T. [2013]. The Role of Evidence-Based Design in Health Communities/Benchmark of Life Cycle Work. Presented at the 2015 Planners' Patient Engagement and Patient Conference, Chicago, IL.

Wennerg DE, Marr A, Lang L, Olshavsky S, Bennett G. A randomized trial of a telephone case-management strategy. N Engl J Med. 2010 Sep 24;363(12):1105-15.

Weiner, RH et al (2011) Patient responses to decision aids in the United States. Int J Pers Cent Med, 5 (3), 105-111.

Werkman, R. [2009]. Understanding failure to change: A pluralistic approach to shared values. Leadership and Organization Development Journal, 30(7), 684-688.

Williams JA, Metzger J, Arranz, C, Gurin FA, Chang C, Gurin FA et al. Patients' religious and spiritual concerns: predictors and association with patient satisfaction. J Geriatr Psychiatry Neurol. 2011 Nov;26(1):125-7.

Wilson SR, Strub AJ, Davis AS, Knowles SB, Lawori PV, Lapinski J, Volmer WH. Better Outcome of Asthma Treatment (BOAT) Study Group. Shared treatment decision making improves patient adherence and outcomes in poorly controlled asthma. Am J Respir Crit Care Med. 2010 Sep 14;182(11):566-77.

Woff, L. J., & Roter, D. L. [2008]. Hidden presence in routine medical visits: A meta-analysis review. Social Science & Medicine [online]. 2011; 70(1):10-20. Available from: [http://www.sciencedirect.com/science/article/pii/S0966782910001898](#).

Woff, L. J., & Roter, D. L. [2008]. Hidden in plain sight: medical visit companions as a resource for vulnerable older adults. Archives of Internal Medicine, 168(13), 1409-1415. [http://doi.org/10.1007/archinte.168.13.1409](#)

Wong, S. S. Patient Falls Reduction Initiative. Sharp Healthcare. Annual Nursing Report, 2011.

Ström, L. L., & Egge, L. E. [2012]. The impact of social support on outcomes in adult patients with type 2 diabetes: a systematic review. Current Diabetes Reports, 12(6), 769-781. [http://doi.org/10.1007/s12089-012-0137-0](#)



# Patient Engagement

## Blockbuster Drug of the Century

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*“All this is so different for healthcare providers. It’s like a great restaurant learning that their new business is going to be – in addition to continuing to provide a great in-restaurant experience – teaching people how to cook at home. What? This isn’t what we do! It’s impossible!”*

*Leonard Kish,  
Forbes Magazine  
September 9, 2012*



# The Challenge of Engaging





# Co Design

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## **Procter & Gamble's Connect + Develop**

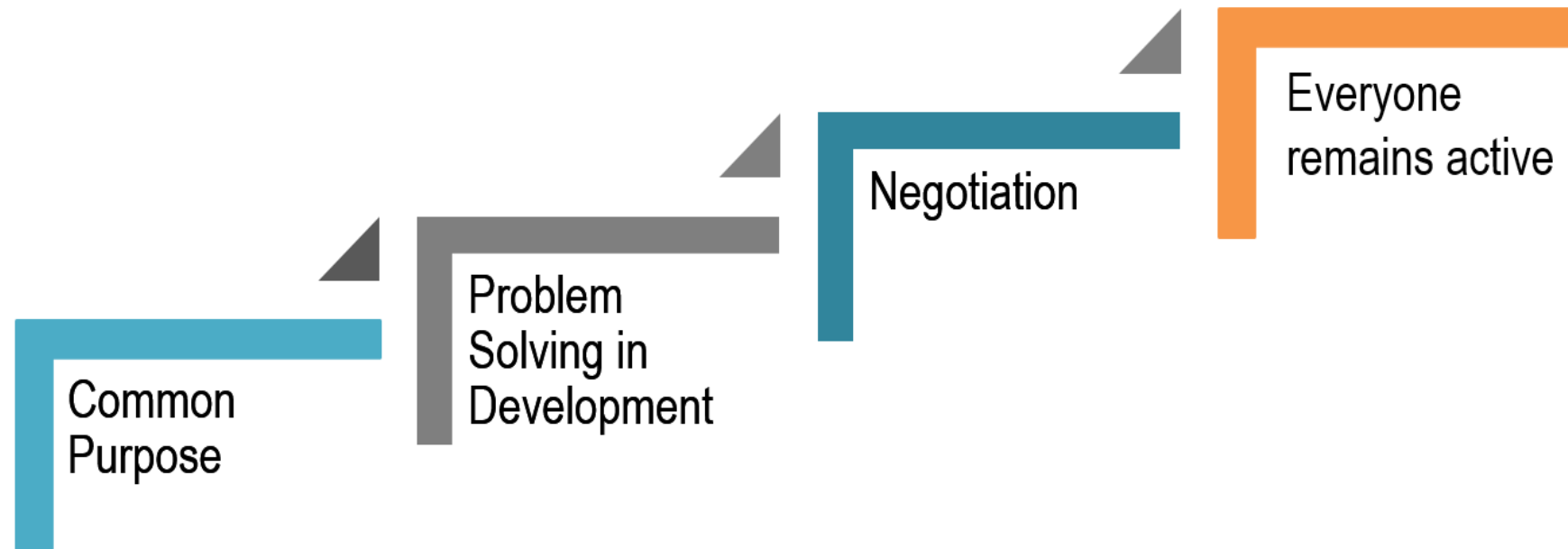
*Launched "with the goal of having at least 50% of its new products derived from ideas generated by non-employee experts. Beside its own R&D employee base of 7,000, the company now has access to millions of potential innovators.*

**The results so far?** Everything from Swiffer Wet Jet, Olay Daily Facials, Crest Whitestrips & Night Effects to Mr. Clean Autodry, Kandoo baby wipes and Lipfinity. (Source: Tech Central Station, Industry Week.)



# Collaboration

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# Patient Family Advisors

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Patient & family advisors work in a variety of healthcare settings **sharing** their personal stories to represent all patients & families in providing an educated perspective of care by bringing authenticity, empowerment, **respect** and inspiration to the design and delivery of healthcare systems. Patient & Family Advisor roles include partner, educator, speaker, listener, advocate, **collaborator** and leader, ensuring the focus of healthcare is centered on the patient & the family.

*Collaboratively authored by the Patient & Family Advisors assembled for the 2012 Institute for Healthcare Improvement Forum, Orlando December, 2012*



# Core Competencies of Effective Advisors

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*PFANetwork, 2014*



# Elements of Impactful Advisor Efforts

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## High Impact

- Reciprocal
- Tied to the strategic goals of the organization
- Proactive
- Co Design
- Integrated across areas of the organization
- Vision & Mission as North Star
- Focus on the structure

## Low Impact

- Customer Service approach
- Lack anchor to organizational priorities
- Rubberstamp
- Facilitator Presents information for feedback
- Siloed into Pt Experience efforts or Quality or Safety
- North Star is the improvement goal
- Focused on the people



# Interdisciplinary TEAMwork!

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- **Facilitator**
- **Leadership Representative**
- **Communications**
- Project Managers
- Clinical Staff Representative
- Administrative Support



# Set the Table

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1. Vision
2. Charter
3. Address Challenges
4. Align with Strategic Goals
5. Make it easy



# Preparation

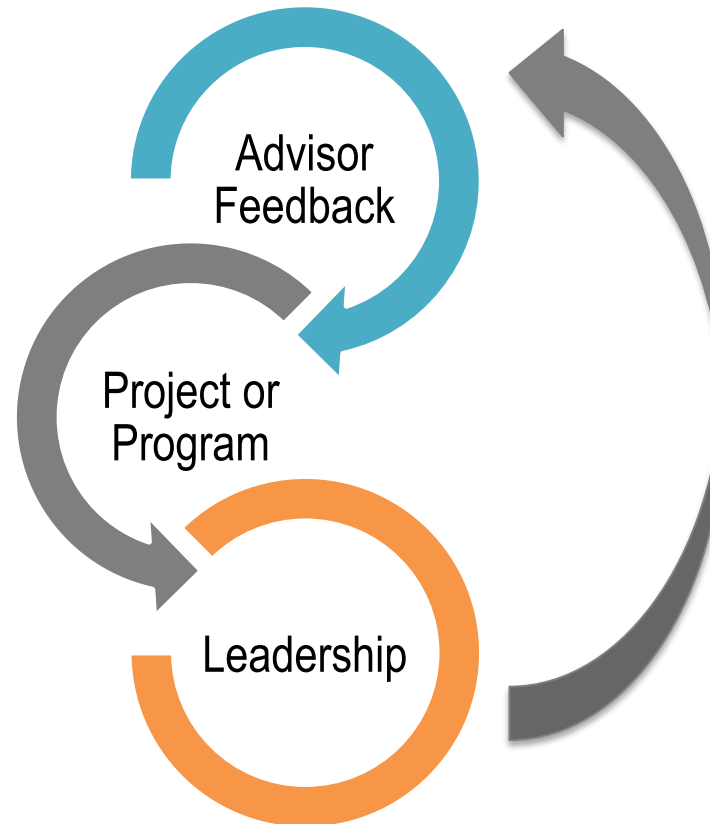
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# Communication Loop

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# Facilitation Skills

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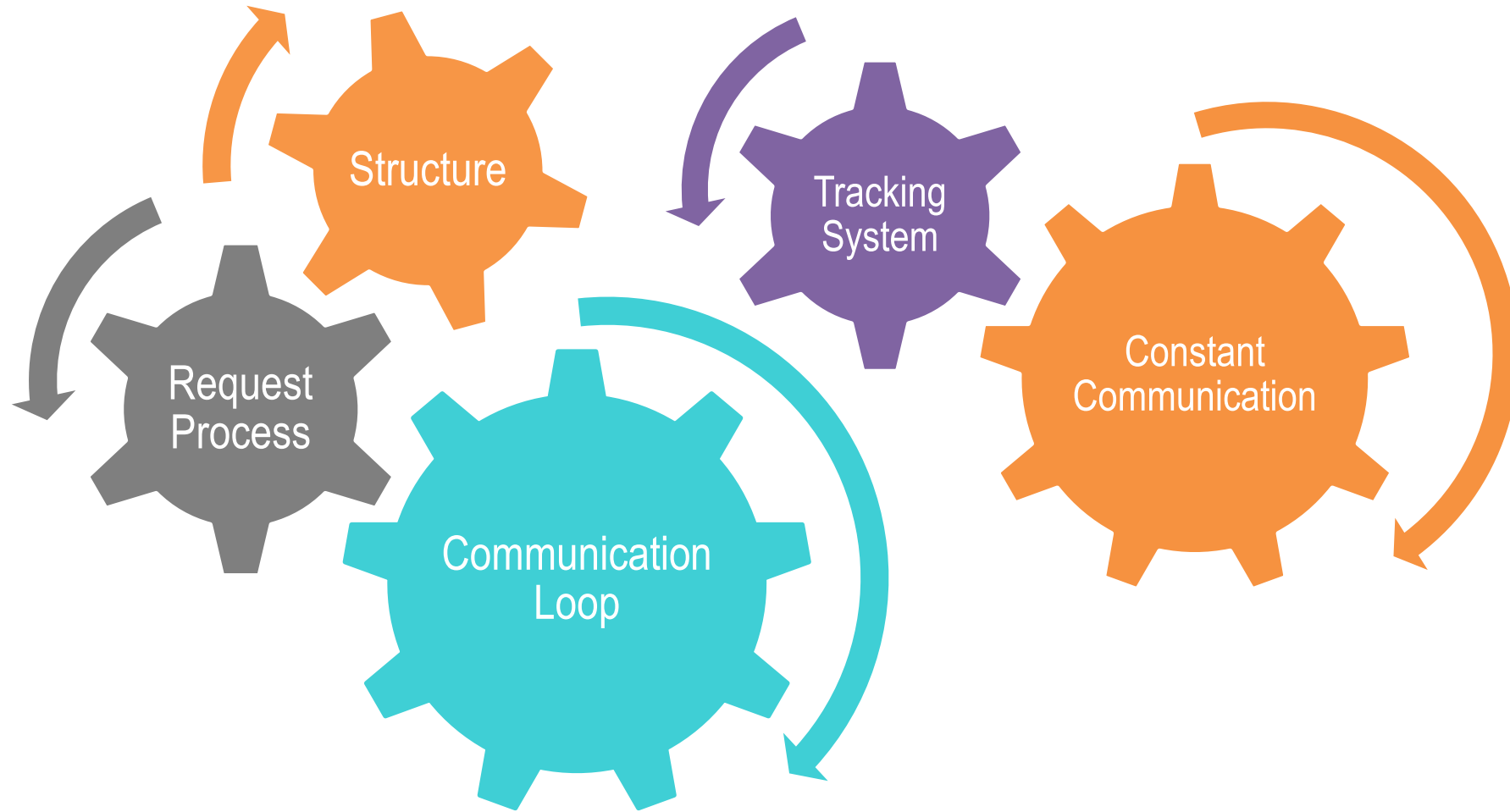
*A facilitator is an individual who enables groups and organizations to work more effectively; to collaborate and achieve synergy. She or he is a “content-neutral” party who by not taking sides or expressing or advocating a point of view during the meeting, can advocate for fair, open, and inclusive procedures to accomplish the group’s work. A facilitator can also be a learning or a dialogue guide to assist a group in thinking deeply about its assumptions, beliefs, and values and about its systemic processes and context.*

*Facilitators Guide to Participatory Decision Making by Sam Kaner*



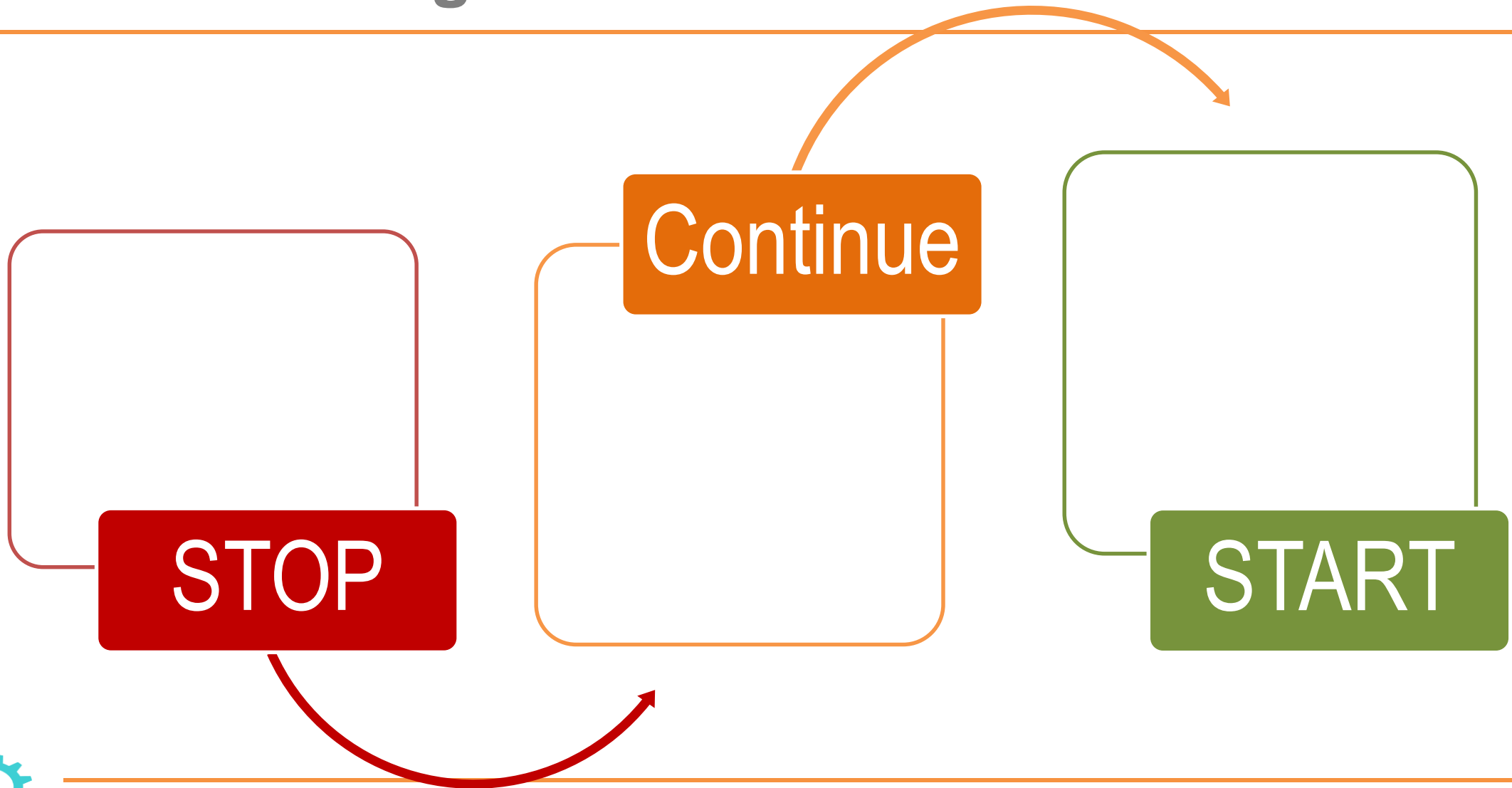
# Managing Success

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# Action Planning

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# Resources

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PFCCpartners

[www.pfccpartners.com](http://www.pfccpartners.com)

IHI Principles for Radical Redesign

<http://www.ihl.org/resources/Pages/Publications/10NewRulesAccelerateHealthcareRedesign.aspx>

American Institute of Research, RoadMap to PFE

<http://patientfamilyengagement.org/>

American College of Physicians

<https://www.acponline.org/practice-resources/patient-care-resources-and-tools>

National Academy of Medicine

<https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care/>

