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***Using Patient and Family Advisory Councils
in a Post-Covid World:
Washington Patient Safety Coalition
Virtual · June 11, 2020***

Martin J Hatlie, JD
President, Project Patient Care · Co-Director, MIQS

Objectives today

- Information sharing
 - What Patient and Family Advisory Councils (PFACs) are working on (or getting ready to) during the Pandemic
 - Policy issues/vectors in play
 - Current opportunities to advance Patient Safety
- Comments, thoughts, questions



What PFACs are working on now: Support for hospital patients

Issues

- Family communication with hospital providers from a distance
- Communication with patients
- Patient isolation, anxiety and mental health
- Decision-making and End of Life care

Resources

- AARP *Tips for Family Members Managing Medical Matters*: <https://www.aarp.org/caregiving/health/info-2020/managing-medical-care.html?intcmp=AE-HP-TTN-R4-POS2-REALPOSS-TODAY>
- Patient Safety Movement Foundation (PSMF) *Guide to Medical Care at a Distance*: <https://www.dropbox.com/s/m052xhjxsjrv/Guide%20to%20Medical%20Care%20at%20a%20Distance.pdf?dl=0>
- *iPads Are Crucial Health Care Tools in Combating Covid-19*: <https://www.wired.com/story/ipads-crucial-health-tools-combating-covid-19/>
- Centers to Advance Palliative Care (CAPC): *COVID-19 Response Resources* (<https://www.capc.org/toolkits/covid-19-response-resources/>)
- University of Wisconsin: *Best Case/Worst Case: ICU, with Special Content for Patients with COVID-19* (https://www.hipxchange.org/BCWC_COVID-19)



Grandma Rocket, the Virus and a Family Whose Love Bridged 2,500 Miles: <https://www.nytimes.com/2020/05/02/nyregion/hospital-family-coronavirus.html>



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Guide to Medical Care at a Distance

HOSPITAL ADMISSION: DAY ONE



Print or Download the Plan of Care (POC) Form from PSMF Website

- Fill out any information you already know
- Access the patient portal with permission from the patient to complete the rest
- Download and complete a home medication list (this will be important to compare to medications upon discharge)
- **Plan of care blank template** on PSMF website
- **Plan of care example template** on PSMF website



Exchange Contact Information, Including Names and Direct Dial Numbers

- Family spokesperson- one person to be designated as the communicator
- Nursing department phone number or direct bedside RN number



Contact the Bedside RN by Phone or in Person, if Possible

- If the bedside RN is not available, contact the charge nurse
- Schedule 10-15 minutes to discuss the plan of care



Discuss the Process for Care Planning on the Unit

- What are the virtual communication options?
- What time each day is best to communicate updates?



Share that You are Tracking the Plan from Home as the Spokesperson

- Share pertinent health information about your loved one
- Request the missing information on the form from the RN
- Get a list of medications being given and compare it to your downloaded med list
- Schedule twice-daily calls to review the plan of care with the bedside or charge nurse
- Locate hospital resources
 - Patient Right's page
 - COVID-19 Updates page
 - Patient experience office
- Ensure the patient is equipped with a phone, charger, and headset
 - Add contacts on speed dial
 - Use an iPad if possible for stiff or swollen hands
 - Ask what telecommunication technologies, such as an iPad used for translation services, the hospital might have
 - Ask if an appointment can be made for virtual discussion that includes the entire interdisciplinary team at least every three days
 - Ask if you can use a nanny cam or baby monitor for ICU patients

YOUR NOTES

Blank area for notes.



Patient Safety Movement Foundation | patientsafetymovement.org

Patient Safety Movement Foundation: *Guide to Medical Care at a Distance*

Downloadable Family Management tool, organized by:

- Admission
- During the stay
- Discharge

https://www.dropbox.com/s/9wvcrbnqi5ofr39/PSMF_Guide_to_Medical_Distance.pdf?dl=0



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What PFACs are working on now: Support for hospital patients

Issues

- Advanced Directives & POLST portable medical orders
- Elective Surgery
- Support for Covid19 survivors

Resources

- AARP Advance Directives forms for all States: <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>
- Respecting Choices: Covid-19 Resources: <https://respectingchoices.org/covid-19-resources/>
- POLST Portable Medical Orders: <https://polst.org/about/>
- Project Patient Care podcast, *Advance Care Planning During “Normal” and Covid-19 Times*: <https://www.projectpatientcare.org/podcasts/>
- Project Patient Care: *Recommendations for and by Patients, Families, and Caregivers for Elective Surgeries and Invasive Procedures During COVID-19 Pandemic*: <https://www.projectpatientcare.org/wp-content/uploads/2020/05/patientandcaregiverperspectiveselectivefinal.pdf>
- Vizient Covid-19 Resource Page (updated daily): <https://www.vizientinc.com/covid-19>
- Blog post, *Covid Cohorts: You are sick but not alone*, <https://joshuaweissburg.com/2020/04/12/covid-cohorts-you-are-sick-but-you-are-not-alone/>



What PFACs are ready to work on:

Gratitude

Issues

- Giving back, e.g. plasma donation
- Staff morale

Resources

- Blog post, *In a pandemic, does patient feedback still matter?*
https://blogs.bmj.com/bmj/2020/03/30/james-munro-in-a-pandemic-does-patient-feedback-still-matter/?utm_source=twitter&utm_medium=social&utm_term=hootsuite&utm_content=sme&utm_campaign=usage
- Twitter thread: *7 tips on boosting the effects of gratitude:*
<https://twitter.com/GiskinDay/status/1241303041015513088>
- AARP: *Innovative ways to say thank you.*
<https://www.aarp.org/health/conditions-treatments/info-2020/tributes-to-health-care-workers.html>



What PFACs are ready to work on soon: Hospital+ policy issues

Issues

- Visitation policy
- Discharge planning & continuity of care
- Safety in long term care
- Telehealth

Resources

- Medicare and C-19 landing page: <https://www.medicare.gov/medicare-coronavirus>
- Hospitals, Psychiatric Hospitals and Critical Access Hospitals – CMS visitation waivers: <https://www.cms.gov/files/document/qso-20-13-hospitals-cahs-revised.pdf>
- Nursing homes – CMS visitation: https://skillednursingnews.com/wp-content/uploads/sites/4/2020/03/QSO-20-14-NH-REVISED-3-13-2020_0.pdf
- Project Patient Care guidance on visitor rules in hospitals and nursing homes: <https://www.projectpatientcare.org/wp-content/uploads/2020/04/ppccovid19april5.pdf>
- National Alliance on Mental Illness (NAMI): *COVID 19 Information and Resources* (<https://www.nami.org/Support-Education/NAMI-HelpLine/COVID-19-Information-and-Resources>)
- American Association for Retired Persons (AARP)
- *6 Questions to Ask if Your Loved One Is in a Quarantined Facility* (<https://www.aarp.org/caregiving/health/info-2020/questions-for-quarantined-facility.html>)
- *The COVID 19 Imperative: Keep Family Caregivers and Long-Term Care Facility Residents Connected* (<https://blog.aarp.org/thinking-policy/the-covid-19-imperative-keep-family-caregivers-and-long-term-facility-residents-connected>)



What PFACs are ready to work on soon: Prevention, health & safety at home

Issues

- Covid
 - Masks
 - Distancing
 - Hand hygiene
- Stress & mental health
- Care for caregivers

Resources

- [Coronavirus.gov](https://www.cdc.gov/coronavirus) is the source for the latest information about COVID-19 prevention, symptoms, and answers to common questions.
- [CDC.gov/coronavirus](https://www.cdc.gov/coronavirus) has the latest public health and safety information from CDC and for the overarching medical and health provider community on COVID-19.
- [USA.gov](https://www.usa.gov) has the latest information about what the U.S. Government is doing in response to COVID-19.
- World Health Organization information and advice: https://www.who.int/health-topics/coronavirus#tab=tab_1
- National Alliance on Mental Illness (NAMI): *COVID 19 Information and Resources* (<https://www.nami.org/Support-Education/NAMI-HelpLine/COVID-19-Information-and-Resources>)
- AARP family caregiver resources: <https://www.aarp.org/caregiving/health/>
- Patient Safety Movement Foundation (updated frequently): *Helpful Covid-19 Resources* (<https://patientsafetymovement.org/helpful-coronavirus-covid-19-resources/>)



ARTICLES | [ONLINE FIRST](#)

Mortality due to low-quality health systems in the universal health coverage era: a systematic analysis of amenable deaths in 137 countries

Margaret E Kruk, MD   • Anna D Gage, MSc • Naima T Joseph, MD • Goodarz Danaei, SD • Sebastián García-Saisó, MD • Prof Joshua A Salomon, PhD • [Show all authors](#) • et al.

[Open Access](#) • Published: September 05, 2018 • DOI: [https://doi.org/10.1016/S0140-6736\(18\)31668-4](https://doi.org/10.1016/S0140-6736(18)31668-4) •

Findings 15·6 million excess deaths from 61 conditions occurred in LMICs in 2016. After excluding deaths that could be prevented through public health measures, 8·6 million excess deaths were amenable to health care of which 5·0 million were estimated to be due to receipt of poor-quality care and 3·6 million were due to non-utilisation of health care. Poor quality of health care was a major driver of excess mortality across conditions, from cardiovascular disease and injuries to neonatal and communicable disorders.

Interpretation Universal health coverage for SDG conditions could avert 8·6 million deaths per year but only if expansion of service coverage is accompanied by investments into high-quality health systems.

Funding Bill & Melinda Gates Foundation.



Commissions from the Lancet journals

View all Commissions

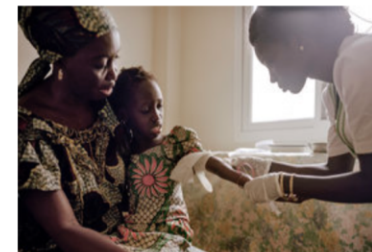
High-quality health systems in the Sustainable Development Goals era: time for a revolution

Published: September 5, 2018

Executive Summary

Although health outcomes have improved in low-income and middle-income countries (LMICs) in the past several decades, a new reality is at hand. Changing health needs, growing public expectations, and ambitious new health goals are raising the bar for health systems to produce better health outcomes and greater social value. But staying on current trajectory will not suffice to meet these demands. What is needed are high-quality health systems that optimise health care in each given context by consistently delivering care that improves or maintains health, by being valued and trusted by all people, and by responding to changing population needs.

In this Commission, we assert that providing health services without guaranteeing a minimum level of quality is ineffective, wasteful, and unethical. Moving to a high-quality health system—one that improves health and generates confidence and economic benefits—is primarily a political, not technical, decision. National governments need to invest in high-quality health systems for their own people and make such systems accountable to people through legislation, education about rights, regulation, transparency, and greater public participation. Countries will know that they are on the way towards a high-quality, accountable health system when health workers and policymakers choose to receive health care in their own public institutions.



Audio

Download

Mortality due to low quality health systems
Margaret Kruk talks about her latest work on health system quality and related mortality, appearing in *The Lancet* and in a Commission in *The Lancet Global Health*.

Related links

HQS Commission


<https://www.thelancet.com/commissions/quality-health-systems>






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Re-framing patient safety



Even though medical harm is prevalent nationwide, experts and advocates struggle to increase awareness about patient safety risks and spark support for effective solutions. The Betsy Lehman Center is partnering with FrameWorks Institute – a D.C.-based nonprofit that uses research to shape public discourse on social and scientific issues – to change how people think and talk about this important public health issue.

Key takeaways

There is a noticeable gap between the way experts think about how best to improve the safety of health care and the understanding of the general public – and many health care professionals – about the challenges and solutions to the problem of medical error across the country.

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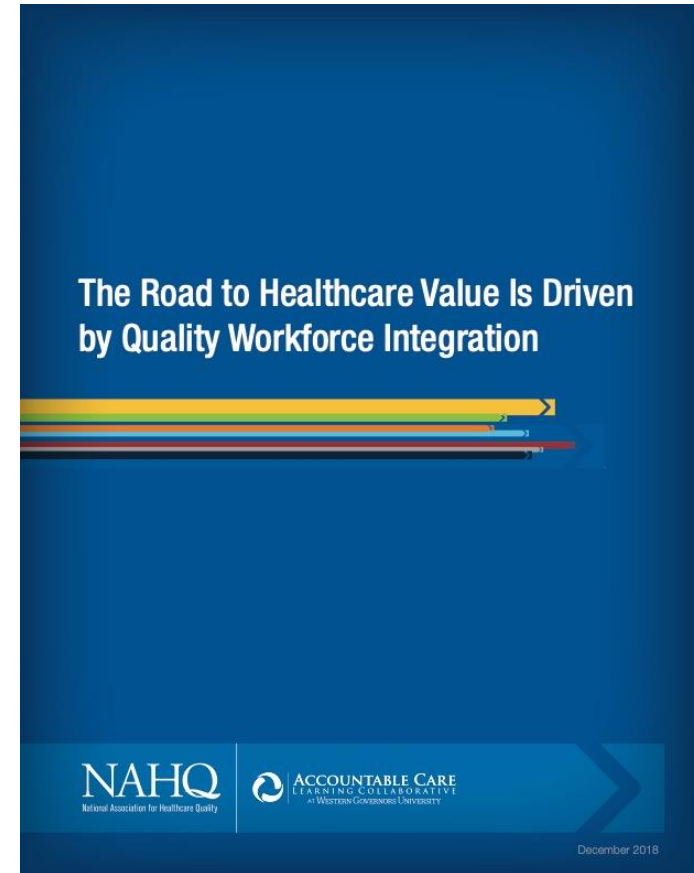
National Assn for Healthcare Quality (April 2019)

<https://www.qualitydrivenhealthcare.org/workforce-report>

As the U.S. health system rapidly shifts to business models designed to reward cost-efficient, quality care that improves patient outcomes, healthcare quality professionals are playing an increasingly central role in this transformation.

Are Healthcare Quality Professionals Up to the Challenge?

New research asked that question by inviting healthcare quality professionals to assess their work against the only industry standard for healthcare quality competencies, the NAHQ Healthcare Quality Competency Framework. The research, conducted by the National Association for Healthcare Quality (NAHQ), found mixed results about the readiness of the quality workforce to meet current and new demands in healthcare. While healthcare quality professionals are succeeding at moving their organizations in the directions prioritized by healthcare leaders, a surprising number said key aspects of their work were more aligned with competencies ranked on the novice end of the spectrum than the more advanced levels of proficient and expert.



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Home Alone Revisited:

FAMILY CAREGIVERS PROVIDING COMPLEX CARE

<https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>

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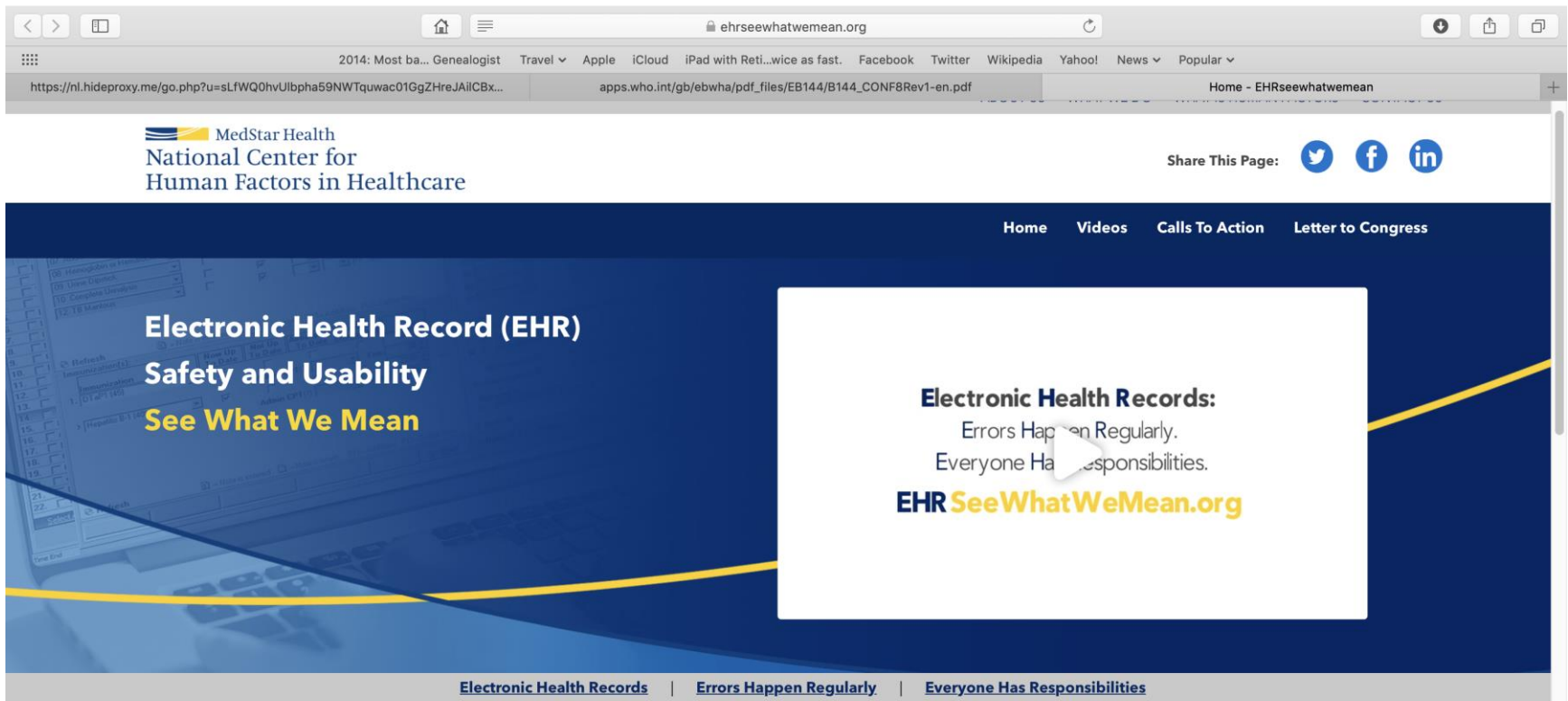
AARP Foundation



The John A. Hartford
Foundation

Susan C. Reinhard, Heather M. Young, Carol Levine,
Kathleen Kelly, Rita B. Choula, Jean Accius

Special Report by the Founders of the Home Alone AllianceSM




New Campaign on EHR errors <https://ehrseewhatwemean.org>
New *Fortune* article: <http://fortune.com/longform/medical-records/>

Not Secure — apps.who.int

2014: Most ba... Genealogist Travel Apple iCloud iPad with Reti...wice as fast. Facebook Twitter Wikipedia Yahoo! News Popular

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World Health Organization

EXECUTIVE BOARD
144th session
Agenda item 6.6

EB144/CONF./8 Rev.1
1 February 2019

Global Action on Patient Safety

Draft resolution proposed by Algeria, Angola, Argentina, Australia, Austria, Botswana, Brazil, China, Eswatini, Germany, Greece, Indonesia, Japan, Kenya, Latvia, Luxembourg, Oman, Portugal, Saudi Arabia, Slovakia, South Africa, Sri Lanka, Switzerland, Thailand, United Kingdom of Great Britain and Northern Ireland and the United States of America

http://apps.who.int/gb/ebwha/pdf_files/EB144/B144_CONF8Rev1-en.pdf

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World Health Assembly

May 2019 PS Resolution Deconstructed

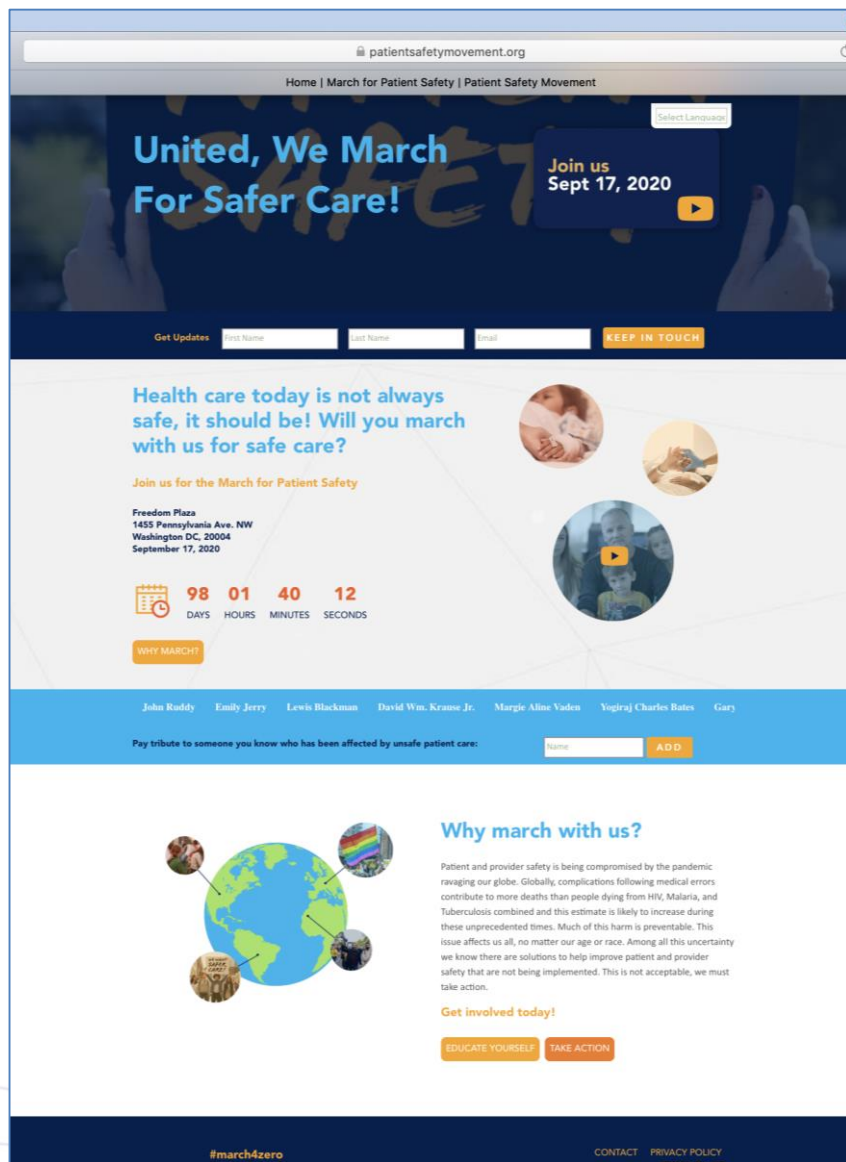
Challenge

- PS not a top policy priority despite being one of “top 10” causes of death
- Access to “safe infrastructures, technologies and devices” & their safe use
- Adequate workforce skills & competencies in respective roles & functions
- Continuous professional development to maintain a “competent, compassionate and committed” workforce
- Safe, effective, affordable medicines
- Hygiene
- International cooperation to achieve safety culture and spread best practices
- Failure to implement simple solutions where “value of prevention outweighs the cost of care.”

Member States urged to:

- Make PS a top policy priority
- Accurately assess & measure magnitude
- Invest adequate resources
- Engage professional & civil stakeholders
- Spread best practice
- Culture, e.g. leadership, transparency, reporting, moving beyond blame
- Education, “human resource capacity”
- More translational research
- Use of innovative technology
- PFE – “use experiences of safe and unsafe care positively to build harm prevention strategies and compensation schemes”
- Address gaps in “knowledge, policy, design, delivery and communication at all levels”¹⁷
- Raise awareness by recognizing 9/17 as World Patient Safety Day





Other opportunities in the policy arena

- 20 year milestone(s)
- Election Year
- IHI National Steering Committee Recommendations
 - Culture & Leadership
 - Patient & family engagement
 - Workforce safety
 - Continuous learning systems
- Patient Safety Movement Foundation [March for Patient Safety](https://www.patientsafetymovement.org/march-for-patient-safety), Washington, DC September 17, 2020



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PFE Resources

The Joint Commission Journal on Quality and Patient Safety 2020; 000:1-9

Lessons Learned from a Systems Approach to Engaging Patients and Families in Patient Safety Transformation

Martin J. Hattlie, JD; Armando Nahum; Roger Leonard, MD; Laria Jones; Victoria Nahum; Seth A. Krevat, MD; David B. Meyer, MD; Kelly M. Smith, PhD

Background: Effective patient- and family-centered care requires a dedication to engaging patients and family members in health system redesign to improve the quality, safety, and experience of care. Provided here are lessons learned six years after establishing an infrastructure of patient and family advisory councils (PFACs) focused on improving health care quality and safety.

Context: A large regional health care system with multiple hospitals and ambulatory care delivery sites in the eastern United States adopted a systemwide approach to Patient and Family Advisory Councils on Quality and Safety (PFACQS®) in 2012.

Approach: This conceptual article describes the barriers and facilitators of adopting, implementing, and sustaining the PFACQS model across a large, geographically diffuse health system. Successful strategies that emerged include active board engagement, co-creation and mentorship by experienced patient advocates to support enhanced engagement by local PFACQS community members, and clear alignment with and line of sight on organizational quality and safety goals.

Conclusion: Implementing a robust network of PFACQS focused on improving quality and patient safety requires leadership commitment to transparency, as well as mutual respect and trust. Establishing clear guidelines, structures, and processes supports early adoption. Openness to continuous improvement and adaptations are important to program success and contribute to program sustainability.

In the last half of the twentieth century, principles of patient-centered care emerged in the context of ensuring human rights.^{1,2} These principles focused on the dignity of the patient as owner of his or her own body, including the patient in decision making, and patient experience as assessed by measures of patient satisfaction.³⁻⁶ Traditionally, patient and family engagement within hospitals and health systems was focused on strategies at the point of care delivery, such as informed consent and patient compliance with prescribed medicine use. Starting in 1978, with leadership from the Planetree organization, patient and family advisory councils (PFACs) emerged as a strategy for respecting the dignity of the patient and improving satisfaction.^{7,8} PFACs are generally composed of community members who use the services of the hospital or health system for their own care or that of family members.⁸⁻¹⁰ PFACs were established in many hospitals seeking patient and community input on a range of matters, including facilities design, comfort, respect, and other elements of patient experience.¹¹ Patient advocacy groups then began encouraging—sometimes challenging—health care systems and thought leaders to incorporate their experiences and insights on safety and quality concerns.¹²⁻¹⁴ In 2004 the

World Health Organization integrated patient and family engagement into its World Alliance for Patient Safety. This included patient advocates in leadership initiatives addressing hand hygiene, safe surgery, and the reporting of adverse events.¹⁵ Health care culture and systems transformation leaders began to recognize the value of incorporating patient perspectives in both improvement work and culture transformation.

True partnership with patients and families requires dedication to engaging them with caregivers as partners in quality, safety, and continuous improvement of care. A systematic review of randomized controlled trials found that patient information materials were more relevant, readable, and understandable to patients when designed with patient input.¹⁶ A report of state hospitals in New York found that facilities with high-performing PFACs (29% of PFACs) reported lower rates of pressure ulcers, sepsis, septic shock, and 30-day hospital readmissions, along with better patient experience scores, when compared to hospitals with low-functioning PFACs.¹⁷ Hospitals with a PFAC reported better outcomes than hospitals without a PFAC on all performance measures.¹⁷ Together, these studies suggest opportunities for engaging patients and family members in health system quality and safety activities, particularly those with patient-facing elements (for example, safety reporting). The evidence of the impact of patient and family engagement on health care systems transformation, however, remains weak. Liang et al. found that studies of strategies to engage pa-

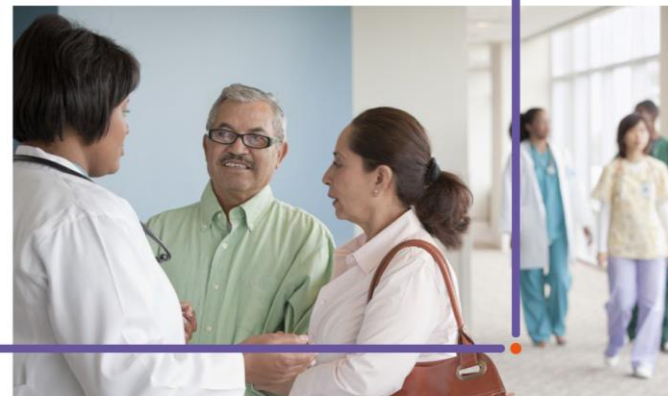
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(<https://doi.org/10.1016/j.jcqs.2019.12.001>)

Embargoed copy awaiting approval

vizient.

Person and Family Engagement-integrated Quality and Safety Change Package

September 2018



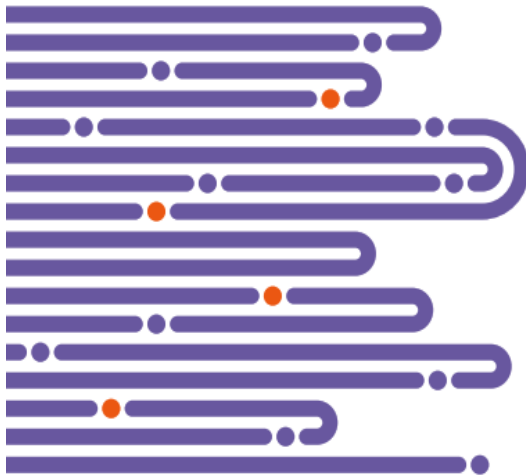
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Vizient HIIN Patients First Project for CMS

Examining the relationship
between high-performing
person and family engagement
hospitals and quality and
safety performance

September 2018



Findings include:

- a correlation between higher levels of PFE and lower rates of falls (with injury) and 30-day readmissions
- specific activities and processes that most impact those improvements
 - PFACs
 - PFE in operations
 - Organizational leadership support
- little to no financial investment (excluding staff time and resources)



MedStar Franklin Square Medical Center (MFSMC) Pilot Site Visit

Sam Moscovitz FACHE, President

Colleen LoPresto RN, BoD Member

Patient & Family Advisory Council for
Quality & Safety Members



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MedStar Franklin Square Hand Hygiene Initiative

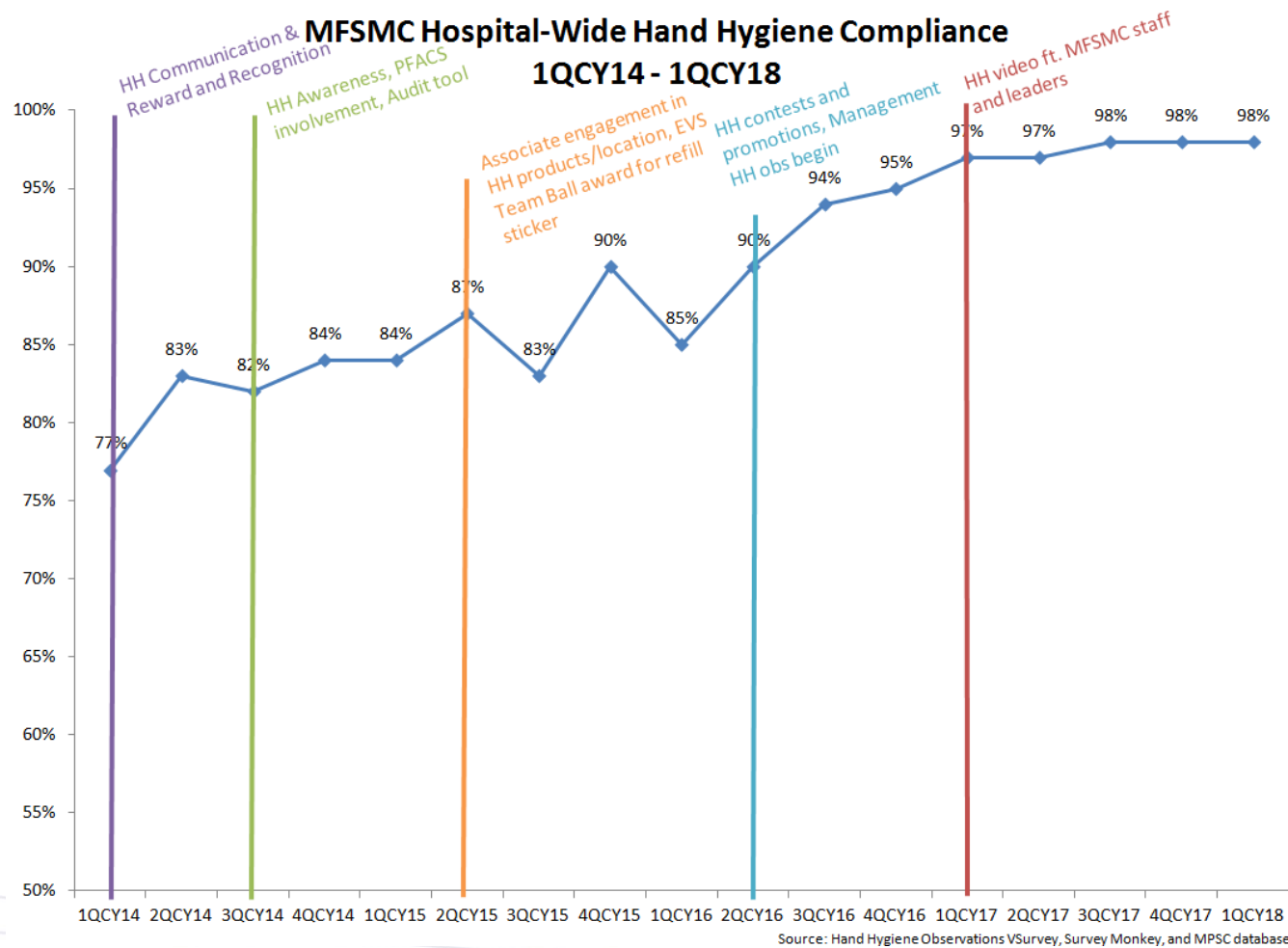


June 10, 2020



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2018 Special Project: *Patients First*

Goal: Better understand of PFE Impact & Best Practices for Maximizing Impact

Project Design

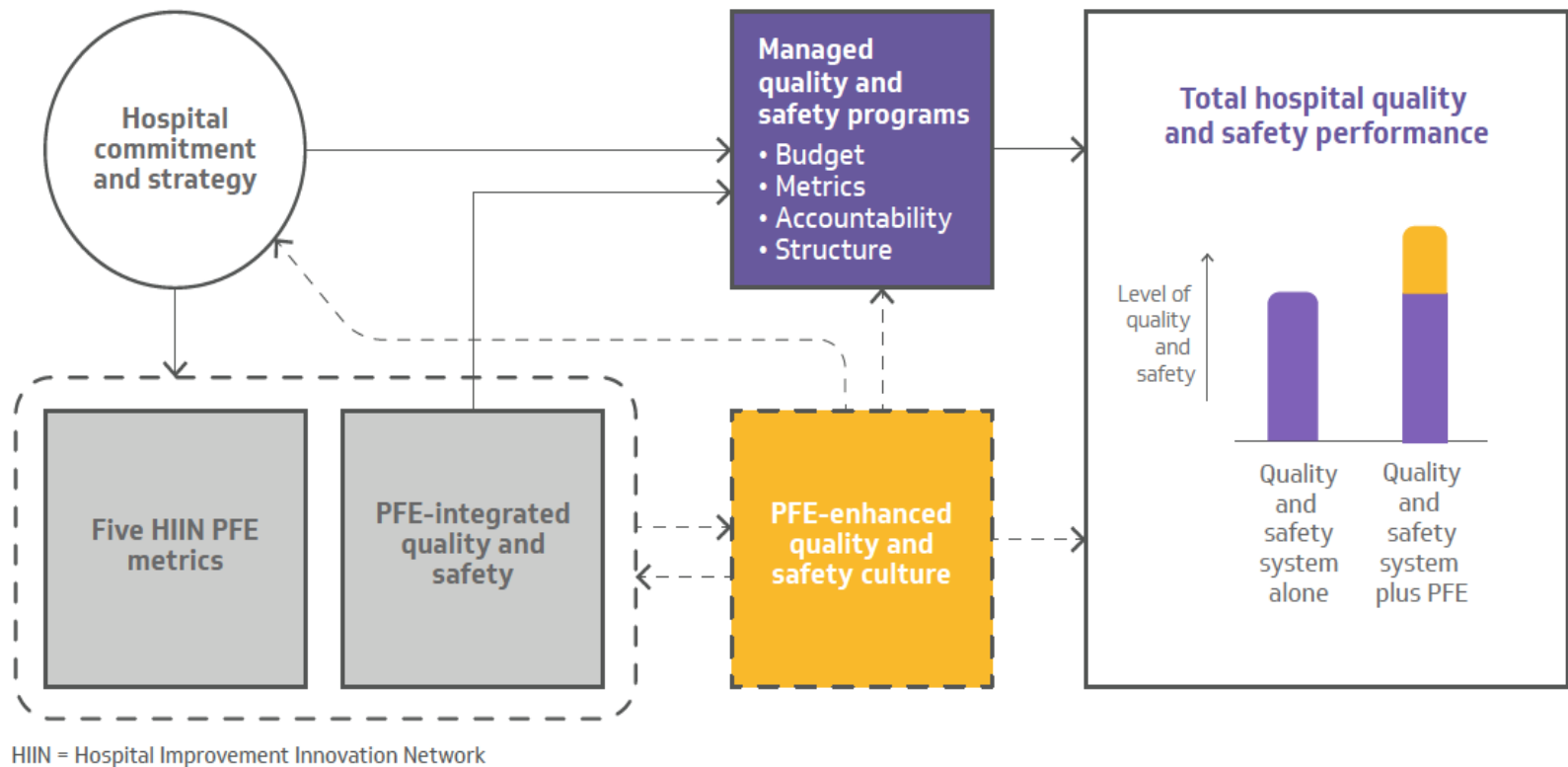
- Survey & analysis
- Follow up telephone survey to interview high performing hospitals
- Site visits
- Spread of Best Practices & Promising Innovations

Site Visits

- Cheyenne Regional, Cheyenne, WY
- Emory University Hospital, Atlanta, GA
- Medical University of South Carolina, Charleston, SC
- MedStar Franklin Square, Baltimore, MD
- Ohio State Wexner Medical Center, Columbus, OH
- Palmetto Health Richland, Columbia, SC
- Parrish Medical Center, Titusville, FL
- Sanford Hospital, Bismarck, ND
- Seabasticook Valley Hospital, Pittsfield, ME
- University Hospital Medical Center, Cleveland, OH
- UCLA Ronald Regan Medical Center, Los Angeles, CA



Vizient Patients First Logic Model



What We Found at the High Performers...

- PFE programs are managed as a strategic priority with Board oversight
- Patient and family advisers are embedded in quality, safety and operational improvement efforts
- PFE programs are leveraged to foster continuous learning and innovation



PFE programs are managed as a strategic priority with Board oversight

Executive leadership and staff manage high-performing PFE programs as a part of quality, safety and operations improvement, and report outcomes to the Board of Directors.

- Leaders align PFE with organizational vision/mission/values and drive organizational behaviors through explicit internal and external messaging.
- Leaders dedicate staff and resources to develop a structured PFE program that includes a Patient and Family Advisory Council (PFAC).
- PFE staff identifies, selects and on-boards patient and family advisers through standardized processes that include outreach to people who have experienced service issues.



CMS/Vizient Patients First Change Package

This change package synthesizes the common themes observed at high-performing PFE hospitals and delineates a road map of leading practices and innovative approaches hospitals and health systems can use for quality, safety and operational improvements.

PFE-integrated Quality and Safety Program

1. PFE programs are managed as a strategic priority with board oversight.

Executive leadership and staff manage high-performing PFE programs as a part of quality, safety and operational improvement, and report outcomes to the board of directors.

1.1 Leaders align PFE with organizational vision/mission/values and drive organizational behaviors through explicit internal and external messaging.

1.2 Leaders dedicate staff and resources to develop a structured PFE program that includes a PFAC.

1.3 PFE staff identifies, selects and onboards PFAs through standardized processes that include outreach to people who have experienced service issues.

2. Patients and families are embedded in quality, safety and operational improvement efforts.

Organization trains and educates PFAs to partner with clinical and operational staff and leaders to achieve quality, safety and operational improvement goals.

2.1 Organization prepares PFAs to contribute to quality, safety and operational improvements.

2.2 Organization prepares staff to partner with PFAs.

2.3 PFAs engage in process redesign at the earliest possible point to co-create solutions that avoid unnecessary delay, rework and cost.

2.4 Organization tracks contributions made by PFAs, as well as their impact on outcomes.

3. PFE programs are leveraged to foster continuous learning and innovation.

PFAs engage broadly throughout the organization; learnings further implementation of PFE practices that impact outcomes.

3.1 Organization "liberates" PFAs from conference rooms and deploys them across the organization.

3.2 Organization communicates lessons learned from the PFE program throughout the organization, including outpatient facilities and settings.

3.3 PFE program continuously evolves to meet the needs of the organization.

PFE = person and family engagement; PFAs = patient and family advisers;
PFAC = patient and family advisory council



Thanks!

Comments, thoughts, questions?



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