Patient, Family and Caregiver Engagement

"Key to the future vision of care is engaging the patient, patient family and caregivers and enabling engagement with easy-to-find, reliable, trustworthy medical information. The current state of healthcare doesn't support engagement and finding the necessary medical information is difficult. See these 2 videos with perspectives from 3 leading patient advocates:

The Importance of Evidence and Patient Partnering to Make Change (Rosie Bartel)
Reframing Learning Health Systems to Better Reflect the People They Serve (Danny van Leeuwen and Janice Tufte)

Current Gaps and Problems

Evidence ? Guidance ? Action

Patients, Families and Caregivers (PFC) seek medical information from many places. Currently there is no easy place to find specific medical information that is reliable, easy to understand, timely and trustworthy. PFC often first ask friends and family and or search the internet, then their providers. How do individuals know that the medical information they are finding is the right care, for the right condition and right for them?

We know current evidence knowledge generation is less than optimal; health and digital literacy and communication gaps thrive within this space. There are limited opportunities for PFC involvement in evidence production where later, at points of care, misunderstandings and medical errors too often occur.

What information is available is spread across multiple sources.

"One thing I can add is how records are used / not used in patient care. My mother only went to one hospital and at certain points 5/6 times during a year.

It was if she was a new patient each time. Very hard on her (she was 95 at the time) when I couldn’t leave work and give them all the information"

Patient/ Caregiver

Small Sampling of Informative Resources

- Patient, Family, Caregiver Centered Organizations ([IPFCC, PowerofPatients, PFCC](http://www.ipfcc.org), [PowerofPatients](http://www.powerofpatients.net), [PFCC](http://www.pfcc.org))
- ‘Be the expert on you’ Toolkit for Engaging Patients To Improve Diagnostic Safety | Agency for Healthcare Research and Quality (ahrq.gov)
- Opportunities for PFC with CSCP involvement Development of an Electronic CKD Care Plan
- Shared decision support tools that are FAIR (ONC, CDS, CDC, HealthCatalyst)
Medical errors and under/over-treatment happen when there are disconnects in information sharing and communication as above graphic shares. PFC involvement in all areas of evidence processes can help to mitigate problems later.

**PFC Involvement in Health Evidence Exists - Though is Limited**

Patients Family and Caregivers have been increasingly involved with research, guidance and decision-making activities though more diverse participation is necessary to better address current gaps in health equity and information sharing. Inclusion of PFC as subject matter experts in evidence-based guidance processes will help to ensure patient-centeredness principles are incorporated throughout the knowledge generation ecosystem.

- A growing body of evidence shows that people with higher patient activation (i.e., the knowledge, skills, and confidence to become actively engaged in their health care) have better health outcomes (Health Literacy CDC, REAL data CMS, PFC as Key Drivers in Evidence and QI 5 AHRQ, Implementation Science RAND) How do we involve the PFC who need to be involved? Incentives for outreach and PFC compensation are needed to involve PFC in research, evidence, guidance and decision-making activities.

- Agencies and institutions have been instrumental with bringing PFC and health professionals together, working in partnership to promote improvements in care (e.g. COVID-END, *Meaningful Measures 2.0 CMS IDEAL AHRQ, Evidently Cochrane, Patient Safety WHO, IHI)*
This graphic was collaboratively developed by CMS for *Meaningful Measures 2.0. Multiple domains are called out for areas to work together collectively in future measurement activities.

Adopters and Innovators: Patients, Families and Caregivers in the Ecosystem Cycle
Evidence > Guidance > Action

Today more PFC are involved in the evidence knowledge generation ecosystem where innovators have adopted some of the IOM/NAM recommendations from 'Crossing the Quality Chasm' the seminal publication from two decades ago. More work is to be done to effectively implement patient-centered care principles; including PFC at all levels of evidence work, development of reliable digital information sharing and more.

"I think we should not think in a "condition-centered" way (that is producing silos), "vetted" should be addressed from the consumer point of view with a broad approach, where narrative should have a central role."

PFC Facilitator

PFC Bring Relevance and Story to Evidence:

- Research partnerships (PCORI, CIHR, NIH, SPOR, Aging Initiative HCSRN-OAIC, Convening The Center RWJ,)
- Co-design efforts in LHS Research and QI (Kaiser, Paradigm Project Academy Health, CAPS & IHI, QI)
- Co-authoring/authoring papers and serving on editorial boards (BMJ, JHD, PCORI)
- Systematic review participation (FevIR.net, Cochrane)
- Co-producing guidelines and guidance (G-I-N, ACP, MuSE)
- Shared decision support tools (ONC, PCORI, SDIM)
- Measurement panel members (Meaningful Measures 2.0 CMS, NOF, National Center NCS, PPI Online,)
- App and communication e knowledge tool opportunities (Docola, HL7, Patient Emp., Pocket Health, Abridge)
- PFC participation in digital knowledge evidence generation projects as advisors with lived experience (CDS, FevIR.net, AHRQ-ACS)
- PFC as presenters at venues (PCORI, EVBRES, Consumers United Evidence, Cochrane, CMS) and as faculty for societies and institutions (IHI, PCC)

The diagram below shares some of the current and possible opportunities around the digital knowledge ecosystem cycle for PFC to be involved; where their voice and lived experiences can add value to processes, decision-making tools and care improvement efforts.

Opportunities for Patients, Families, and Caregivers to Engage in LHS Cycle Activities

- AHRC ACTS LHS Phase I Proposal: Offers PFC collaborative engagement opportunities where PFC, as subject matter experts with lived experience, knowledge, skills and assets can participate in discussions and on committees directly impacting patient and family goals.
- PFC have access to participate and follow evidence synthesis tool development within the COVID Knowledge Ecosystem – a collaborative opportunity to participate in the development of human readable interoperable systematic meta-reviews. Current opportunity for PFC: Citizen Scientific; Consumers and PFC to be involved as evidence advisors, shaping their roles in the interoperable ontology into world
- Co-produce research in an understandable PFC friendly/computable way: Diversity, equity and inclusion are currently prioritized to address disparities across the healthcare ecosystem and referenced in the initiatives. involving PFC who have diverse backgrounds, skills, and knowledge areas will enrich the evidence foundation and processes and provide valuable insights going forward (e.g. PCORI, NIH, NIA, COI)
- Participate with Data: Nothing about us without us = PFC provide ideas / insights on data privacy efforts. Lack of collecting data and inequalities data too often results in disparities in care. Digital access to notes are mandated by 2024. Today some PFC are demanding access to all of their data (Granity Project, H7 Common Data Model, MeaningGraph, CMS Meaningful Measures 2.0)
- Proposed AHRC ACTS Knowledge Portal: PFC can participate on strategic initiatives, providing insights to inform the evidence knowledge generation ecosystem and with guidance advancement as subject matter experts. PFC are currently involved with research, patient-driven guidance, writing papers and sharing evidence via networks and social media (e.g. PCORI, SPOR, Cochrane Consumers, CMS-IND, MHRA, FDA)
- Recommendations and Summaries: PFC participate bringing relevance into the computable evidence guidance discussion (e.g. analysis of recommendations can be co-produced by PFC and groups like Cochrane Consumers, CIHR, PCORI)
- Computed Reviews and Guidelines: PFC can be involved with guidance and guideline development, e.g., key question and PICOT development, as subject matter experts and ratings of outcomes at Cochrane, AF, AUA, BSA, GNP + opportunities are increasing to guideline developers embrace PFC involvement
- Tool Development: AHRC ACTS - PFC were involved with the CDS authoring tool through crowd sourcing idea mapping that provided foundational insights. PFC are end users and appreciate effective shared decision making (SDM) tools and can contribute to iterative organizational efforts (Patient Advisory groups, boards, councils, consultants)
- End User Feasibility: PFC utilize the wish for health guidance and a comprehensive knowledge Portal for evidence guidance would benefit all users
- CDS Connect Repository: include PFC with intervention language development
- App Marketplaces: PFC are involved with multiple App product developments in real-time as partners, evaluators and as end users, helping to catch problems during development mitigating user problems early
- End User Approval: PFC can provide direct input/feedback that can effectively improve equitable CI impacts, tool delivery (e.g. PFC Advisory and or Advocate from groups) *Case of Understanding with health and digital literacy improvements
- Understandable Comprehensive Shared Care Plans (CSSP): Decision making tool development co-production including videos and infographics, co-design care plans implementation efforts (Gestion that our PFC centers addressing digital and health literacy levels, available in plain language patients are)

Formulating New Roles to Transform and Improve Care - Crosswinds Quality Digest - With Beth Stoddart (F8; April), Using Information Technology - Crosswinds Quality Digest - With Beth Stoddart (F8);

*IOM / NAM Sentinel guidelines paper written 30 years ago
Known Gaps around PFC Involvement

Healthcare quality improvement efforts never stop, they are on-going and require diverse multi-stakeholder collaborations that meet over time to ensure that current PFC and population healthcare needs are being met. COVID19 has forced all healthcare facilities to rethink how to address disparities, adopt telemedicine and advance safety precautions incorporating PFC priorities in care.

- Limited co-design, research, evidence and quality improvement collaborations that include Patients, Families and Caregivers (PFC) (some that do exist: RWJ, PATIENTS, AHROQ, Academy Health, PORTAL Kaiser)
- Miscommunication and gaps with shared language – bi-directional health and digital literacy divide
- Inconsistencies in care plans, CSCP hard to find in EHRs, uncoordinated, often not recognizing or reflecting PFC priorities, preferences, goals and values or social needs.
- Findable, Accessible, Interoperable, Reusable resources – currently (Un)FAIR
- Inability to find and access medical information and relevant infographics and medical informative videos
- Few Incentives, lack of compensation and unstructured trainings for onboarding PFC into evidence and QI

Including PFC as partners in research is an underutilized role and an important one to help identify what to prioritize and what matters to the end user.

PFC involved with CSCP benefits all parties: Development of an Electronic CKD Care Plan. We should see more information sharing like the PCORI funded project highlighted below where evidence reports are now available for both clinicians and patients.

What is Possible with PFC- Opportunities for Adding Value

Evidence > Guidance > Action

A place where patients, families and caregivers can freely access reliable, vetted, trustworthy and timely medical information through a digital knowledge platform. An evidence space where PFC can actively participate, comment and contribute in a meaningful manner that is mutually beneficial to all involved.
The Future of Evidence...

- Trusted information is collected, shared, and used ethically and equitably to advance well-being. (RWJ) (AHRQ-CSCP)
- Patient-centric health IT tools and methods enhance information sharing, communication, coordination, and patient participation in care plan development and implementation
- Diversity and equity are drivers and levers at all levels of the evidence generation ecosystem including PFC efforts (UIHI Decolonizing Data, More house Equity Tracker, NACME)
- Patients, care teams, and populations experience coordinated, efficient care that achieves health goals supported by computable, interoperable, current, evidence-based information available when, where, and how needed.

Enablers -What Will It Take to Initiate Effective PFC Partnerships?

Enablers will reflect specific needs of PFC involved at various points along the evidence knowledge generation ecosystem. Just compensation, the advancement of health and digital literacy inclusion efforts, co-production activities along the full knowledge ecosystem are a few that are called out by PFC themselves.