PCOR DEM Workshop

Steven L. Coffee, Lt Col, USAF
Desiree Collins Bradley
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Overview

➢ Coffee Break

➢ What If’s

➢ Patient Engagement

➢ Patient Resources
Married
Dec '11

Military Move
Jul '12

Steven II Born Sep '12

Liver Failure Nov '12

Liver Transplant Dec '12
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“Nothing About Me Without Me”

"The quote above has become a rallying cry of many shared decision-making advocates. It’s from Valerie Billingham, from a session at the Salzburg Global Seminar, (session 356) in 1998, “Through the Patient’s Eyes.”
My Why
Rationale for Engaging Patients & Families in Medical Research

• Patients and families offer unique perspectives and insights
• Patients and families contribute to the thinking, approaches, and innovations in medicine
• Patients and families can improve the way care is delivered and support achievement of the triple aim
Recruitment

- Attending health care conferences such as the CMS Quality Conference, IHI National Forum, Beryl Institute Conference and other PFE-related conferences held each year
- Recommendations from other patient and family members
- Hospital PFACs and PFA members
- Condition-specific associations (example: American Cancer Society, Sepsis Alliance etc.)
- Networking through other affiliations (examples: state hospital associations, Partnership for Patients)
- Social media and Community organizations
- Personal contacts who have a health care story
- Patient Networks (example: PCORI, IPFCC, PPIC etc.)
Patient Engagement 101

- Prepare and orient the patient and family advisors
- Speak using plain language
- Identify a clear role/expectations for the research project
- Mutual respect is essential
- Utilize technology to include the patient voice
- Be open to possibilities
- Debrief to discuss what worked and what didn’t for future planning
Evidence Based Information for You

- https://www.uspreventiveservicestaskforce.org/Tools/ConsumerInfo/Index/information-for-consumers
- https://www.cdc.gov/publichealthgateway/program/resources/evidence.html
- https://www.acponline.org/practice-resources/patient-education/online-resources
- https://www.acponline.org/clinical-information/guidelines
- https://g-i-n.net/library/relevant-links/patients-and-consumers-resources
- https://www.pcori.org/research-results/putting-evidence-work/evidence-updates
Training and Reads outside PCORI

Trainings / Search

• **Cochrane Evidence** Essentials is a free online resource offering an introduction to health evidence, and how to use it to make informed health choices. [https://training.cochrane.org/essentials](https://training.cochrane.org/essentials)

• **Stanford Online** Partnering with the Public and Patients in Medical Research [https://lagunita.stanford.edu/courses/course-v1:Medicine+MEDX0002+Y01/about](https://lagunita.stanford.edu/courses/course-v1:Medicine+MEDX0002+Y01/about)


• PCORI CME/CE Activities [https://www.pcori.org/research-results/putting-evidence-work/cmece-activities](https://www.pcori.org/research-results/putting-evidence-work/cmece-activities)


• Google Scholar [https://scholar.google.com/](https://scholar.google.com/)

• ResearchGate [https://www.researchgate.net/](https://www.researchgate.net/)

Reads

• **Mathematica** [https://www.mathematica.org/evidence/projects#sort=relevancy&f:FocusArea=[Health]&f:FocusArea:operator=and](https://www.mathematica.org/evidence/projects#sort=relevancy&f:FocusArea=[Health]&f:FocusArea:operator=and)


• Evidence Based Care Bundles [http://www.ihi.org/topics/Bundles/Pages/default.aspx](http://www.ihi.org/topics/Bundles/Pages/default.aspx)
