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Starfield Summit II: Health Equity Summit
Curriculum Toolkit

Understanding health experiences and values to address social determinants of health

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Module by Sarah Davis, JD, MPA

Appropriate Audience: All learners

Related Modules:

- Identifying and Addressing Patients' Social and Economic Needs in the Context of Clinical Care
- Communities Working Together to Improve Health and Reduce Disparities
- Intersectionality—The Interconnectedness of Class, Gender, Race and other Types of Vulnerability

Learning Objectives

After participating in this learning module, the participant will be able to:

1. Define health experiences (or patient experiences), patient-centered outcomes, and patient engagement.
2. Understand that health experiences and values influence personal health choices, utilization of services, treatment decisions, and ultimately outcomes.
3. Identify methods to reveal nuanced information about patient experiences across individuals' physical, economic, and social contexts.
4. Appreciate the role of "representative" patient engagement to understand the broad range of health experiences, engage diverse voices, and involve patients and the public in health improvement.

Background

Creating a culture of health equity involves a multi-pronged approach. Family medicine physicians and other care team members can engage in this work in the clinic encounter, quality improvement (QI) activities, and health care transformation efforts. Key to all approaches is a nuanced understanding of patients' health experiences and values, as these influence personal health choices, utilization of services, treatment decisions and ultimately outcomes.

On the individual patient level, people perceive health holistically and many experiences shape their views. In contrast, the provision of health services is often reductionist, focused on specific disease states and/or care processes. Furthermore, patients and clinicians often prioritize desired health outcomes differently[1] and have different incentives for doing so.[2] To achieve health equity in individual encounters, physicians must probe for patient's priorities (patient-centered outcomes). Such attentiveness to patient health experiences and engagement is also strategic as they are positively associated with health outcomes.[3,4,5] In tandem, policies and systems must intentionally address this tension, elevating patients' values and priorities.

In terms of broad patient populations, understanding diverse experiences and values requires multiple participatory approaches that engage diverse voices, include patients in QI, and broadly reveal nuanced information across individuals' physical, economic, and social contexts.[6-9] Having this understanding is necessary for designing effective interventions that can achieve health equity. The lack of "representative" input to policy and programmatic decisions can inadvertently perpetuate health inequalities and power imbalances.

Ignite Video

Please follow the link below to view the full talk given by Dr. Pandhi (6 min):
https://www.youtube.com/watch?v=OQXJ0iDS2SY

Accompanying Slides

http://www.starfieldsummit.com/s/11-PandhiDavis-Presentation-bdpk.pdf

Possible Questions for Group Discussion

After watching the talk, consider splitting your learners into smaller groups and facilitate discussion on the following questions. Consider also having students view one or more modules of patient experiences with illness on healthexperiencesusa.org (see below) to guide discussion.

1) What about how medicine is "delivered" today and how patients view wellness makes it incumbent to intentionally understand patient experiences and values?
2) What is the relationship between health experiences and health equity?
3) What methods exist to elicit health experiences and values – in individual patient encounters, quality improvement initiatives, and health care transformation efforts?
4) What is needed to robustly incorporate health experiences and values into practice interventions and research (e.g. structures, resources, policies, incentives)?
5) What barriers might you encounter with regard to incorporating health experiences and values into practice transformation and what strategies might overcome these barriers?

Applying an equity lens in professional practice

As you reflect on the material in this module consider how you will apply it in your professional practice by asking questions based upon the Equity and Empowerment Lens' 5Ps:

Purpose: What is my purpose towards elevating patients' values? What is my organization's purpose?
People: How will people be affected if I fail to use multiple participatory approaches to understand diverse patient experiences?
Place: As you probe for patients' priorities (patient-centered outcomes) how will you ensure individual patient's emotional safety?
Process: How will you contribute to processes - policy development - that elevate patients' values and priorities?
Power: Who is accountable in your organization to ensure that patient experiences drive interventions?

For more in depth discussion read and refer to:

- Patient Experience modules on healthexperiencesusa.org or in the United Kingdom – Healthtalk.org .
  Decisions Involving Values and Difficult Personal Choices. healthtalk.org website. http://www.healthtalk.org/peoples-experiences/improving-health-care/shared-decision-making/decisions-involving-values-and-difficult-personal-choices Accessed September 26, 2018.
    - These modules seek to describe the widest possible range of individual experiences from the patient's point of view. HealthExperiencesUsa.org is a non-commercial, non-profit group, part of an international movement (DIPEx International). It provides a place for sharing patients' stories.
- Herxheimer A, Ziebland S. The DIPEx project: collecting personal experiences of illness and health care. In: Hurwitz B, Greenhalgh T, Skultans V, eds.*Narrative Research in Health and Illness.* Malden, MA: Blackwell Publishing; 2004:115-131.
    - This chapter describes how and why The Database of Personal Experiences of Health and Illness (DIPEx)(http://www.dipex.org) transpired, what it covers, and the many issues the project has raised about the methodology of collecting patients' narratives.
- Kovacs Burns K, Bellows M, Eigenseher C, Gallivan J. 'Practical' resources to support patient and family engagement in healthcare decisions: A scoping review. *BMC Health Serv Res.* 2014;14:175.
    - This resource catalogs tools, guides and models to support patient engagement.
- Beresford P. Beyond the usual suspects: towards inclusive user involvement. Shaping our Lives. INVOLVE website. http://www.invo.org.uk/beyond-the-usual-suspects-towards-inclusive-user-involvement. Accessed September 26, 2018.
    - Created through a "user controlled project", this report identifies barriers to involvement by "seldom-heard" service users and solutions. Note: "users" is the United Kingdom term for "patient."
- Arcia A, Suero-Tejeda N, Bales MD, et al. Sometimes more is more: Iterative participatory design of infographics for engagement of community members with varying levels of health literacy. J *Am Med Inform Assoc*. 2015;23(1):174–83.

  - This article describes a collaborative process to develop accessible infographics that will motivate health-promoting behavior.

Resources for further exploration

Macro: In Health Care Transformation

- Frampton SB, Guastello S, Hoy L, Naylor M, Sheridan S, Johnston-Fleece M. Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care. Discussion Paper. National Academy of Medicine website. https://nam.edu/wp-content/uploads/2017/01/Harnessing-Evidence-and-Experience-to-Change-Culture-A-Guiding-Framework-for-Patient-and-Family-Engaged-Care.pdf Published January 31, 2017. Accessed September 26, 2018.
  - Developed by a scientific advisory panel, this discussion paper aims to address barriers to system-wide transformation necessary to achieve Patient and Family Engaged Care (PFEC). It offers a comprehensive framework based upon evidence-based strategies and patients' lived experience.
- Rowland P, Kumaga, AK. . Dilemmas of representation: Patient engagement in health professions education. *Acad Med.* 2018 Jun;(93)6:869-873. doi: 10.1097/ACM.0000000000001971
  - This article tackles the problem of representation raised by patient engagement efforts. The authors argue for an understanding of representation that not only is inclusive of who is being represented but also takes seriously what is being represented, how, and why.

Meso: In Quality Improvement

- Davis S, Pandhi N, Gaines M. Patient Engagement in Redesigning Care Toolkit. HIPxChange website. https://www.hipxchange.org/PatientEngagement. Accessed September 26, 2018.
  - This practical resource contains worksheets and tools to guide stakeholder engagement in quality improvement efforts.

Micro: In Clinical Encounters- Shared Decision Making

- Muhlbacher AC, Juhnke C. Patient preferences versus physicians' judgement: Does it make a difference in healthcare decision making? *Appl Health Econ Health Policy.* 2013;11(3):163-180.
  - This article highlights differences between patient and physician preferences as most studies reveal a disparity between the preferences of actual patients and those of physicians. It concludes that because differences exist between physicians' judgement and patient preferences, it is important to incorporate the needs and wants of the patient into treatment decisions.
- The SHARE Approach. Agency for Healthcare Research and Quality website.http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html. Published July 2014. Reviewed August 2018. Accessed September 26, 2018.

  - AHRQ’s SHARE Approach is a five-step process for shared decision making that includes exploring and comparing the benefits, harms, and risks of each option through meaningful dialogue about what matters most to the patient.

Words and Concepts Used in this Module that are defined in the Guidebook

- Health Equity
- Health Experiences
- Health Experiences Research
- Health Inequity
- Patient-Centered Outcomes
- Patient Engagement
- Patient Experiences
- Power
- Quality Improvement
- “Representative” Input

References

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2. Martin C, Sturmberg J. Complex adaptive chronic care. *J Eval Clin Pract.* 2009;15(3):571-577.
3. Frampton SB, Guastello S, Hoy L, Naylor M, Sheridan S, Johnston-Fleece M. Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care. Discussion Paper. National Academy of Medicine website. https://nam.edu/wp-content/uploads/2017/01/Harnessing-Evidence-and-Experience-to-Change-Culture-A-Guiding-Framework-for-Patient-and-Family-Engaged-Care.pdf. Published January 31, 2017. Accessed September 26, 2018.
4. Coulter A. Patient engagement--what works? *J Ambul Care Manage.* 2012;35(2):80-89.
5. Doyle C,Lennox L, Bell D.. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. . *BMJ Open 2013;3:e001570. doi:10.1136/bmjopen-2012-001570*
6. Kovacs Burns K, Bellows M, Eigenseher C, Gallivan J. 'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review. *BMC Health Serv Res.* 2014;14:175.
7. Herxheimer A, Ziebland S. The DIPEx project: collecting personal experiences of illness and health care. In: Hurwitz B, Greenhalgh T, Skultans V, eds. *Narrative Research in Health and Illness.* Malden, MA: Blackwell Publishing; 2004. 115-131.
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