



Discussion Summary and Engagement Analysis

Monitoring Together: Integrating Patient-Generated Health Data

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High-level overview

Patient-generated health data (PGHD) represents an opportunity for remote patient monitoring and timely intervention of chronic illnesses. The benefits of incorporating and increasing the use of PGHD undoubtedly exist, but the switch toward this new paradigm poses non-trivial challenges and barriers

Conversation points that correlate with IHMI

- Conversation pointed toward the work that IHMI is doing. The following points were discussed throughout the duration of the discussion:
 - Device manufacturers and their accountability
 - Validated Data and Data Integrity
 - Approaches to collect and organize PGHD/remote and wearable device data (i.e. Epic's 3 tiers)
 - Approval of data as "trusted"

Featured Experts

- [David Bates, MD, MSc](#) – EVP for Community Child Health at Connecticut Children's Medical Center
- [Scott Collier, PhD](#) – Department of Psychiatry & Behavioral Sciences, Howard University College of Medicine
- [Kevin Patrick, MD, MS](#) – Professor of Family and Preventive Medicine at the University of California, San Diego
- [Elissa Foster, PhD](#) – Director of Graduate Programs in Health Communication, DePaul University
- [Stavros Stavrakis, MD, PhD](#) – Associate Professor of Medicine at University of Oklahoma Health Sciences Center

Featured Moderators

- [Mark Olschesky](#) – Chief Data Officer, Datica



Summary of relevant conversation points

- The discussion provided clear indication that IHMI (platform) could be considered a space for reference and resource. Adam Dicker, MD, PhD asked for resources to provide to first year medical students at Thomas Jefferson University. This question sparked a series of responses and resources that supported his request.
- The initial welcome post that asked experts to provide their work or experience with PGHD, generated the most feedback in comments, leading to many IHMI related topics.
- Conversation pointed toward the work that IHMI is doing. The following points were discussed throughout the duration of the discussion:
 - Device manufacturers and their accountability
 - Validated Data and Data Integrity
 - Approaches to collect and organize PGHD/device data (i.e. Epic's 3 tiers)
 - Approval of data as "trusted"
- A suggestion that there is a need for "interoperability data standards" for medical devices, was made. John Zaleski, PhD, MS, CPHIMS, CAP provides examples of data standards for medical interoperability based in HL7.
- Topics of patient experiences and health coaching/coaches were discussed and related to consumer experiences, such as Apple Genius bar, and new professions in health care.
- It was suggested that the main issue with PGHD is the "magnitude of this potentially limitless source of data."
- Patient-centeredness was introduced to the discussion at multiple points.
- A nearly equal amount of contributions/posts by panelists and non-panelists (31 vs. 30) could indicate a strong measurement for organic engagement.
- Epic's 3 tiers of PGHD integrity was suggested as a pragmatic approach and referenced in relation to concerns over "unvalidated data."
- Data types/categorization (Clinical vs. Repository) was discussed throughout.
- Concern for "over-medicalization" of data/PGHD is worth noting.

Resources generated from Discussion:

- <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2017.1315?journalCode=hlthaff>
- <http://ascopubs.org/doi/full/10.1200/jop.2015.003715>
- <https://meetinglibrary.asco.org/record/163343/abstract>
- <https://www.ncbi.nlm.nih.gov/pubmed/26969518>
- <https://www.wired.com/story/digital-puppy-seniors-nursing-homes/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5496465/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5893853/>
- <https://www.healthit.gov/topic/scientific-initiatives/patient-generated-health-data>
- <https://www.sciencedirect.com/science/article/pii/S0738399109004960>
- MyStrengthsMyHealth.com