Big Data for Patients: Background Information

Komen's Big Data For Breast Cancer

Big data holds great promise for advancing research and improving breast cancer patient care and outcomes, driving progress that will help Susan G. Komen® achieve our Bold Goal of reducing the current number of breast cancer deaths by 50% in the U.S. by 2026. For our purposes, big data is defined as the integration of data across sources, e.g., Electronic Health Records (EHR), administrative databases, large data repositories and genomics/other -omics data.

We envision a world in which healthcare is a seamless web of information - patients are informed about their personal data and are empowered to share it and participate in their health care; data systems are linked and easily accessible; genomics (and other -omics) are universally available and user-friendly; and electronic health records (EHR) are connected to other sources of data to provide evidence-based support to drive research and improve outcomes for those with breast cancer.

However, the present reality is challenging:

- Electronic Health Records (EHR), "-omics" and the "Internet of Things" remain unconnected and often highly siloed, without interoperability
- EHR systems have failed to increase, and may have in fact decreased, clinical efficiency and job satisfaction
- Genomic data remains inaccessible and poorly understood by physicians and patients
- Clinical decision support based on real data remains only a dream
- Clinical trials remain difficult to access for the average patient
- Healthcare remains fragmented, expensive, often ineffective and relatively unchanged by the Big Data revolution

Komen started the Big Data for Breast Cancer (BD4BC) conversation in 2015, by convening more than 130 experts representing approximately 100 organizations, both non- and for-profit, to explore the opportunities and challenges of incorporating Big Data applications into breast oncology research and clinical care.

With the insights gained at our BD4BC meetings and the guidance of Komen's Scientific Advisory Board, we established Komen's Big Data for Breast Cancer Initiative aimed at using Big Data to fuel scientific discoveries and accelerate the delivery of equitable, patient-focused care.

Through this initiative, Komen will:

1. Empower breast cancer patients, advocates and the public with information and tools to make data sharing understandable and easy to do.
2. Address challenges of incorporating Big Data applications into breast cancer research and clinical care.
3. Support data science projects to improve breast cancer outcomes and save lives.

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Big Data for Patients (BD4P) is a curriculum designed by Komen for patient advocates. Utilizing a mix of webinars and in-person trainings, BD4P provides participants with a broad overview of big data and the knowledge needed to empower them to participate in the data science research process (e.g., serve as advocate peer reviewers and be a member of a data science research team). Relying on a faculty of subject matter experts, the following curriculum was developed:

- Module 1: Advocates and other big data stakeholders (webinar).
- Module 2: Introduction to big data and data science (webinar).
- Module 3: Ethics and privacy issues associated with big data (webinar).
- Module 4: ethics, law, privacy, security.
- Module 5: Clinical trial data.
- Module 6: Genomics.
- Module 7: Real World Evidence (RWE).
- Module 8: Patient-generated data.
- Module 9: Artificial intelligence and machine learning.

In addition to learning about those topics, the training will also empower patient advocates to share their health-related data and speak with other patients about the importance of sharing data for projects that use big data applications to fuel scientific discoveries and accelerate the delivery of equitable, patient-focused care. To ensure a unique learning environment where trainees will have privileged access to faculty, up to 20 research patient advocates will participate in each training session.

Big Data for Patients was originally developed by the Reagan-Udall Foundation for the FDA (RUF) to help patient advocates enhance their data science literacy and critical appraisal skills. The goal of BD4P was to inform and empower patient advocates to understand what big data is, how it is being used in research and medicine, its promises and limitations, the challenges that exist, the impact on patients, and how patients can use this knowledge. That development was funded by a Eugene Washington PCORI Engagement Award, concluding in 2017 with one delivery of the program.

With the program discontinued, Komen was well equipped to continue the legacy of BD4P: Komen was increasing its efforts around big data and had a proven track record of empowering patients. Komen took over the leadership of BD4P in 2018, and the chairs of the original program, Jane Perlmutter and Joel Beetsch, committed to continue leading Komen's review, update and delivery of BD4P. in addition to the chairs, a planning committee was assembled, comprised of Melissa Goldstein, Cheryl Jernigan, Nikhil Wagle, and Kelly Walborn. A pilot of the BD4P program was run in Fall of 2019, and Komen plans to offer the inaugural BD4P training in early to mid-2020.

Email bd4bc@komen.org for more information.