

BD4BC\WC Meeting Executive Meeting Summary

AT A GLANCE

Dates

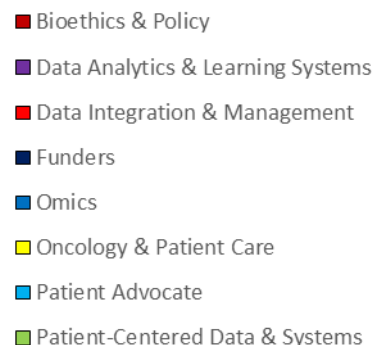
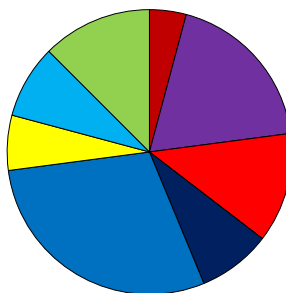
February 23-24, 2017

Venue

Quadrus Conference Center in Menlo Park, CA

Number of participants

48 (see chart for expertise distribution)



PLANNING COMMITTEE

- **Amy Abernethy**, M.D., Ph.D.; Flatiron Health
- **Cheryl Jernigan**, CPA, FACHE; Komen Advocate in Science and Scientific Advisory Board
- **Mia Levy**, M.D., Ph.D.; Vanderbilt-Ingram Cancer Center and Komen Scholar
- **George Sledge, Jr.**, M.D.; Stanford University and Komen's Chief Scientific Advisor
- **Crystal Valentine**, Ph.D.; MapR Technologies
- **Nikhil Wagle**, M.D.; The Broad Institute of MIT and Harvard and Dana-Farber Cancer Institute

BACKGROUND

Komen convened **BD4BC - West Coast Conference (BD4BC\WC)** to continue the conversation about Big Data, defined as the integration of EHR, administrative databases, large data repositories, and genomics and other -omics data. The goal of this meeting was to better understand current capabilities of Big Data applications and to encourage the development of multidisciplinary collaborations that will work together to demonstrate the feasibility of applying Big Data technology to several breast cancer-focused use cases including development of evidence-based decision support to improve breast cancer treatment, quality improvement of health care delivery, and basic discovery to drive research.

To best leverage the participants' expertise and outline the most promising breast cancer applications of Big Data, the agenda for BD4BC\WC was developed around three main topics:

1. **Data infrastructure:** How is Big Data structured? How is it accessed? By whom? What are the best practices to ensure data can be shared, integrated and analyzed for multiple purposes?
2. **Research:** The latest advances in research using Big Data, whether it is genomics, proteomics or other "omics." Examples highlighting the many ways in which Big Data drives breast cancer research, from generating hypotheses to creating the tools that will help design tomorrow's therapies.
3. **Clinical applications:** The current efforts to harness Big Data to provide the solutions needed to overcome the challenges faced by breast cancer patients.

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TAKEAWAYS & OUTCOMES

Throughout the discussions, participants focused on **defining specific roles for Komen to play in ensuring that Big Data benefits breast cancer patients:**

- With BD4BC and BD4BC\WC, Komen demonstrated that it is uniquely positioned to convene the right mix of stakeholders to tackle the challenges of delivering the promises of Big Data to breast cancer patients. Attendees mentioned that they had participated in many Big Data meetings, but these meetings had neither the right mix of expertise convened, nor the richness of the discussions heard at BD4BC\WC.
- Komen has a track record of advocating for patients. It can make one of its advocacy priorities to encourage access to Big Data and ensure that policies are in place to guarantee privacy and security of patients' data as well as appropriate reparations should a breach occur.
- Komen can lead by example by requiring researchers to share data generated with Komen funding.
- Komen can serve as an honest broker for patients' data. Patients generally don't trust for-profit companies with their data – an organization like Komen would be seen as a nonpartisan broker that could partner with appropriate data service provider(s) to develop or expand a platform where data can be safeguarded, with access provided to the stakeholders who will provide the most benefits to breast cancer patients.
- As a grassroots organization, Komen can also leverage its wide network of influence to further educate patients and the public about Big Data and encourage data donations.
- Komen can consider providing programs to address the barriers to participating in clinical trials, such as financial help to cover participants' transportation and lodging.
- Komen can once again be a trendsetter by creating a research program that will develop a workforce fluent in informatics and biology – the only way seen by the attendees for Big Data to be fully harnessed to advance our knowledge of breast cancer and to leverage that knowledge into actionable roadmaps to curing breast cancer.

While the conversation continues, the BD4BC\WC meeting resulted in several outcomes:

- In order to address the barriers to harnessing Big Data, we must first understand what they are and are not: These **barriers are not technologic in nature, but social, legal and economic.**
- Technology exists that can aggregate and make sense of unstructured data from multiple sources, but barriers still exist that make data sharing and aggregation challenging. However, several pilot projects were presented that show promise in overcoming these barriers.
- Participants noted that continuing to break these barriers will require incentives - both rewards and penalties.
- It was clear from the discussions that the goal of Big Data is not to relentlessly and aimlessly amass information. Oncologists at BD4BC\WC warned against a trend toward over-structuring medical data, leading the doctors to spend more time entering data into electronic medical records than attending to breast cancer patients. As one attendee summarized: "saving doctors' time will save patient lives."