

# BD4BC Meeting Executive Meeting Summary

## AT A GLANCE

Dates

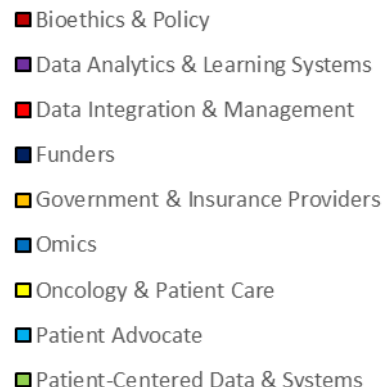
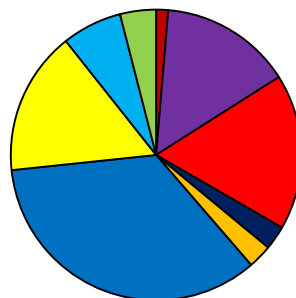
October 8-9, 2015

Venue

Rockefeller University, New York, NY

Number of participants

75 (see chart for expertise distribution)



## PLANNING COMMITTEE

- Ambassador **Nancy Brinker**, Susan G. Komen
- **Elad Gil**, Ph.D.; Color Genomics
- **Todd Golub**, M.D.; Dana-Farber Cancer Institute
- **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
- **Judy Salerno**, M.D., M.S.; Susan G. Komen
- **George Sledge, Jr.**, M.D.; Stanford University and Komen's Chief Scientific Advisor
- **Marc Tessier-Levigne**, FRS, FRSC, F.Med.Sci.; Rockefeller University
- **Eric Winer**, M.D.; Dana-Farber Cancer Institute and Komen's Chief Scientific Advisor

## BACKGROUND

Komen envisions a world in which healthcare is a seamless web of information: patients are informed about their 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 for the generation of research hypotheses and clinical decision-making. In this world, many, if not all, would participate in clinical research and the research enterprise would be able to mine aggregated data across multiple platforms to identify and address critical questions. Most importantly, fewer people will die from breast cancer and quality of life will be higher for those living with the disease. While the Big Data explosion holds immense promise for research to improve cancer care, the present reality is challenging:

- Electronic Health Records (EHR), “-omics” and the “Internet of Things” remain unconnected and often highly isolated, without interoperability. EHR systems have failed to increase, and may have 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.

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## TAKEAWAYS & OUTCOMES

While this meeting focused specifically on the challenges and opportunities of Big Data for Breast Cancer, the intent was to facilitate big data applications for oncology in general, using breast cancer as a “case study” or “proof of concept”.

Participants felt that Komen could lead in a number of key areas including:

- Assessing patient attitudes about **privacy and informed consent**.
- Influencing the **development of future policies** to make data accessible and enable integration.
- Promoting the **collection of standardized patient-reported outcomes data**.
- **Convening scientists and those who “hold the keys” to big data** (e.g. payers, EHR providers, patients, policy makers).
- **Educating and engaging patients** to participate in research.
- **Soliciting and providing funding** for projects that demonstrate the feasibility of merging and mining data from different sources.