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.

Susan G. Komen® envisions 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 for the generation of research hypotheses and clinical decision-making.

Komen started the big data for breast cancer conversation in 2015 by convening BD4BC: Big Data for Breast Cancer at Rockefeller University in New York, NY. We subsequently convened BD4BC–West Coast Conference (BD4BC\WC) in 2017 in Menlo Park, CA. Both conferences were generously supported by the Robertson Foundation. The intent of those meetings was to explore the opportunities and challenges of incorporating big data applications into breast oncology research and clinical care, and to encourage the development of multidisciplinary collaborations that will apply big data technology to improve breast cancer treatment and the quality of health care delivery, and fuel scientific discovery to accelerate breakthroughs.

On February 1-2, 2018, Komen continued the big data conversation by convening the BD4BC - annual conference in Menlo Park, CA to take a deeper dive into how big data can be leveraged toward Komen's Bold Goal to reduce the current number of breast cancer deaths by 50% in the U.S. by 2026.

The goals of this meeting were to leverage big data to identify breast cancer disparities and variances in care, and to improve the methods for aggregating and analyzing clinical, genomic and other sources of data for metastatic breast cancer patients. Big data certainly holds great promise for breast cancer patient care and improving outcomes. Focusing on these topics will map out strategies that will unlock big data to save lives. The meeting aimed at strengthening existing and building new partnerships to provide the necessary expertise, resources, and timelines needed to launch the implementation of several BD4BC initiatives following this annual conference.
OPPORTUNITIES IN THE BIG DATA REVOLUTION

With the insights gained at our BD4BC meetings and the guidance of Komen’s Scientific Advisory Board, we have identified key roles for Komen and specific big data programs that will drive the field forward. Our Big Data for Breast Cancer Initiative aims at using big data to fuel scientific discoveries and accelerate the delivery of equitable, patient-focused care. It takes a three-pronged approach to:

1. Empower the public with information and tools to make data sharing understandable and easy to do. Komen will deploy programs, targeting a broad range of audiences, that will increase understanding of big data and its potential in breast cancer and accelerate the use of big data in the fight against breast cancer.
   a. BD4BC Public Education/ Knowledge Portal (website)
   b. BD4P (training for patient advocates)

2. Address challenges of incorporating big data applications into breast cancer research and clinical care. Among the challenges identified during the BD4BC meetings were an urgent need for collaborations between data scientists, breast cancer researchers/oncologists, and a workforce that understands both data science and breast cancer biology.
   a. Big Data Travel Scholarship Program
   b. Breast Cancer Data Directory

3. Fund data science projects to improve breast cancer outcomes and save lives. Komen will leverage its premier grant-making capabilities to identify and support big data research resources and projects that will put the patient at the center of cancer innovation to inform and accelerate the pace of breast cancer research and allow researchers to use real-time but also real-life data to revolutionize the way cancer is understood and treated.
   a. Research Project Investigator: Regina Barzilay – Predicting Disease Progression from Imaging Data
   b. Research Project Investigators: Alex Cheng (young investigator)/Mia Levy (Komen Scholar, mentor) – Managing Treatment Burden and Capacity in Breast Cancer Patients
c. Research Project Investigator: Mia Levy (Komen Scholar) – Clinical decision support for precision breast cancer treatment.
d. Research Project Investigator: Sohrab Shah (Komen Scholar) – Exploiting new patterns of genome damage in triple negative breast cancer
Last Name, First Name (Institution)
Barzilay, Regina (Massachusetts Institute of Technology)
Beetsch, Joel (Celgene)
Boone, Christopher (Pfizer)
Carey, Lisa (UNC Lineberger Cancer Center)
Carson, Ken (Flatiron Health)
Collyar, Deborah (Patient Advocate In Research (PAIR); Komen Advocates in Science (AIS))
Cook-Deegan, Bob (Arizona State University)
Dunn, Michelle (Data Collaboratory)
Dunphy, Michael (The Broad Institute)
Dutkowski, Janusz (Data4Cure)
Finestone, Sandy (Komen Advocates In Science (AIS))
Goldstein, Melissa (George Washington University)
Gray, Joe (Oregon Health & Science University)
Guinney, Justin (Sage Bionetwork)
Hauser, Robert (Cancer Treatment Centers of America)
Herzig, Abbe (3M Health Information Systems)
Hoadley, Katherine (UNC Lineberger Cancer Center)
Howell, Michael (Google Research)
Howie, Lynn (FDA)
Hsu, William (University of California, Los Angeles)
Ide, Lucienne (Rimidi)
Jernigan, Cheryl (Komen Scientific Advisory Board (SAB))
Kaushik, Gaurav (Foundation Medicine)
Kolacevski, Andrej (ASCO CancerLinQ)
Kurbegov, Dax (Sarah Cannon)
Kurian, Allison (Stanford University)
Kurtzman, Kate (GRAIL)
Lang, Kathryn (Pfizer Oncology)
Levy, Mia (Vanderbilt-Ingram Cancer Center)
Mann, Joshua (SHARE For Cures)
Mattison, John (Kaiser Permanente)
Neuner, Joan (Medical College of Wisconsin)
Newman, Lisa (Henry Ford Health System; SAB)
Olopade, Olufunmilayo (Funmi) (University of Chicago)
Peng, Lily (Google Research)
Perlmutter, Jane (Gemini Group; Komen Advocates in Science (AIS))
Pietenpol, Jennifer (Vanderbilt-Ingram Cancer Center)
Reeder-Hayes, Katherine (UNC Lineberger Cancer Center)
Schneider, Paula (Susan G. Komen)
Shak, Steve (Genomic Health)
Sledge, George (Stanford University)
Spears, Patty (Komen Advocates in Science (AIS))
List of Attendees

Last Name, First Name (Institution)
Stemple, Claudia (NanoString)
Storniolo, Anna Maria (Komen Tissue Bank)
Sun, Alan (Syapse)
Thompson, Gary (CLOUD, Inc.)
Tucker, Conrad (Pennsylvania State University)
Valentine, Crystal (MapR Technologies)
Walborn, Kelly (3M Health Information Systems)
Yang, Shan (Invitae)
BIG DATA FOR BREAST CANCER (BD4BC)

Komen envisions 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 for the generation of research hypotheses and clinical decision-making.

In this world, many, if not all, would participate in clinical research, allowing the research enterprise to mine aggregated data across multiple platforms to address critical questions related to treatment and care decisions. Most importantly, fewer people will die from breast cancer and quality of life will be higher for those living with the disease.

BD4BC3 Planning Committee:

Amy Abernethy, M.D., Ph.D.
Flatiron Health
New York, NY

Cheryl Jernigan, C.P.A., F.A.C.H.E.
Advocate in Science
Komen Greater Kansas City
Kansas City, MO

Mia Levy, M.D., Ph.D.
Vanderbilt-Ingram Cancer Center and Komen Scholar
Nashville, TN

Joshua Mann
SHARE for Cures and Inspirata
Washington, DC

George Sledge, Jr., M.D.
Stanford University and Komen’s Chief Scientific Advisor
Stanford, CA
General Meeting Information

Meeting Location:
Quadrus Conference Center, 2400 Sand Hill Road, Menlo Park, CA 94025.
Free self-parking available at Quadrus.

Dinner Location:
Allied Arts Guild, 75 Arbor Rd, Menlo Park, CA 94025

Conference Media Policy
Komen's Communications staff will be present at the meeting to conduct interviews and document the meeting. Content will be recorded and may be posted on komen.org/BD4BC following the meeting. If you do not wish to be on video or photographed please stop by the registration desk to make arrangements.

No Smoking
In keeping with Susan G. Komen’s policy and our vision of a world without breast cancer, the BD4BC meeting is a strictly nonsmoking event.

Shuttle Information
Shuttles will be provided between the Westin Palo Alto and Allied Arts Guild on Thursday evening and Quadrus Conference Center on Friday.
Please reference the schedule below.

Thursday, February 1
5:00 p.m. — First shuttle will depart from the Westin Palo Alto for Allied Arts Guild; second shuttle will depart at 5:15 p.m.
9:00 p.m. — Shuttles will also be available immediately following the conclusion of dinner for transport back to the Westin Palo Alto.

Friday, February 2
7:45 a.m. — First shuttle will depart from the Westin Palo Alto for Quadrus Conference Center; second shuttle will depart at 8:00 a.m.
4:00 p.m. — Shuttles to SFO, SJC and Westin Palo Alto will be outside the Quadrus front entrance.
The Impact of a Promise

Susan G. Komen® is the world’s largest breast cancer organization, funding more breast cancer research than any other nonprofit outside of the federal government while providing real-time help to those facing the disease.

Komen has set a Bold Goal to reduce the current number of breast cancer deaths by 50 percent in the U.S. by 2026. Since its founding in 1982, Komen has funded more than $956 million in research and provided more than $2.1 billion in funding to screening, education, treatment and psychosocial support programs. Komen has worked in more than 60 countries worldwide. Komen was founded by Nancy G. Brinker, who promised her sister, Susan G. Komen, that she would end the disease that claimed Suzy’s life.
Friday, February 2

Quadrus Conference Center | 2400 Sand Hill Rd, Menlo Park, CA 94025  (All in QCC)

8:00 a.m. - 8:30 a.m.  Registration & Breakfast

8:30 a.m. - 9:00 a.m.  BD4BC3: Overview & Goals
  • Jennifer Pietenpol, Ph.D. – Komen Chief Scientific Officer; Vanderbilt-Ingram Cancer Center
  • Stephanie Birkey Reffey, Ph.D. – Susan G. Komen

9:00 – 9:15 a.m.  BD4BC3: Highlight #1
  • John Mattison, M.D. – Kaiser Permanente

9:15 – 9:30 p.m.  An update on Komen’s African American Health Equity Initiative
  • Shyrea Thompson – Susan G. Komen

9:30 – 10:15 a.m.  Session #1: Eradicating Unnecessary Deaths
  Addressing variance in care toward Health Equity
  Facilitator: Olufunmilayo Olopade, M.D., F.A.C.P. – University of Chicago
  Speakers:
  • Christopher Boone, Ph.D., F.A.C.H.E. – Pfizer
  • Joan Neuner, M.D., M.P.H. – Medical College of Wisconsin
  • Katherine Reeder-Hayes, M.D., M.B.A., M.S. – UNC, Chapel Hill

10:15 – 10:30 a.m.  Break

10:30 – 11:45 a.m.  Session #1: Facilitated Group Discussion (all participants)

11:45 a.m. – 12:45 p.m.  Lunch

12:45 – 1:00 p.m.  BD4BC3: Highlight #2
  • Regina Barzilay, Ph.D. – Massachusetts Institute of Technology

1:00 p.m. – 1:45 p.m.  Session #2: Finding and Treating Incurable Breast Cancer
  Unlocking EHR to solve metastatic breast cancer
  Facilitator: *Mia Levy, M.D., Ph.D. – Komen Scholar; Vanderbilt-Ingram Cancer Center
  Speakers:
  • Lily Peng, M.D., Ph.D. – Google Research
  • Gaurav Kaushik, Ph.D. – Foundation Medicine
  • Aradhana Ghosh, M.D. – Syapse

1:45 – 2:00 p.m.  Break

2:00 p.m. – 3:15 p.m.  Session #2: Facilitated Group Discussion (all participants)

3:15 – 4:00 p.m.  Wrap Up & Closing Remarks

* member of the BD4BC3 Planning Committee.
Susan G. Komen® Scientific Advisory Board

Chief Scientific Advisors

George Sledge, Jr., M.D.
Stanford University School of Medicine
Stanford, CA

Jennifer Pietenpol, Ph.D.
Vanderbilt-Ingram Cancer Center
Nashville, TN

Scientific Advisory Board Members

Carlos Arteaga, M.D.
UT Southwestern
Dallas, TX

Myles Brown, M.D.
Dana-Farber Cancer Institute
Boston, MA

Karen Gelmon, M.D.
British Columbia Cancer Agency
Vancouver, Canada

Cheryl Jernigan, C.P.A., F.A.C.H.E.
Advocate in Science
Komen Greater Kansas City
Kansas City, MO

Lisa Newman, M.D., M.P.H.
Henry Ford Health System
Detroit, MI

Eric Winer, M.D.
Dana-Farber Cancer Institute
Boston, MA
Past Chair

Susan G. Komen
Board of Directors

Jane Abraham
Kim Bohr
Linda Custard
Alan Feld
Janet Frantz
Affiliate Board Representative
Dan Glennon
Melissa Maxfield
Olufunmilayo (Funmi) Olopade, M.D., F.A.C.P.
Connie O’Neill
Chair
Andrew Robinson
Meghan Shannon
Affiliate Board Representative
Trish Wheaton
Angela Zepeda
Follow Along on Social Using #BD4BC

We encourage you to engage with Komen and other attendees by joining the BD4BC social conversation, using #BD4BC. Share inspiring mission moments, interesting and educational facts, and kudos to those making a difference.
OUR BOLD GOAL

Reduce the current number of breast cancer deaths by 50% in the U.S. by 2026.
BD4BC3 – Overview and Goals

JENNIFER PIETENPOL, PH.D.
Vanderbilt-Ingram Cancer Center;
Komen’s Chief Scientific Advisor

STEPHANIE REFFEY, PH.D.
Susan G. Komen
For our purposes, Big Data is defined as the integration of Electronic Health Records (EHR), administrative databases, large data repositories, "–omics" and other data.
BD4BC3 – planning committee

Amy Abernethy, M.D., Ph.D.
*Flatiron Health*

Cheryl Jernigan, CPA, FACHE
*Komen’s Scientific Advisory Board; Advocate-in-Science*

Mia Levy, M.D., Ph.D.
*Vanderbilt-Ingram Cancer Center; Komen Scholar*

Joshua Mann
*SHARE For Cures; Inspirata*

George Sledge, Jr., M.D.
*Stanford University; Komen’s Chief Scientific Advisor*
• October 8-9, 2015
• Rockefeller University
  New York, NY
• Funded by the
  Robertson Foundation
• Attendance: ~100

• February 23-24, 2017
• Quadrus Conference
  Center in Menlo Park, CA
• Funded by the
  Robertson Foundation
• Attendance: ~50
Big Data: Role(s) for Susan G. Komen

• **Convener**

• **Advocate for policies**
  – Access
  – Privacy
  – Security

• **Grassroots**
  – Provide information
  – Educate Patients/Public
  – Encourage data donation

• **Funder**
  – Require data sharing for all research projects
  – Develop workforce fluent in informatics and biology
  – Address barriers to clinical trials (e.g. transportation and lodging)

• **Partner with public and industry**
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<tr>
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* member of the BD4BC3 Planning Committee

Susan G. Komen Mission: Save lives by meeting the most critical needs of our communities and investing in breakthrough research to prevent and cure breast cancer.

#BD4BC
Questions & Challenges

• How do you envision the use of “big data” will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?

• What are some of the biggest challenges that will need to be addressed to realize that vision in the next decade?

• What could patient advocates and patient advocacy organizations do to help overcome those challenges?

• What current uses/features of “big data” are or have the potential to be of highest benefit to breast cancer patients?

• What specific uses/features of “big data” are or will be able to address reducing breast cancer deaths? Specifically addressing deaths due to metastatic breast cancer and/or to breast cancer disparities?
Title TBD

BD4BC3 – Big Data Highlight #1

JOHN MATTISON, M.D.

Kaiser Permanente
An update on Komen’s African American Health Equity Initiative

SHYREA THOMPSON
Susan G. Komen
Eradicating Unnecessary Deaths
Addressing variance in care toward Health Equity

BD4BC3 – Session #1

Facilitator: Olufunmilayo Olopade, M.D., F.A.C.P.
University of Chicago; Komen’s Board of Director; Komen Scholar

Speakers:
• Christopher Boone, Ph.D., F.A.C.H.E. – Pfizer
• Joan Neuner, M.D., M.P.H. – Medical College of Wisconsin
• Katherine Reeder-Hayes, M.D., M.B.A., M.S. – UNC, Chapel Hill
Session #1: Questions & Challenges

• How can “big data” help to improve equitable access to care and appropriate use of current therapies?

• How can “big data” be used to identify and address variance in care and improve the quality of health care delivery?

• How can we ensure that “big data” will reduce breast cancer disparities and not introduce new disparities?

• What resources and/or tools are needed to improve diversity of clinical trial participants and of samples used in research?

• What data sources are available to study these questions? Are there any datasets missing?
Learning about Disease Progression from Images and Text

BD4BC3 – Big Data Highlight #2

REGINA BARZILAY, PH.D.
Massachusetts Institute of Technology
Finding and Treating Incurable Breast Cancer

Unlocking EHR to solve metastatic breast cancer

BD4BC3 – Session #2

Facilitator: Mia Levy, M.D., Ph.D.
Vanderbilt-Ingram Cancer Center; Komen Scholar

Speakers:
• Lily Peng, M.D., Ph.D. – Google
• Gaurav Kaushik, Ph.D. – Foundation Medicine
• Aradhana Ghosh, M.D. – Syapse
Session #2: Questions & Challenges

• How can “big data” be used to identify patients at higher risk for recurrence and metastases?

• What technologies should be explored for best prediction and earliest detection of recurrence/metastasis?

• How can “big data” be used to identify targets in metastatic breast cancer? Can “big data” help us better address tumor heterogeneity?

• How can “big data” help accelerate the development of new and better treatments for metastatic breast cancer? How can “big data” be used to overcome treatment resistance?

• What data sources are available to study these questions? Are there any datasets missing?
BD4BC3 – Wrap-Up Session

JENNIFER PIETENPOL, PH.D.
Vanderbilt-Ingram Cancer Center;
Komen’s Chief Scientific Advisor

GEORGE SLEDGE, JR., M.D.
Stanford University;
Komen’s Chief Scientific Advisor
Questions & Challenges

• How do you envision the use of “big data” will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?

• What are some of the biggest challenges that will need to be addressed to realize that vision in the next decade?

• What could patient advocates and patient advocacy organizations do to help overcome those challenges?

• What current uses/features of “big data” are or have the potential to be of highest benefit to breast cancer patients?

• What specific uses/features of “big data” are or will be able to address reducing breast cancer deaths? Specifically addressing deaths due to metastatic breast cancer and/or to breast cancer disparities?
Keep the conversation going!

Comments, suggestions, follow-ups?

Email Jerome Jourquin at JJourquin@komen.org