An integrative approach to improving outcomes for inflammatory breast cancer (IBC) patients: Creating a diagnostic tool, advocating for ICD-10-CM codes and establishing a task force to address critical research gaps

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PROBLEM

Inflammatory breast cancer (IBC) is a rare, highly aggressive form of advanced breast cancer that has historically been challenging to diagnose due to its ambiguous clinical nature. For decades, the lack of clear diagnostic criteria and specific medical codes for IBC has created barriers to timely care and desperately needed research. These issues are compounded by a general lack of awareness about IBC within the clinical and patient communities further contributing to delays in diagnosis and treatment. Together, these issues hinder IBC research advancements, leaving patients with limited treatment options and poor prognoses.

To address these challenges, Susan G. Komen partnered with IBCRF and the Milburn Foundation to form the IBC Collaborative and launch a multidimensional initiative aimed at tackling systemic barriers to the advancement of IBC research and care by focusing on four key areas of need (Figure 1).

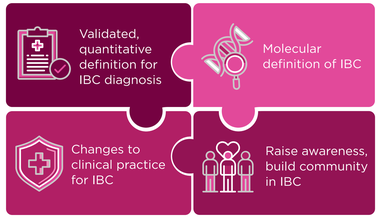


Figure 1. Diagram of the IBC Collaborative's four key focus areas.

CONCLUSIONS

Using an integrative, patient-driven approach, Komen has made significant strides in advancing IBC research, diagnosis and care through the development of impactful tools and resources including:

- **IBC Scoring System:** A globally used online tool that enhances diagnostic accuracy, guides treatment decisions and accelerates research.
- **New ICD-10-CM Codes:** Komen-led advocacy secured new ICD-10-CM codes for IBC that will enable faster, more coordinated care, streamline insurance processing and improve data collection for research.
- **Research Roadmap:** The IBC Collaborative united experts to identify critical knowledge gaps and define research priorities to advance understanding of IBC biology.
- **IBC Educational Resources:** Materials on Komen.org/ibc raise awareness, equip clinicians to recognize and manage IBC and empower patients to advocate for timely diagnosis and care.

Continued momentum in these areas should ultimately lead to improved outcomes for people with IBC.

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SOLUTIONS

The IBC Scoring System: An online tool to aid clinicians in diagnosing IBC worldwide

To improve and accelerate IBC diagnosis, the IBC Collaborative convened a panel of expert clinicians, researchers and patient advocates to develop the IBC Scoring System, a quantitative diagnostic tool for IBC (Jagsi et al. Breast Cancer Res Treat 2022).

The IBC Scoring System:

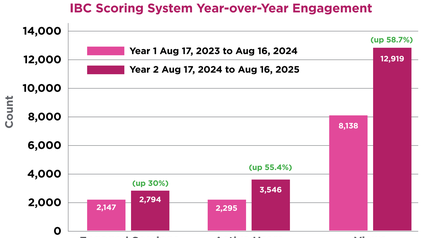
- Helps clinicians to recognize and more effectively diagnosis IBC.
- Has been validated in patient cohorts at two leading U.S. IBC centers (Lynce et al. JNCI 2025).
- Komen is supporting ongoing efforts to enhance the system's clinical utility.

In August 2023, Komen launched an easy-to-use online version of the IBC Scoring System.

Impact since launch:

- Used by > 6,900 individuals across all 50 states in the U.S. and in 114 countries worldwide.
- Increasingly implemented by tumor boards, multi-institutional networks and community oncology centers.
- Featured internationally at SABCS 2024, ESMO Breast 2025 and ESMO 2025.

A



Scan the QR code to access the IBC Scoring System Online Tool

B

> We use the IBC Scoring System on all gray-zone cases discussed at the IBC Connect Case Conference (a national IBC group).
> *RADIATION ONCOLOGIST, MDACC*
>
> The Birmingham UK, IBC Clinic have been using this tool and have found it really helpful.
> *REPRESENTATIVE OF THE ASSOCIATION OF BREAST SURGERY, UK*
>
> I recently had a patient that I thought was non-IBC but the surgeon thought it was. We applied the IBC scoring system and based on the results (Likely IBC) we treated her as such. It helped to bring the team and patient together around her diagnosis.
> *MEDICAL ONCOLOGIST, DFCI*

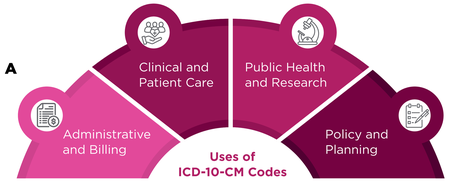
Figure 2. Global use of the IBC Scoring System Online Tool. Google Analytics (G4A) tracked tool usage including engaged sessions, user counts, views and geographic location from (8/17/2023 to 8/16/2025). **A)** Graph showing year-over-year growth in engaged sessions, active users and views. **B)** Quotes from clinicians at leading IBC centers highlighting the clinical utility of the IBC Scoring System.

Advancing care and research through new ICD-10-CM codes for IBC

The International Statistical Classification of Diseases, 10th Edition (ICD-10), is a globally recognized system used by health care providers, government agencies, and researchers to classify, track, and report diseases. The codes are essential for accurate diagnosis documentation, billing/reimbursment, epidemiological research and more.

- Before October 2025, IBC lacked a unique code and was classified under the location-driven subcodes within C50 (malignant neoplasm of the breast), a set of general codes encompassing all breast cancers.
- Advocacy led by Komen resulted in the approval by the Centers for Disease Control and Prevention (CDC) of three new ICD-10-CM codes for IBC (C50.A0, C50.A1, C50.A2), effective October 1, 2025.
- The new codes will enable distinction of IBC from other breast cancers, support timelier, more coordinated multidisciplinary care, help insurance claims go through with fewer delays, strengthen disease surveillance and research, and inform public health efforts.

A



B



C

New ICD-10-CM Codes for IBC - Effective as of October 1st, 2025

C50 Malignant neoplasm of the breast

C50.A Malignant inflammatory neoplasm of breast

C50.A0 Malignant inflammatory neoplasm of unspecified breast

C50.A1 Malignant inflammatory neoplasm of right breast

C50.A2 Malignant inflammatory neoplasm of left breast

Figure 3. Komen-led advocacy efforts resulted in the approval of IBC-specific ICD-10-CM diagnosis codes to support patient care and research. A) Diagram showing the various aspects of patient care and research supported by ICD-10-CM diagnosis codes. **B)** Timeline of steps taken to advocate for ICD-10-CM diagnosis codes for IBC. **C)** Starting on October 1st, 2025, three new codes for IBC went into effect.

A task force of IBC researchers identify knowledge gaps and needed resources to advance IBC biology

Overarching Areas of Needed IBC Biological Research	Prioritized Research Gaps (1 = highest priority)
IBC Onset and Development	1. Host and tumor microenvironment, with emphasis on role of the immune system 2. Role of epigenetics 3. Health disparities 4. Role of host polymorphisms
IBC Metastatic Dissemination	1. Biology of tumors that respond well to therapies 2. Mechanisms of cell migration and mobility 3. Host and tumor microenvironment, with emphasis on role of the immune system 4. Role of epigenetics 5. Role of proteomics
IBC Monitoring and Detection	1. Detecting minimal residual disease (MRD) 2. Prognostication of IBC 3. Response assessment 4. Theragnostics for IBC

Prioritized Resources Needed to Advance IBC Biological Research
1. Central data repository for existing/publicly available IBC data
2. IBC muti-omic database
3. IBC biorepository
4. Multi-institutional cohort of IBC treated tumors
5. Ranked list of potential IBC drugs
6. Virtual tumor bank with common set of IHC staining (digitized images)
7. AI diagnostic tools
8. IBC patient-derived xenograft (PDX) models
9. IBC organoids
10. Genetically engineered mouse model (GEMM) of IBC
11. IBC exosome profiles

Figure 4. Prioritized list of current IBC research gaps and needed resources to advance the field. IBC research gaps were prioritized based on 1) their ability to advance biology and patient care, 2) feasibility of the research and 3) overall significance of the work within areas of IBC onset and development, metastatic dissemination and monitoring and detection. The group also made recommendations for the development of key resources that could significantly advance the field, and prioritized them based on their 1) urgency/priority, 2) availability, 3) feasibility and 4) utility/applicability.

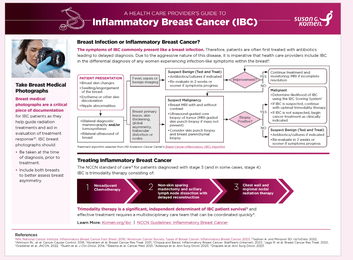
Educational resources to drive earlier recognition and better care for IBC

Komen.org/ibc provides important IBC resources and tools including:

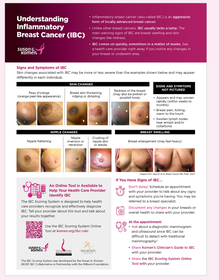


- Videos featuring IBC expert insights
- IBC research articles, blogs and press releases
- Access to the IBC Scoring System Online Tool
- A Health Care Provider's Guide to IBC
- IBC Educational Guide for Patients

Scan the QR code to view all of Komen's IBC resources and tools on Komen.org



Scan the QR code to access A Health Care Provider's Guide to IBC





Scan the QR code to access IBC Educational Guide for Patients

Figure 5. Educational resources to support clinicians and patients in the recognition, diagnosis and treatment of IBC. An IBC-dedicated webpage was created on Komen.org to drive and support use of the IBC Scoring System Online Tool and to house important information and resources for the IBC community.