Bridging the DCIS Information Gap: A Patient-Centered, Community-Engaged Approach

#03-40

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Background: Why DCIS Is Unique

- Ductal carcinoma in situ (DCIS) accounts for **20-25% of breast cancer diagnoses**
- Nearly **60,000 people** are diagnosed annually in the U.S.
- Classified as "Stage 0" and **non-invasive, yet prompts invasive treatment**
- Standard treatments of surgery, radiation, and hormone therapy can permanently affect physical health, fertility, body image, finances, and quality of life
- Natural progression of DCIS remains **poorly understood**
- Many cases may never progress to invasive disease, but **risk prediction remains imprecise**

DCIS exists in a gray zone where uncertainty and variability complicate decision-making.

Our DCIS Patient Brochure (available in English and Spanish)

What Patients Face

- Conflicting language from physicians: "cancer" vs. "pre-cancer" vs. "risk factor"
- Variation in treatment recommendations
- Reassurance ("you're lucky") paired with aggressive interventions
- Limited time to process complex information

Common Outcomes:

- Confusion
- Anxiety
- Decisional regret
- Disengagement from care

Equity & Access Gaps:

- Access to nuanced discussions of risk profile and treatment options varies by:
  - Academic vs. community care settings
  - Health literacy and language access
  - Financial and geographic constraints
- Unequal access to second opinions and varied medical perspectives
- Scientific uncertainty becomes a **driver of inequity** when information is unevenly distributed

Information gaps widen disparities in care.

An excerpt from our website, www.dcisunderstood.org

The Education Gap

- Most breast cancer resources are **not DCIS-specific**
- Materials often:
  - Overstate risk
  - Lack nuance
  - Fail to explain uncertainty and gaps in the evidence
  - Fail to highlight emerging research that may impact decision-making
- Patients are left interpreting complex science during a period of emotional vulnerability
- Patients often turn to online support groups that are not vetted or evidence-based, which can exacerbate confusion, anxiety and fear

Education is foundational to shared decision-making and informed care.

The Intervention: DCIS Understood

Founded in 2024 by a DCIS patient advocate, DCIS Understood is the first and only national nonprofit exclusively dedicated to education and support for DCIS patients.

What We've Built:

- Evidence-based educational website
- Plain-language DCIS brochures (English & Spanish)
- Partnerships with breast health centers
- Expert Advisory Council made up of leading physicians and researchers

What We're Building:

- Expanded educational resources
- AI-powered chatbot drawing from vetted and trusted medical sources to answer common questions and explain DCIS research (without giving medical advice)
- Centralized community of trusted information and support for DCIS patients
- Advocacy movement for more DCIS research

To learn more, visit: dcisunderstood.org

Early Reach & Patient Engagement

At-a-Glance Impact (June 2025-Present):

3,800+	2,600+	18+	200+
unique website visitors	visitors based in the U.S.	countries represented by website visitors	DCIS-focused e-newsletter subscribers

Why This Matters for Care and Research

Patient-centered education improves care satisfaction:

- Better-informed patients are calmer, more prepared to ask questions, and better able to participate in shared decision-making.
- Clear explanations of uncertainty help patients align treatment decisions with personal values, risk tolerance, and quality-of-life priorities.
- Improved understanding supports patient confidence in decision-making and engagement in longitudinal follow-up.
- Extending DCIS-specific education beyond academic centers can help reduce inequities in care.

DCIS-specific education plays a critical role in advancing research:

- An accessible, centralized source of DCIS research and clinical trial information helps build a community of informed patients and advocates.
- Informed patients are more likely to:
  - Inquire about emerging research and evidence gaps
  - Participate in ongoing studies and clinical trials when appropriate
  - Engage in prevention and de-escalation research
  - Advocate for additional research and funding
- A DCIS-focused educational and advocacy movement increases public awareness, amplifies patient priorities, and elevates DCIS within the research agenda.
- Patient education strengthens both the **supply of research participants** and the **demand for DCIS research**.

Education is not only a tool for better care–it enables more research by supporting trial participation, public engagement, and the generation of patient-centered evidence.

Early website engagement metrics suggest that accessible, DCIS-specific education meets an unmet need and may support more informed participation in care and research.

Patient Reflections

"Different doctors described DCIS in very different ways, and I didn't know how to make sense of that."

"This was the first place that made it feel okay to be confused and helped me think through my options and questions for my care team."

Key Takeaways

- DCIS patients face **high uncertainty** with limited tailored education
- Information gaps drive **care inequity** and patient disengagement
- Patient-led, community-engaged education is an **implementable intervention**
- Education today enables **better care now and better research tomorrow**