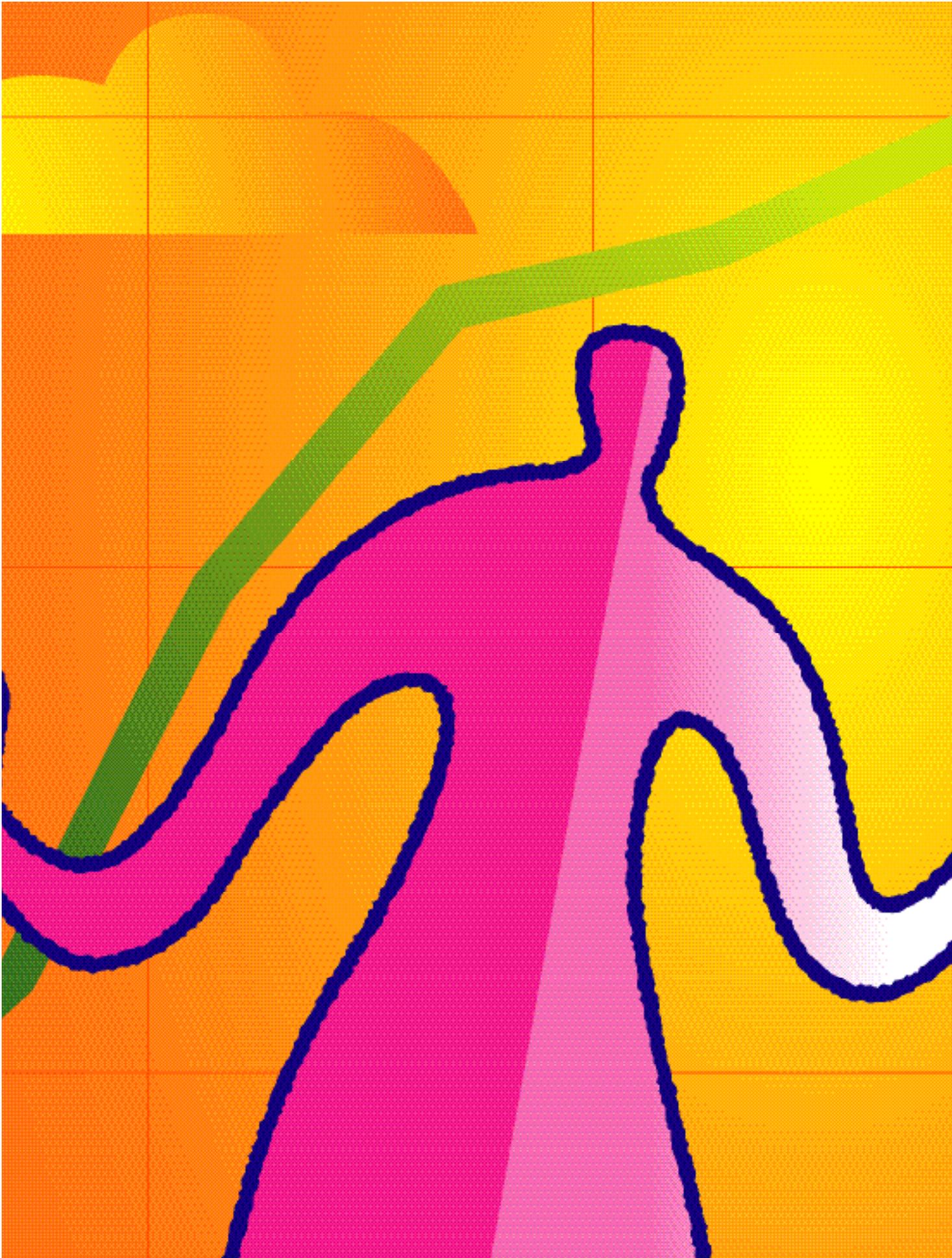


NATIONAL BREAST CANCER COALITION FUND • NATIONAL BREAST CANCER COALITION FUND • N
QUALITY CARE • QUALITY CA
NATIONAL BREAST CANCER COALITION FUND • NATIONAL BREAST CANCER COALITION FUND • N
QUALITY CARE • QUALITY CA
NATIONAL BREAST CANCER COALITION FUND • NATIONAL BREAST CANCER COALITION FUND • N
QUALITY CARE • QUALITY CARE • QUALITY CARE • QUA

IMPROVEMENT



NATIONAL BREAST CANCER COALITION FUND • NATIONAL BREAST CANCER COALITION FUND • N
QUALITY CARE • QUALITY CA
NATIONAL BREAST CANCER COALITION FUND • NATIONAL BREAST CANCER COALITION FUND • N
QUALITY CARE • QUALITY CA
NATIONAL BREAST CANCER COALITION FUND • NATIONAL BREAST CANCER COALITION FUND • N
QUALITY CARE • QUALITY CA



IMPROVEMENT

Quality care is not a destination. It's a journey in the right direction. That's why NBCCF sees quality care as a set of core values, not a checklist of items. Core values help us focus on what matters most. They tell us if we're heading in the right direction. But core values are never finished. Breast cancer care needs to keep getting better.

We need our whole health care system to look at what is and is not working. That way we can continue to improve the quality of care. We need a way to admit past mistakes and make things better. We want changes that will improve the quality of breast cancer care starting right now. Here are some ways you can help make this happen.

Quality Breast Cancer Care Means:

Becoming a Breast Cancer Activist

Learning from Patient Care

Measuring What Matters

Becoming a Breast Cancer Activist

If you've just learned you have breast cancer, you need to focus on your own healing. But many of us living with breast cancer soon ask:

- How can I help others who are going through what I went through?
- What can I do to help someone else get the breast cancer care they need?
- What can I do to help end this disease?

Reaching out to help others is often an important part of our own healing.

It takes courage to look beyond your own breast cancer to the larger system. But that's what it takes to make a difference. History shows that breast cancer **activists** can help improve breast cancer care. Not long ago, many women were ashamed to admit they had breast cancer. Since then, brave breast cancer survivors have stepped forward to make breast cancer a public and national issue. Breast cancer **advocates** are now a powerful voice in breast cancer research and policy. To learn more about breast cancer **activism** and NBCCF, see pages 115-116.

What You Can Do:

Become a member of NBCC.

The other sections of this guide focus on what you can do to help yourself get quality breast cancer care. But many quality problems are systemwide. So the solutions need to be systemwide as well.

One person can make a big difference. But a group of people who share a vision and are ready to work toward common goals can do even more. That's why we need you to join NBCC. We are millions of breast cancer activists across the nation. Together we can and do make a difference in the quality of breast cancer care in this country. We need each and every one of you. Please join us today! Contact NBCC (page 99) for membership information. Or you can join by using the printed envelope in the back of this guide.

There are lots of ways to make a difference in the breast cancer movement. Some folks spend thousands of hours year after year. Others spend just an hour here or there. You can attend a rally, organize a rally, attend a meeting, or host a fund-raiser. You can write a letter, write a hundred letters, call someone, or call everyone. You can vote, honor a hero, collect signatures, or write a law. You can hold someone's hand, ask questions, thank a supporter, or demand answers. You have your own special talents. Use them. Make breast cancer care better for someone else who may need it all too soon.

Join us when you're ready to look beyond your own breast cancer to the world of breast cancer. When it comes to improving breast cancer care, there is no limit to great ideas. We'd love to hear your ideas and stories. Please share them with us.

Together we can and do make a difference in the quality of breast cancer care in this country.

Ideas for Improving the Quality of Breast Cancer Care in Your Community

1. Give copies of this guide to breast cancer patients, caregivers, and community groups in your area. To order more copies of the guide, see the order form in the back of this book.
2. Meet with breast cancer caregivers in your area to explain this guide. Ask them to give it to their patients. And ask them to give evidence-based information to all their patients. The information should include both standard and **complementary medicine**.
3. Tell low-income women with no **health insurance** that they can get a **mammogram** through the NBCCEDP (see page 15). That way, if they have breast cancer, they may be able to get **Medicaid** to pay for their treatment.
4. Ask local health plans to explain how they decide about covering breast cancer care. Ask them to explain the process *publicly*. For example, they could write a letter to their members. It could explain what **evidence** they use to decide what to cover.
5. Meet with your local cancer center, hospital and/or **health plan**. Ask them how they care for breast cancer patients who don't have health insurance. Who is falling through the cracks in your community? Breast cancer activists and care centers can work together to be sure all breast cancer patients get all the care they need.

Build your advocacy skills.

Each spring, NBCCF holds its Advocacy Training Conference in Washington, D.C. Breast cancer advocates from every part of the country come together to learn and get inspired. Everyone who cares about breast cancer is welcome.

The conference is three days long. You'll learn about breast cancer research,

care, policy, and **advocacy**. You'll also be able to choose workshops on topics that especially interest you. There are dozens of workshops—something for everyone. Here are a few examples of workshops from other years:

- Starting Breast Cancer Advocacy in Your Community
- The Nuts and Bolts of Congress

-
- Complementary and **Alternative Medicine** and Quality Breast Cancer Care
 - **Genetic Testing: Do You Really Need to Know?**

NBCC holds its Annual Lobby Day the day after the conference. On Lobby Day, NBCC activists meet with their members of Congress to ask them to support NBCC's agenda to end breast cancer. The conference prepares activists for these meetings. Everyone is welcome. Contact NBCCF (page 99) for more information on our Annual Advocacy Training Conference.

Take NBCCF's Project LEAD® Course.

Project LEAD® is an intensive science program. It teaches breast cancer activists how to recognize well-designed research. It also helps them understand scientific concepts. For example, students learn about basic science, genetics, and epidemiology. (Epidemiology is the study of what causes specific **health outcomes** in populations.)

Project LEAD® prepares advocates to take part in meetings where breast cancer research decisions are made.

It is a busy four-day program held four times a year in different cities around the country. Contact NBCCF (page 99) for more information on Project LEAD®.

Fight for health care reform.

Federal and state laws could make breast cancer care much better. Contact NBCC (page 99) to learn about our legislative priorities. Learn how you can:

- fight for access to health care for everyone,
- fight for more breast cancer research to bring us closer to finding prevention and cures,
- demand more and better research into the links between breast cancer and the environment,
- work for protections against genetic discrimination, and
- fight for meaningful patient protections.

We need a health care system that *always* learns from patient care.

Learning from Patient Care

We need to find out what health care is and is not working. That's the only way we can change things for the better. But our health care system doesn't do well at measuring health care quality. Right now we *rarely* learn from patient care. That's because very few breast cancer patients take part in **clinical trials**. And we don't collect very much data on patient care. We need to turn that around. We need a health care system that *always* learns from patient care. This means more and better:

- clinical trials studying new ways of understanding and treating breast cancer, and
- information collected on patient care and experiences.

This is a whole new way of thinking. It would change what medical research means to the average patient.

What You Can Do:

Learn about clinical trials.

Then let other breast cancer patients know what you've learned. Clinical trials are not about proving what we already know. They're about asking questions that we don't have answers to. Clinical trials are how we learn to make breast cancer treatment better. They're also how we get answers about causes, prevention, and cures. Well-designed clinical trials are a good way for patients to get care. All breast cancer patients should know about clinical trials they could take

part in. To learn more about clinical trials, see pages 23-25 of this guide.

Improve the laws about clinical trials.

Trial sponsors pay most of the costs of clinical trials. But sometimes there are "routine patient care" costs that aren't covered. Some states have laws to make **health plans** pay those costs. If your state doesn't, you can ask your state representative to try to pass a new law in your state. NBCC (page 99) has written some model state legislation to help get you started.

Increase access to clinical trials.

Ask local doctors and hospitals how you can help them get more patients into quality breast cancer clinical trials. Ask them if they give information on clinical trials to their breast cancer patients. Offer to help them create a system for telling patients about clinical trials.

Learn about health outcomes research.

One way to learn from patient care is to measure the end results of health care. Research that looks at the end results of care is called **outcomes research**. These results can include changes in:

- what you are able to do,
- how you feel, and
- how long you can hope to live.

This research is key to developing better care.²¹

21 Outcomes Research.Fact Sheet.AHRQ Publication No.00-P011, March 2000.Agency for Healthcare Research and Quality, Rockville, MD.

We need a national **health outcomes** database. It would help us learn how to best treat patients with all types of health problems. But this kind of program needs a strong national commitment. It needs to involve national leaders and local, state, and national teamwork. It needs data standards and a framework for the information. It needs ways to keep patient data private.

A national health outcomes database would give information we can't get from clinical trials. New treatments usually work better in clinical trials than they work in the real world. This is because clinical trials take place under closely controlled conditions. The outcomes database would tell how treatments work when the average patient sees the average doctor.²²

Contact the Health Legacy Partnership (page 102) to learn more about the group's effort to create a national health outcomes database.

Measuring What Matters

One strategy for improving health care quality is to measure what matters most in health care. We need better quality measures to do this. Comparing **health plans** by how many patients get **mammograms** each year doesn't tell you much. Knowing how many patients say they are "satisfied" with their health plan doesn't help much, either. People answer differently based on their mood. And magazines usually judge the "best" hospitals by asking doctors what they think. But that only tells us what doctors like. It doesn't tell us how well the hospital cares for patients.

Not long ago, researchers were the only ones who tried to measure the quality of care. Now breast cancer survivors and **activists** bring a unique and important viewpoint to this issue.

So we should help shape, judge, and improve research on the quality of breast cancer care.

Once we measure something about breast cancer care, the public needs to know the results. People need to know about the quality of care in this country. That's true whether it's good news or bad.

How You Can Make a Difference:

Learn more about quality measures. Researchers tend to measure things that are easy to count. For example, how many women over age 50 got a mammogram last year? This is easy to measure, but the answer to this question isn't very helpful. It doesn't tell us anything about what happened after the woman got a mammogram. Some important questions include:

22 McGlynn, EA. Building a health care information system for decision making in the 21st century. (unpublished article) 2000.

Once we measure something about breast cancer care, the public needs to know the results.

- Were the women who got mammograms given accurate **diagnoses**?
- Did those with abnormal mammograms get needed follow-up care?
- Were they informed of all of their treatment options?
- Were they told about **clinical trials** and if they could join one?
- Were they treated with respect?
- Were problems solved quickly and fairly?

NBCCF is interested in creating better quality measures for breast cancer. We want to use the core values presented in this guide to judge the quality of breast cancer care. Our vision and core values say what we think matters most in health care.

More and better quality measures will create more and better information about the quality of care in the United States. This information will help:

- consumers make more informed choices about their care;
- purchasers of health care make value-based purchasing decisions;
- the health care industry focus and prioritize its quality improvement efforts;
- **advocates** direct their passion and energy; and
- the public hold the system accountable.

Contact the National Health Law Program (page 105) to learn more about quality

measures. Ask for a copy of their fact sheet, “Getting the Best Out of Managed Care #2: Understanding Quality Measures.”

Help measure the quality of breast cancer care.

Ask for a meeting with your local breast cancer center or hospital. Ask them how they measure what works for breast cancer care. And ask what they do with that information.

Ask your local breast cancer center or hospital to see their quality improvement plan. If they don’t have one, they should make one. Insist that breast cancer activists work as partners in making the plan. Maybe they have a plan, but it is confusing to you. If so, ask them to explain exactly what it really means. Then you can suggest how to make it better. Base your comments on what you wish you had known when you were a patient.

Work with local health plans and centers to measure and reduce **medical errors**. Medical errors are mistakes that could be prevented. Many states have programs to track and prevent medical errors. To learn more, contact the Institute of Medicine (IOM) (page 102). Ask for its report, “To Err is Human: Building a Safer Health System.” You may also want to ask for a copy of its report, “Crossing the Quality Chasm: A New Health System for the 21st Century.” This report gives excellent advice for improving the quality of care in the United States.

Conclusion

NBCCF'S GUIDE TO QUALITY BREAST CANCER CARE

We wish we could give you a simple answer about breast cancer. We can't. This guide is not simple because breast cancer isn't simple. But we've tried very hard to be clear and accurate.

Like any book, this guide will become out-of-date. Check the bottom of the table of contents page to see when it was published. To be sure that what you are reading is up-to-date, visit NBCCF's web site at www.stopbreastcancer.org. You can find this entire guide on our web site, and we update it regularly. If you need help getting to our web site, go to a library. A librarian should be able to help you get onto the Internet.

We hope we've given you some new ways to think about quality health care for breast cancer. And we hope it will help you get the quality care you deserve. We also hope you will join us in the movement to end breast cancer.

Many organizations and individuals make up the National Breast Cancer Coalition Fund. On behalf of all of them, we wish you the very best in your search for quality health care.