

# The Role of Patient Advocacy in Research & Community Involvement

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## INTRODUCTION

**Tom Simon** – Patient Advocate, NRG Oncology

I've been deeply involved in cancer advocacy since retiring in 1999. Through my work with NRG Oncology and my nonprofit, **I CARE, Inc.**, I focus on bridging the gap between patients, researchers, and community needs.

### NRG Oncology Roles:

- Former Vice-Chair, NRG Oncology Patient Advocate Committee
- Member, NRG Lung Cancer Committee
- Member, NRG Genitourinary Cancer Committee

### Additional Advocacy:

- Director, I CARE, Inc., supporting senior independence through free transportation services
- Volunteer with multiple nonprofits and community groups to extend research access and care equity

### Professional Background:

- Pharmacy graduate
- Former positions: FBI, United Airlines, Southern Airways, Georgia-Pacific, Georgia Gulf
- Management and operational experience across industries

### Volunteer Activities:

- Support group facilitator for lung and general cancer communities
- Peer mentor for patients with atrial fibrillation
- Fundraiser for nonprofits serving those in need of support in healthcare

### Why, As Advocates, We Advocate:

- To support patients facing serious illness with compassion and clarity
- To help survivors navigate clinical trials and treatment systems
- To ensure patients and caregivers know their options and feel empowered

## THE ROLE OF PATIENT ADVOCATES IN RESEARCH

As Patient Advocates, we work side-by-side with clinical researchers to bring the patient perspective into every stage of research. Our insights help make studies more patient-centered, inclusive, and accessible.

### Research Involvement:

- Review clinical trial concepts and protocols
- Highlight barriers and access issues
- Advocate for quality of life research
- Educate about the role of advocates in research

### Collaborations:

- NRG Oncology
- Former NCI Cooperative Groups: RTOG, CALGB
- FDA Patient Representative and committee member for Oncology Drug Advisory Committee
- Cardiovascular and Renal Drugs Advisory Committee
- Microbiology Devices Advisory Committee

### Organizational Partnerships:

Lung Cancer Caring Ambassadors Program (*former President*)  
St. Joseph's Cancer Survivors Network (*Executive Committee*)  
Local churches, hospitals, and civic organizations

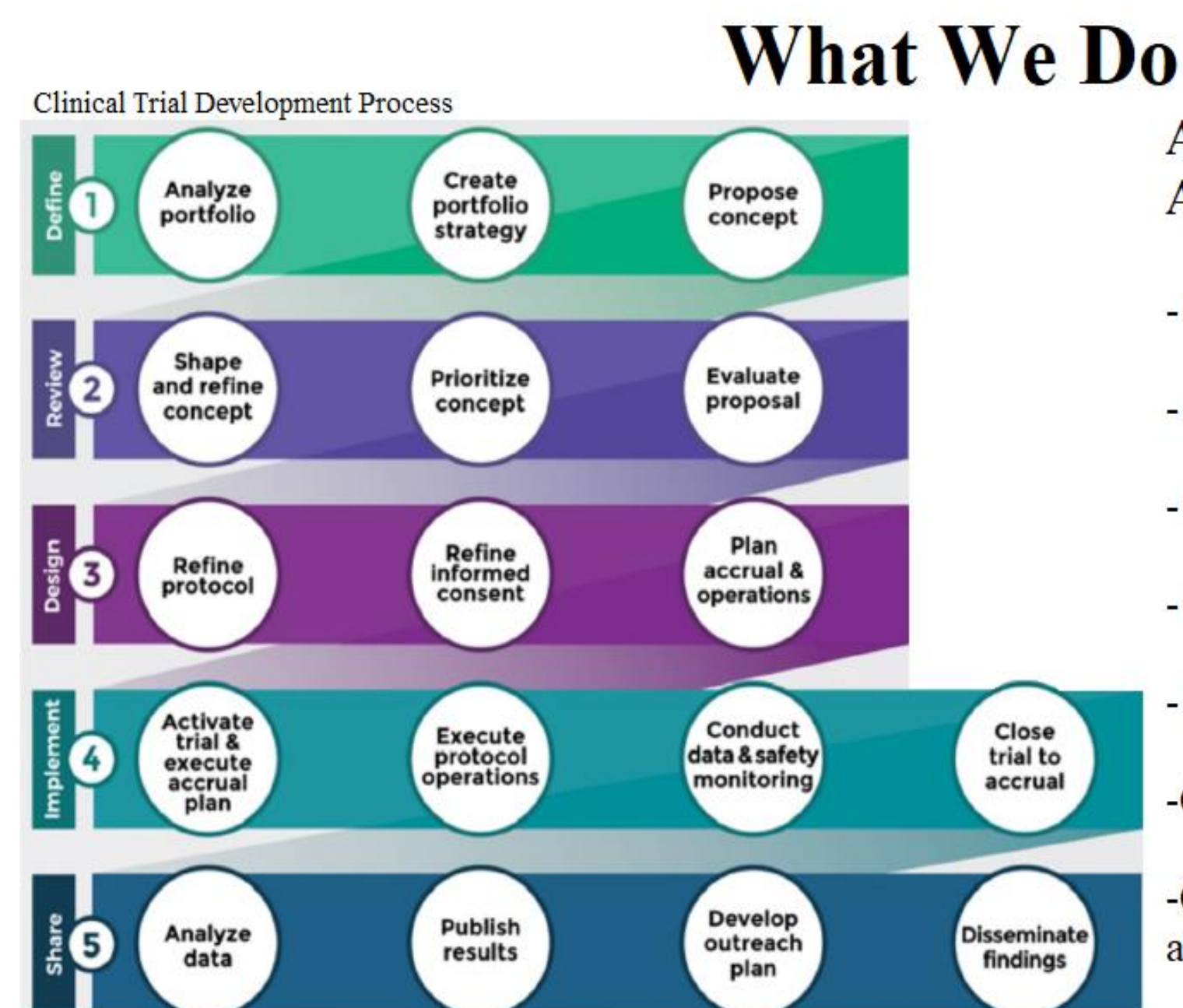


Image Source: SWOG Patient Advocate Resource Guide

At NRG Oncology, Patient Advocates assist with:

- Clinical trial design
- Study protocol review
- Lay person summary editing
- Letters of support
- Community education
- Clinical trial recruitment
- Connecting researchers to advocacy and community organizations

## CONCLUSIONS

Three things I've learned from my years of advocacy:

- 1. Patient voices belong in research.** We see things researchers might miss. When we're involved, the science becomes more relevant and more human.
- 2. Local impact matters.** Programs like I CARE, Inc. show how advocacy can meet immediate needs and improve daily life for people who might otherwise be left behind.
- 3. Advocacy fills the gaps.** Whether it's at the FDA, in a support group, or behind the wheel of a car giving someone a ride to the doctor, advocates step in where systems fall short.

This work isn't just what I do, it's who I am. I'm honored to keep showing up for patients, every step of the way.

## LOCAL COMMUNITY ADVOCACY & OUTREACH

Local advocacy work that advocates engage in is just as important as national research roles.

For example, through **I CARE, Inc.**, we help meet real-world needs in my own community.

### Program Mission:

Our mission is to promote health, independence, and quality of life for seniors in DeKalb County, Georgia.

### What We Provide:

Free, reliable transportation for seniors—including those with disabilities—to medical appointments, grocery stores, pharmacies, and allied health services.

**FREE TRANSPORTATION TO:**

- Medical appointments
- Allied health services
- Pharmacies
- Grocery stores
- Personal connection and reliability many seniors can't get from public services

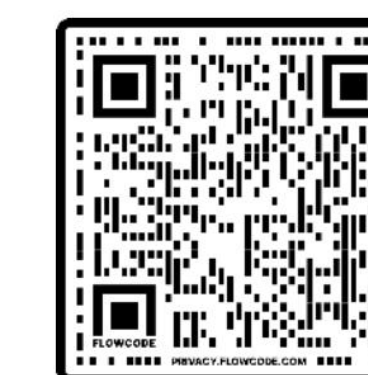
\* A safety net for older adults who would otherwise miss care or go without essentials

### Why It Matters:

- Transportation is one of the top barriers to healthcare access for seniors
- Missing appointments or medications can lead to avoidable health decline

### Our Impact:

- This work fills a critical gap in care by ensuring that older adults can:
- Access timely medical care and medications
  - Maintain proper nutrition and independence
  - Avoid isolation and health decline due to transportation barriers



Learn More About  
**I CARE, Inc.**  
[www.icareseniors.org](http://www.icareseniors.org)