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CANCER WORLD

Finding Her Voice

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NOT FOR SALE

We often describe progress in oncology through the language of discovery.

Scientific breakthroughs. Technological innovation. Deeper biological insight.

These advances have transformed medicine, helping millions of people live longer and better than ever before. Yet alongside every scientific breakthrough, a broader change has been unfolding across oncology.

For generations, expertise was defined almost exclusively by science. It emerged from laboratories, clinical trials, and decades of clinical practice. That foundation remains the cornerstone of progress. But today, oncology is embracing another source of knowledge—one grounded not only in research, but also in lived experience.

Patients, survivors, caregivers, and advocates are no longer viewed simply as recipients of care. Increasingly, they are shaping research, influencing policy, improving communication, and challenging healthcare systems to better reflect the realities of living with cancer. Their perspectives are broadening our understanding of what truly defines quality cancer care.

Few stories embody this changing landscape more powerfully than those of Martha Raymond and Gloria Okwu.

For more than four decades, ***Martha Raymond*** *has been at the forefront of patient advocacy in gastrointestinal oncology, helping establish patient partnership as an essential pillar of modern cancer care. Her work demonstrates that scientific excellence and lived experience are strongest when they advance together.* ***Gloria Okwu,*** *whose own breast cancer diagnosis became the catalyst for one of Nigeria's leading advocacy movements, reminds us that information, trust, empathy, and shared experience can shape outcomes just as profoundly as treatment itself.*

The same perspective runs throughout this issue. ***Tamika Felder*** *reflects on turning cervical cancer survivorship into a global movement for prevention and education.* ***Carmen Monge*** *challenges us to rethink survivorship in an increasingly mobile world, while* ***Dr Michael Janse*** *van Rensburg offers a deeply personal reflection on recurrence, caregiving, and resilience, reminding us that cancer is never experienced by patients alone.*

Science, too, is reinforcing these perspectives. ***Victoria Forster*** *explores compelling evidence that patient-reported outcomes provide prognostic information beyond traditional clinical measures, while Adrian Pogacian examines emerging approaches that broaden how mental health is understood in oncology. In our new series, Oncology Couch: Questions, Answers, and the Space in Between,* ***Dr Aleksandra Filipović*** *explores the intersection of science, communication, and human connection, reminding us that healing is shaped not only by treatment, but also by communication, trust, and meaningful relationships.*

Beyond the clinic, our coverage of the ***2026 Cancer Patients Europe Annual Meeting*** *highlights the growing role of patients as partners in shaping cancer policy. Our feature on* ***AI-supported patient navigation*** *explores how technology can strengthen—not replace—the human relationships that guide patients through increasingly complex healthcare systems. We also honour the legacy of* ***Dr Mary Buchanan,*** *whose pioneering work helped build one of Europe's most influential breast cancer advocacy movements.*

Finally, our ***News*** *section reminds us that discovery itself never stands still, highlighting research that challenges long-held assumptions about cancer cachexia and opens new directions for understanding one of oncology's most devastating complications.*

Together, these stories point towards a fundamental shift in cancer care.

Scientific discovery will always remain the foundation of progress in oncology.

The next chapter of oncology will be written not only by those who study cancer, but also by those who live with it.

Knarik Arakelyan, Managing Editor, CancerWorld

Finding Her Voice

How One Little Girl's Loss Became a Lifelong Lesson in Listening

By Knarik Arakelyan

When Martha Raymond, the Founder and CEO of the GI Cancers Alliance and the Raymond Foundation, was seven years old, she lost her father to colon cancer. Years later, her mother's illness would change the course of her own life. Between those two losses, she discovered something that would shape the next four decades: the courage to speak about cancer openly. That voice would help redefine patient advocacy in gastrointestinal oncology—not by speaking for patients, but by reminding medicine that patients had voices all along. The challenge was learning to listen.

The Questions That Changed Everything

"What happened to your father?"

It was the question waiting for Martha Raymond when she returned to school.

She was seven years old. Her father had died from colon cancer, and she suddenly found herself trying to explain a disease that many adults still avoided naming. It was the late 1960s. Cancer was often wrapped in silence. Her classmates, however, simply wanted answers.

Her mother encouraged her to give them.

Every conversation became a lesson in honesty rather than fear.

Not everyone welcomed those conversations. One parent even complained that Martha was talking about cancer with other children and suggested she should stop. Her mother disagreed. She believed people needed to understand that cancer could happen to any family, and she was proud of her daughter for trying to help others even while their own family was grieving. Afterwards, she took Martha out for ice cream covered in colourful sprinkles—a small ritual that transformed painful moments into acts of quiet courage.

Looking back, Raymond recognises those conversations as the beginning of everything that followed.

"I found my voice," she says.

At the time, she could not have imagined where that voice would lead. What began as a child's attempt to answer difficult questions would become the foundation of a lifetime dedicated to ensuring that patients were heard.

Raymond Family

When Care Continues After Treatment

Years later, another experience would give that voice its purpose.

As life slowly settled into a new normal after losing her father, Raymond found another way to process grief. Her mother introduced her to Broadway musicals, and music became both an escape and a source of confidence. Off stage she remained painfully shy; on stage she discovered a voice she had never known she possessed. She studied vocal performance, earned scholarships and eventually moved to New York to pursue a career in music. She believed she knew what her future would be—until cancer changed its course once again.

Martha was in college and advocacy was nowhere in her career plans until her mother was also diagnosed with colon cancer.

Like countless families, they learned the language of oncology together—appointments, test results, treatment options, hope followed by uncertainty. Not long after her mother's diagnosis, Raymond accompanied her to her first oncology appointment, hoping for reassurance but fearing the worst.

When Raymond asked about treatment options, the physician dismissed her question with a laugh and a roll

of his eyes. Sitting beside her, her mother lowered her head.

In that instant, the advocate in her emerged.

Raymond stood up and told the physician they were leaving. They would find another doctor—one who would provide not only expert care, but humanity and respect.

"My mother had always stood up for me," she says. *"Now it was my turn to stand up for her."*

That moment changed Raymond's understanding of care forever.

Treatment may end. Care cannot.

"I had absolutely no idea what I was doing," she recalls of her first steps into advocacy. *"I simply knew that patients and families needed someone beside them."*

She began visiting oncology centres and academic institutions, speaking with physicians, nurses, researchers and social workers. But, as she puts it, *"most importantly, I listened."* Patients told her what was missing. Families described where they felt abandoned, frightened or unheard. Those conversations became the foundation of every programme and initiative she would go on to build.

What began as volunteering soon became a vocation.

There was no roadmap for this work. Patients were seldom involved in decisions about research, treatment planning or quality of life. Much of what she built came directly from listening to the people she hoped to serve. Those conversations—with clinicians, families and, above all, patients themselves—shaped the programmes and partnerships that followed.

Over the next four decades, Raymond helped transform the role of patients in gastrointestinal oncology, working alongside clinicians, researchers, professional societies and policymakers to ensure that lived experience became part of how cancer care is designed and delivered.

She has never described that work as giving patients a voice.

Patients, she believes, have always had one.

The real challenge was helping healthcare learn to listen.

A Different Story of Progress

The story of modern oncology is often told through scientific breakthroughs.

New medicines. New technologies. New discoveries.

Raymond tells the story of oncology differently. Not through milestones in science alone, but through the gradual recognition that patients belong in the conversations shaping their own care.

It is a transformation she has witnessed firsthand over more than four decades.

Patients as Partners

When Martha Raymond began working in patient advocacy, patients were rarely invited into the conversations that shaped cancer care. Decisions about research, policy and clinical trials were made largely without the people living with the disease. Over the next four decades, Raymond would become one of the people helping to change that reality.

Patients became partners in research, contributors to clinical trial design, advisers to regulatory agencies and collaborators in healthcare policy. What was once considered exceptional is now increasingly recognised as essential.

For Raymond, however, the greatest transformation is not where patients sit.

It is how they are perceived.

In front of the published abstract/poster on patient-reported outcomes, ASCO GI 2026

Raymond believes scientific evidence and lived experience answer different questions. One explains the disease. The other explains what it is like to live with it. Neither, she argues, is complete without the other.

"Patients have always had voices," she says. *"What they too often lacked was a system prepared to listen."*

That simple observation has guided her life's work. Listening is not a gesture of compassion. It is the beginning of better medicine.

Communication is Care

Few ideas have shaped Raymond's philosophy more profoundly than communication.

She has witnessed extraordinary scientific advances transform cancer treatment, yet she believes some of the most important moments in oncology still happen without technology.

They happen in conversation.

It is a lesson that reaches back to her own childhood, when difficult conversations became the beginning of understanding rather than something to avoid.

Patients may not remember every statistic they are given, but they remember how difficult news was delivered.

They remember whether someone paused long enough to let the silence settle, whether they felt able to ask another question, and whether they were treated as individuals rather than diagnoses.

Those moments influence trust every bit as much as treatment itself.

"Communication is not simply how we deliver care," Raymond says. *"Communication is care."*

The distinction matters.

Communication is often viewed as a skill that supports medicine.

Raymond sees it as medicine.

The most effective treatment cannot achieve its full potential if patients do not understand it, trust it or feel confident enough to participate in the decisions surrounding their care.

As oncology becomes increasingly sophisticated, the human conversation becomes more—not less—important.

Every advance in science raises new questions for patients and families. Helping them navigate those questions with honesty, empathy and clarity is not separate from clinical care; it is an essential part of it.

From Representation to Partnership

The language of patient advocacy has evolved alongside oncology.

For years, the goal was often described as giving patients a voice.

Raymond has never been comfortable with that expression.

Patients already have voices, she says.

The responsibility lies with healthcare to hear them.

That distinction reflects one of the most significant cultural shifts in modern oncology.

Raymond has watched patient advocacy evolve from representation to genuine partnership. Increasingly, it means involving people with lived experience from the very beginning—when research priorities are defined, clinical trials are designed and healthcare policies are developed.

The result is better science. Research questions become more relevant. Clinical trials become more patient-centred. Outcomes become more meaningful. Innovation becomes more closely connected to the realities of living with cancer.

For Raymond, this is not simply better advocacy.

It is better oncology.

The transformation, she has witnessed, extends far beyond patient representation. It reflects a broader recognition that scientific excellence and lived experience are complementary forms of knowledge.

As oncology enters an era shaped by precision medicine,

artificial intelligence and increasingly personalised care, Raymond believes the challenge is no longer whether patients should be included, but how every innovation can be developed in partnership with the people it is ultimately meant to serve.

That conviction naturally leads to the next question not how oncology has changed, but where it is going next.

Precision Must Include Equity

After spending more than four decades helping shape patient advocacy, Martha Raymond has earned the rare privilege of looking both backward and forward at the same time.

She has seen multidisciplinary care become the norm, precision medicine redefine treatment, and immunotherapy transform outcomes once thought impossible. Today, artificial intelligence promises to reshape everything from diagnosis to clinical decision-making.

Each advance, she believes, brings oncology closer to truly personalised care.

But only if it reaches the people who need it.

"Precision medicine fulfils its promise only when precision is accompanied by equity."

For Raymond, that is one of the defining challenges of modern cancer care.

Scientific breakthroughs have little meaning if access depends on where a patient lives, which healthcare system they belong to, or whether the necessary diagnostics and treatments are available. Innovation and equity are not competing priorities—they are inseparable.

"The future is incredibly exciting," she says. *"But we have to ensure that innovation benefits all patients, not just those fortunate enough to live in the right place or access the right healthcare system."*

Throughout her career, Raymond has advocated not only for scientific progress, but also for ensuring that progress reaches every patient. For her, the success of precision medicine will ultimately be measured not only by its discoveries, but by its accessibility.

Technology Should Create More Time to Care

For Raymond, the promise of artificial intelligence is surprisingly human. Used thoughtfully, she believes, it can accelerate research, support clinical decision-making and reduce the administrative burden that often keeps healthcare professionals away from what matters most: people.

"The future of oncology depends on bringing technological innovation and human connection together," she says. *"If innovation allows clinicians to spend more time listening, explaining and building trust with patients, then technology will have fulfilled one of its greatest purposes."*

That perspective reflects a philosophy she has carried throughout her career.

Technology should never replace the human relationship at the centre of medicine.

It should strengthen it.

As cancer care becomes increasingly sophisticated, the need for empathy, trust and meaningful conversation only grows. If artificial intelligence can return time to clinicians—time to listen, to explain and to reassure—then it will have achieved something that extends far beyond efficiency.

Its greatest contribution may not be making medicine faster. It may be making medicine more human.

Stewardship Over Ownership

The future Raymond envisions depends not only on innovation, but on collaboration.

Cancer care has become too complex for any one discipline or any one organisation to advance alone. Progress now relies on clinicians, researchers, nurses, patient advocates, policymakers, industry and professional societies working together, each contributing a different perspective to a shared mission.

Raymond describes that responsibility with a single word:

Stewardship.

"The future of oncology will not be shaped by ownership," she says. *"It will be shaped by stewardship."*

Ownership implies control.

Stewardship implies responsibility to share knowledge, build partnerships and leave the field stronger than we found it.

It is also how she defines leadership.

The leaders she most admires are not remembered because they dominated conversations, but because they encouraged others to contribute.

"The most enduring leaders are remembered not because they had the loudest voices, but because they helped others find theirs."

Those words echo the journey that began with a seven-year-old girl answering questions about her father's death.

The voice she found as a child became a lifelong commitment to helping others be heard.

Now, as oncology enters a new era, Raymond believes its greatest advances will come not only from laboratories or algorithms, but from people willing to learn from one another, work across disciplines and keep patients at the centre of every decision.

That, she believes, is how the next chapter of oncology will be written.

Hope in the Next Generation

Ask Martha Raymond what gives her hope, and she does not begin with technology.

She speaks about people.

She sees a new generation of clinicians, researchers and patient advocates entering oncology with a different mindset—one in which collaboration is expected, patient engagement is increasingly embedded in research and care, and communication is recognised not as an optional skill but as an essential part of medicine.

When Raymond began her journey more than forty years ago, much of this was still aspirational.

Today, it is becoming part of oncology's culture.

"The next generation brings new ideas, new perspectives and a genuine openness to collaboration," she says. *"That gives me tremendous hope for where oncology is going."*

Young advocates often ask Raymond how to sustain themselves emotionally in this work. Her answer rarely changes. *"Never forget your 'why,'"* she tells them. Every programme, every initiative and every conversation should begin with the human experience that first inspired them to care.

Hope, she believes, is built not only through scientific discovery, but through curiosity, trust and a willingness to keep learning—from colleagues, from patients and from one another.

After more than four decades of advocacy, Raymond measures progress not only by new treatments, but by a fundamental shift in how cancer care is delivered. For Raymond, one of the greatest changes she has witnessed is that patients are increasingly recognised not simply as recipients of care, but as partners whose experiences help shape research, policy and clinical practice.

For Raymond, that cultural transformation may prove to be one of oncology's most enduring achievements.

Finding Her Voice

Throughout our conversation, Raymond rarely spoke about personal accomplishments.

Instead, she spoke about the people who inspired her, patients who shared their stories, colleagues who became lifelong partners, and young advocates whose voices continue to strengthen the field.

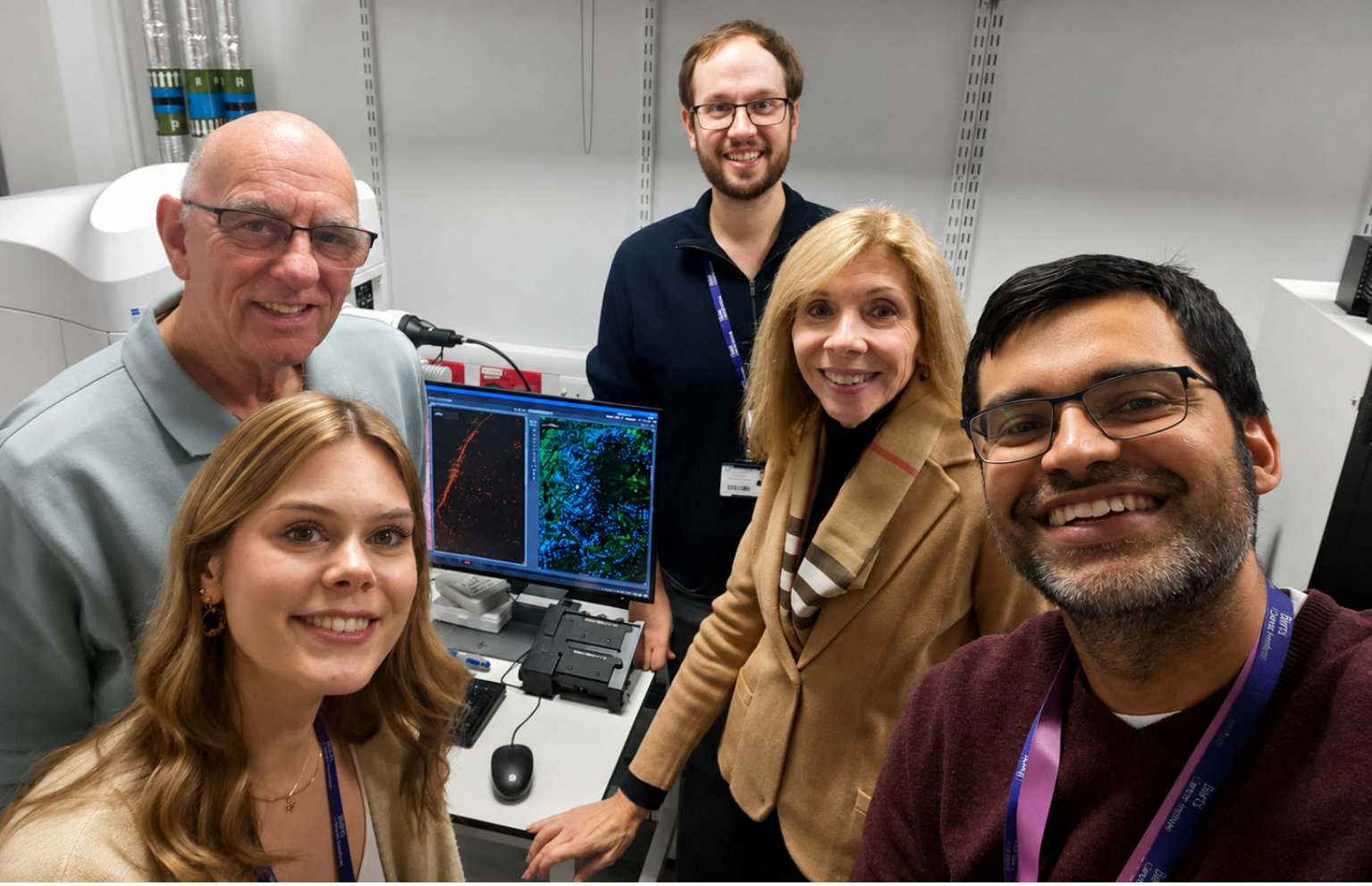
Perhaps that is why the word that best describes her career is not **achievement,** but **connection**.

For more than forty years, she has worked to bridge worlds that once stood apart: patients and professionals, science and lived experience, innovation and compassion. In doing so, she has helped shape a culture in which listening is no longer seen as a courtesy, but as a responsibility.

Nearly half a century has passed since a seven-year-old girl returned to school after losing her father.

"What happened to your father?"

Her classmates asked the question that many adults



Barts Cancer Institute Queen Mary University of London, 2025

were afraid to ask.

Her mother encouraged her to answer.

Those conversations followed by ice cream covered in colourful sprinkles did not erase grief. But they taught her that honesty could replace fear, and that even the hardest conversations become easier when someone is willing to begin them.

Years later, sitting beside her mother's hospital bed, she learned a second lesson.

Treatment may come to an end. Care does not.

Everything that followed grew from those two experiences.

The little girl who learned to speak openly about cancer became an advocate for patients around the world. The daughter who searched for guidance after treatment ended helped oncology recognise that lived experience is a form of expertise. And the woman who found her own voice spent the next four decades helping others ensure theirs were heard.

Oncology will continue to evolve. New therapies will emerge. Artificial intelligence will reshape clinical practice. Yet Martha Raymond believes progress will always depend on something far older than technology: the willingness to listen.

Because patients never lacked a voice. ***Medicine simply had to learn to hear it.***

About the Author

Knarik Arakelyan, PhD, is a psychologist and communications professional with over 14 years of experience in public relations, health communication, and public awareness campaigns. She is currently the Managing Editor of "CancerWorld" magazine, Head of the "OncoDaily TV," and serves as PR and Communications Officer at "EMERTÉ" Clinic.

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The Cost of Silence Has Been Death

By Knarik Arakelyan

After surviving cervical cancer at 25, Tamika Felder transformed personal tragedy into a global movement. In this CancerWorld interview, she reflects on fear, stigma, infertility, survivorship, advocacy, and why the world already has everything it needs to eliminate one of the few cancers we know how to prevent.

There is one moment during our conversation that catches Tamika Felder by surprise.

She has spoken publicly about cervical cancer for more than two decades. She has addressed audiences at the FDA, the G20, and the World Economic Forum in Davos. She has stood before policymakers, researchers, clinicians, and thousands of patients around the world.

But when she learns that another cervical cancer survivor found hope through her advocacy, her voice begins to break.

"That literally makes me want to cry," she says, pausing for a moment.

"Growing up, this is not what I imagined for my life. I didn't want to be the person who talked about cervical cancer. But if along the way I can impact people like Karen, then it's worth it."

That moment says everything about Tamika Felder.

Diagnosed with cervical cancer at the age of 25, she survived a disease that today is largely preventable. What followed was not only recovery, but also transformation. Instead of leaving cancer behind, she chose to confront the silence surrounding it—challenging stigma, advocating for HPV vaccination and screening.

Today, as Founder and Chief Visionary of Cervivor, Inc., she is one of the world's leading voices in cervical cancer advocacy. Yet beneath the international recognition remains the same woman who remembers exactly what it felt like to hear the words: *"You have cancer."*

In this conversation with CancerWorld, Felder reflects on fear, faith, infertility, prevention, survivorship, and why eliminating cervical cancer is no longer a scientific challenge, but a question of education, political will, and compassion.

Growing Up with Purpose

"My parents, who are now my angels, were incredible people. They poured so much love into my siblings and me. Education was always important in our family, but just as important was learning how to be a good human being. Those are the values that have stayed with me throughout my life."

Felder smiles as she speaks about her childhood in South Carolina. Long before advocacy became her life's work, her parents taught her something that would ultimately shape every decision she made: knowledge matters, but kindness matters just as much.

Tamika Felder with her parents and siblings

"I also believe that every stage of life should teach you something. Whether it's something big or something small, there should always be something new to learn. At the same time, there are parts of ourselves that we leave behind as we grow older."

"I turned 51 last month, so I'm now in my sixth decade of life. Sometimes I think about the different versions of myself that belonged to earlier decades. What parts of them remain? What eventually becomes your legacy?"

"I hope my legacy is really about the lives I've helped save. I hope people remember that there was a part of me that simply wanted to make a difference."

After graduating from college, she moved to Maryland, just outside Washington, D.C., to pursue her dream of becoming a broadcast journalist.

Everything seemed to be unfolding exactly as she had imagined.

"And then life kind of threw me a curveball called cervical cancer."

"I Thought I Was Going to Die."

More than twenty-five years later, some memories are as vivid as if they happened yesterday.

"People talk about chemo brain or chemo fog, and you forget so many things," she says quietly. *"But I clearly remember hearing those words: 'You have cancer.'"*

She remembers the fear.

She remembers being told that although treatment would probably save her life, it would almost certainly cost her the chance to have biological children.

"Even though I wasn't in a rush to have children, it was devastating for me."

"And the truth was, even with my faith, I was so scared that I was going to die. I just wasn't going to make it."
Her diagnosis came in 2001, when cervical cancer was rarely discussed openly.

"In 2001, hearing the words cervical cancer was astonishingly shameful. I felt like a leper. I thought I was the only person who had this disease. Whenever I searched for information, everything I found made it feel even worse."

While attitudes have changed over the past two decades, she believes stigma remains one of the greatest barriers to prevention.

"We've made progress. We really have. But we still have a long way to go."

Cancer had already shaped her family's story. It had taken people she loved.

"My father died of colon cancer the day before my seventeenth birthday. Before my own diagnosis, I had already experienced so many deaths in my family from different kinds of cancer."

"So when I heard those words," she says, *"I truly believed it was going to take me too."*

A Preventable Cancer

Today, Tamika Felder speaks about cervical cancer with remarkable clarity. But there was a time when she couldn't help wondering whether her own diagnosis might have been prevented.

"I don't want to blame myself because I don't want to do that anymore," she says. *"I used to do that."*

"When you're young, you think you're healthy. You think, 'What's going to happen to me?' I know differently now."

Looking back, she knows that routine cervical screening could have detected changes earlier. But she is equally aware that her story reflects larger failures—gaps in education, access, and awareness that continue to affect millions of women around the world.

"When I was younger, we didn't have the HPV vaccine. I didn't even know HPV caused cervical cancer. None of us were talking about it."

She had begun having regular Pap smears when she turned eighteen, as recommended at the time. But after graduating from college and moving to Maryland, life became busy, insurance disappeared, and routine healthcare quietly slipped away.

"I just fell off that routine schedule."

It is a story she has heard countless times since—not because women do not care about their health, but because life gets in the way, healthcare is not always accessible, and prevention can feel less urgent than everything else demanding attention.

For Felder, one lesson has become impossible to ignore.

"We have to do a better job educating people about their bodies."

She believes conversations about cervical cancer should begin long before anyone enters an oncology clinic.

"We need people to understand what the cervix is, where it is, and why screening matters. We don't do a great job talking about sexual health—or even about our intimate health in general."

"It should begin with conversations about menstrual health. That's a natural opportunity to talk about cervical cancer and other important health issues."

"This is where I am now. This is my story. And now this is what I'm doing with it."

From Survivor to Advocate

If surviving cervical cancer changed Tamika Felder's life, it did not immediately change her plans.

"I wanted to never think about it again."

She wanted to move on, rebuild her life, and leave cancer

in the past. But that became impossible.

Not because of the disease itself, but because of what people believed about it.

"I started hearing people say things that just didn't make sense."

Some told her cervical cancer was a disease that only affected women who had *"a lot of sex."* Others described it as the consequence of being promiscuous.

"I remember thinking, 'I'm a good person.'"

"Am I a virgin? No. But I don't think there's anything wrong with not being a virgin."

What troubled her most was not the judgement directed at her.

It was the damage those myths were causing to everyone else.

"The truth is, you can get HPV from one partner or from multiple partners."

Reducing cervical cancer to a moral judgement, she says, only discourages women from seeking information, screening, or treatment.

"The longer we keep this ugliness going, the more people we don't educate and unfortunately, the more people will succumb to cervical cancer."

That realization became a turning point. Her anger gradually transformed into purpose as she recognised that silence was costing lives.

That mission has guided every chapter of her life since—from founding advocacy initiatives and supporting survivors to speaking before governments, international organisations, and healthcare leaders around the world.

Yet despite the global stage, her message has remained remarkably simple.

Education saves lives.

Honest conversations save lives.

And breaking the silence around cervical cancer may be one of the most powerful forms of prevention we have.

During event

The Cost of Silence

For Tamika Felder, one truth has become painfully clear over the past two decades.

The greatest barrier to eliminating cervical cancer is no longer science.

It is silence.

"The cost has been death," she says without hesitation. *"The cost has been death, and it's unfortunate."*

She believes stigma continues to shape how people think about HPV and cervical cancer long before they ever meet a healthcare professional.

"You've already decided what kind of person gets cervical cancer," she says. *"So why would someone want to be screened if they're afraid of being judged? Why would they want to talk about it?"*
For many women, she explains, the assumptions begin

even earlier.

"I've only been with my husband."

"I've already had my children."

"This couldn't happen to me."

"We spend so much time focusing on the virus that people don't understand this is really about a cancer we can actually prevent."

"You're missing an opportunity to tell people that we can protect them from cancer."

For Felder, conversations about HPV must move beyond shame.

Yes, HPV is sexually transmitted.

But reducing cervical cancer to that single fact has distracted generations from what truly matters: education, prevention, and early detection.

She sees the same pattern repeating itself whenever cervical cancer appears in popular culture or public conversations.

People focus on blame. Rarely on prevention.

"I was watching a series on Netflix recently," she recalls. *"It mentioned both HIV and cervical cancer. While everyone was talking about the show, I kept thinking we were missing an opportunity to educate people."*

Instead, old stereotypes resurfaced.

People assumed those affected had somehow brought the disease upon themselves.

"Yes, HPV is sexually transmitted. But human beings are sexual," she says. *"That's exactly why education matters."*

The consequences reach far beyond public perception.

"They stop people from seeking help."

Women experiencing symptoms may delay seeing a doctor because they feel embarrassed.

Others avoid conversations about sexual health altogether.

And some remain silent until their disease has progressed.

"If something is wrong and you're having symptoms," she says, *"people need to feel they can speak to their healthcare provider without shame."*

Listening Before It's Too Late

Years of working with survivors have taught Felder that another barrier often appears inside the healthcare system itself.

Too many women speak. Too few feel heard.

"I think many patients are proactive. They notice symptoms. They tell someone."

But their concerns are not always taken seriously.

Unexpected bleeding may be dismissed as a difficult menstrual cycle.

Bleeding after intercourse may be attributed to something else.

Persistent symptoms may receive reassuring explanations rather than thorough investigation.

"I think providers have to listen to patients."

They must listen before symptoms are dismissed and precious months are lost.

"We have to be proactive with caring for people so that, if they do have cancer, it's caught early—not later."

No technological advance can replace the moment when a healthcare professional truly hears a patient's concerns.

Surviving Is Only the Beginning

Medical progress has transformed cervical cancer outcomes.

More women than ever are surviving.

For Felder, that success creates a new responsibility.

"We're living longer now."

She smiles as she says it.

"But we have to listen to survivors."

Because survival, she explains, is not the end of the story.

"When we listen to survivors, we learn."

We learn what life after cancer really looks like—the physical, emotional and quality-of-life challenges survivors continue to face.

"What secondary issues are people dealing with after diagnosis? What challenges are they facing after treatment?"

These experiences help improve care for future generations.

Even as the world works toward eliminating cervical cancer altogether, survivors still have much to teach.

"Until we eliminate cervical cancer," she says, *"we have to keep learning from patients and from survivors."*

Because every survivor carries lessons that science alone cannot measure.

And every story has the power to make care better for the person who comes next.

When we listen to survivors, we learn not only how to treat cancer, but how to help people live beyond it.

Tamika Felder

A World Without Cervical Cancer Is Possible

For the first time in history, the elimination of cervical cancer is no longer an aspiration—it is an achievable goal.

That gives Tamika Felder hope.

"I'm very excited about it," she says. *"But we're not moving fast enough."*

She understands the obstacles. Political will, funding, unequal access to healthcare, and persistent stigma continue to slow progress. Yet she refuses to believe those challenges are insurmountable.

"We're all still moving forward toward that goal. We see that it can be done."

She points to countries already demonstrating what is possible.

"We see it with Rwanda. We see it with Australia. We see it with Scotland. We see it with Denmark."

"There is no reason anyone in this world should die from cervical cancer. We have the tools."

Turning Prevention into Reality

Among those tools, vaccination remains one of the most powerful.

But only if everyone has access.

"We have to be gender-neutral when we vaccinate our young people. Boys and girls both need to be vaccinated."

"We have to make sure people are educated. We have to make sure vaccines are available. We have to make sure there are healthcare professionals who can deliver them."

"These vaccines are safe. Millions of doses have been given, and we're seeing countries move toward eliminating cervical cancer."

For Felder, prevention is not only a medical issue; it is also a political one.

"We need funding. We need vaccine programmes.We need policies that recognise this isn't a 'one day' issue. This is a right now issue."

Throughout the conversation, one message returns again and again.

Education.

Not as a slogan.

As the foundation on which prevention, trust, and ultimately elimination depend.

The Legacy She Hopes to Leave

After more than two decades of advocacy, Tamika Felder still measures progress one life at a time.

She believes data can shape policy, but it is patients' stories that inspire change.

"When someone says a woman in Mozambique, the United States, or Canada has cervical cancer, we can show who she is. We can show her life before cancer, what she endured to survive, and what survivorship really looks like."

Too often, she says, people see survival as the end of the story.

"They look at you and say, 'You survived. You're doing great.' But they can't see what cervical cancer has done to me. They don't see the scars."

Some scars are physical.

Others are invisible.

Cervical cancer took away her fertility. It interrupted the broadcasting career she had dreamed of. It took years of her twenties and thirties as she struggled to rebuild her life.

"I love my son so much. He is the best thing that could have happened to me. But I can also mourn the biological child I was never able to have. Those two things can both be true."

Later, when I tell her that another survivor found strength through her advocacy, she pauses. Her eyes fill with tears.

"That literally makes me want to cry," she says softly. *"I never imagined this would be my life. But if my story can help people—not just one person, but future generations—maybe it was worth it."*

When asked what she hopes healthcare professionals will remember, her answer is immediate.

"We should be talking about cervical cancer. We should be talking about all cancers, but this is one of the few we can actually prevent. We have the vaccine. We have screening. We have the tools."

Then she reflects on the legacy she hopes to leave.

"Maybe that I was brave enough to talk about something really difficult. This horrible thing happened to me. But if it could help other people, maybe it was worth it."

They are the former students now guiding cancer programmes of their own, the organisations that continue to grow, and the patients whose lives were altered by better care.

"The deepest sense of fulfillment comes from seeing the lasting impact of what you have done on people, institutions, and society."

Rapid Fire

Three words that describe you?
Happy. Alive. Determined.

One habit you can't live without?
Reflection. It helps with clarity and progress in one's life.

One book that changed your life?
Who Moved My Cheese?

One person who inspires you?
My mom. She had a tough life, and she made it through.

A lesson cancer taught you that nothing else could?
I knew I was tough, but I didn't realize how resilient I could be or how I would always find a way through difficult times.

One message to every woman reading this interview?
Cervical cancer is preventable. Don't let it happen to you.

One message to your 25-year-old self?
You're going to survive, and you're going to be okay.

What does survivorship mean to you?
The ability to continue to live life. A happy epic life.

About the Author

Knarik Arakelyan, PhD, is a psychologist and communications professional with over 14 years of experience in public relations, health communication, and public awareness campaigns. She is currently the Managing Editor of "CancerWorld" magazine, Head of the "OncoDaily TV," and serves as PR and Communications Officer at "EMERTÉ" Clinic.

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Science in Action

Sixteen Years Clear, Then it Came Back

A Husband's Reckoning with Cancer, Faith, and the Ordinary Courage of Carrying On

By Dr Michael Janse van Rensburg

Michael and Lynn

For sixteen years, cancer became something we spoke about in the past tense.

My wife, Lynn, had survived a rare smooth-muscle cancer (leiomyosarcoma) after two operations in 2009. Year after year the scans came back clear. Gradually, we stopped living from appointment to appointment. We raised two sons. We built careers. We argued over ordinary things, planned family holidays, celebrated birthdays, and quietly assumed that cancer belonged to another chapter of our lives. Looking back, I realise those ordinary years were never ordinary at all. They were a gift.

When Cancer Returned

Then, in October 2025, Lynn developed what seemed like an unremarkable cough. Two courses of antibiotics made no difference. A CT scan, ordered largely to rule out anything serious, revealed a pulmonary embolism and two large masses in her left lung. Within days she was in intensive care. A biopsy confirmed what we had scarcely dared to imagine: the cancer had returned. This time it was metastatic, stage 4. The disease we thought we had left behind had found us again.

Our oncologist outlined the treatment options and their likely outcomes. For a short while, a targeted therapy appeared to offer hope, but the cancer progressed aggressively. After a second bout of pneumonia, one of the tumours grew to the size of a tennis ball within weeks. We were told Lynn likely had only weeks to live.

That conversation took place a few months ago. Lynn is still here. She now depends on oxygen twenty-four hours a day. A couple of months ago, after much discussion, we decided together to try chemotherapy, fully aware that the chances of success are limited and the risks are considerable. When the alternative is to stop trying, hope often looks less like certainty and more like choosing the next step anyway.

Telling Our Sons

Some conversations change a family forever. Our sons, TJ and Daniel, were twelve and nine when we first told them their mother had cancer. We sat together in our lounge, trying to explain something no child should ever have to understand.

Months later, after the devastating ‘weeks’ prognosis, we had to tell them again.

This time the conversation happened in a hospital room. Our sons climbed onto their mother’s bed and held her.

TJ and Daniel, the sons of Michael and Lynn

People sometimes ask about how we told our children, and if we think it was the right thing to do to tell them their mother is dying. The truth is, there is no right way. We chose honesty over false reassurance. Not because honesty hurts less, but because we wanted fear to enter our home through our voices, not through silence or lies

What Theology Could Not Teach Me

Only about a year before Lynn’s cancer returned, I had completed a doctorate in theology examining in part one of humanity’s oldest questions: how a good and all-powerful God can coexist with suffering. Somewhere in that thesis I mentioned cancer almost in passing, simply as an illustration of suffering. I had no idea I was writing about my own future.

The verses I once reached for so confidently suddenly felt too small for an intensive care unit. I found myself sitting on the floor beside Lynn’s hospital bed with nothing meaningful to say. Instead, I found comfort

elsewhere.

In the shortest verse in the Bible, *"Jesus wept."* Those two words gave me permission to grieve without believing that my faith had failed.

I also found myself returning repeatedly to Psalm 88 and what theologians call Holy Saturday—the day between the crucifixion and the resurrection, when no one yet knows Sunday is coming. That is where we have lived. Not in despair. Not in certainty. Simply in the difficult space between devastating news and whatever comes next.

Learning to Write Instead of Explain

Late at night, after the boys had gone to bed, our home would finally become quiet. Almost quiet. The oxygen concentrator in the passage never stopped humming. Its steady rhythm became the soundtrack of our evenings.

I would sit at the dining room table and write. Not because writing changed anything. Not because I expected anyone else to read the pages. I wrote because I was trying to make sense of things and I was afraid of forgetting. I was afraid of forgetting the conversations, the prayers, the fear, the unexpected laughter, and the extraordinary kindness of nurses, doctors, friends, and strangers who quietly carried pieces of our burden. Over time those writings became a memoir: *Where Are You, God? My Wife Has Cancer.*

The book does not attempt to explain suffering or offer easy answers. It is simply a raw and honest story of one family learning to live inside uncertainty. It follows our marriage from our wedding day through the return of cancer, the difficult conversations with our sons, and the ongoing reality of living with a future we cannot predict.

If there is one thing this journey has taught me, it is that faith and honest grief are not opposites. Sometimes faith is simply refusing to pretend everything is okay.

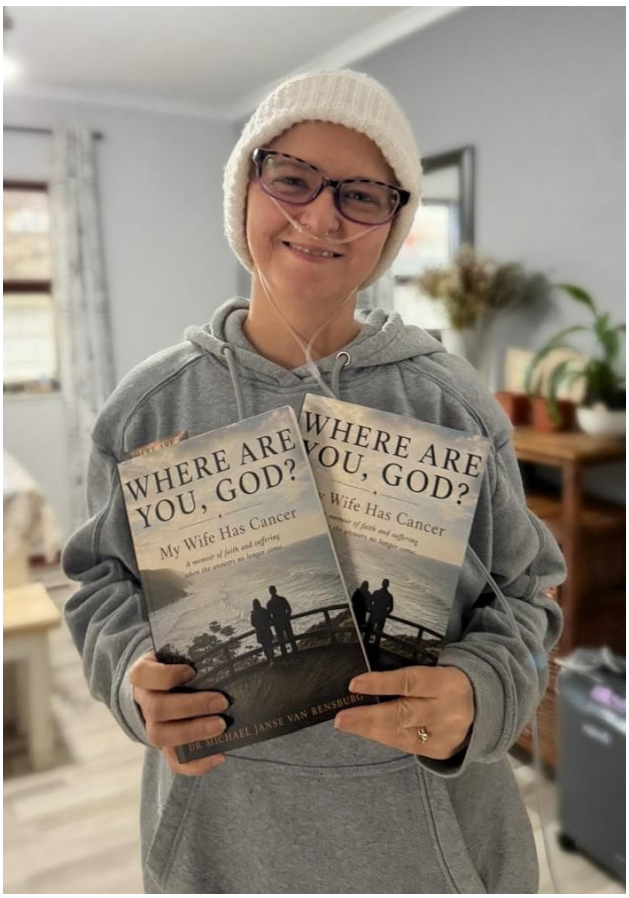
Sometimes hope is accepting that today is enough. Sometimes the greatest gift we can offer one another is not an explanation, but our presence.

Our story is still unfolding.

Lynn is still here.

We still do not know what tomorrow will bring.

If sharing our story helps even one patient, caregiver, husband, wife, or frightened child feel a little less alone, then writing it has been worthwhile.



Lynn during treatment

About the Author

Dr Michael Janse van Rensburg lives in South Africa with his wife, Lynn, and their two sons, TJ and Daniel. In 2024 he completed a doctorate in theology exploring the problem of suffering—a subject that became profoundly personal when Lynn's cancer returned after sixteen years. His memoir, Where Are You, God? My Wife Has Cancer, grew from notes written during his family's ongoing journey with advanced cancer.

Learn more
https://oncodaily.com/project/community-oncology-global-congress-2026

Cancer Patients Europe Annual Meeting, 2026 | Credits: Elza Lőw (Event and Conference Photographer, Graphic Designer)

Protecting Europe's Cancer Care Model in a Changing World

Key discussions and priorities from the 2026 Cancer Patients Europe Annual Meeting

By Cancer Patients Europe

As Europe faces growing pressure on its healthcare systems, Cancer Patients Europe (CPE) brought together patient representatives, policymakers, clinicians, researchers, and industry leaders in Brussels from 24 to 26 June 2026 to examine one central question: how can Europe protect and strengthen equitable cancer care in an increasingly complex political and economic landscape?

While the discussions covered diverse topics—from regional governance and clinical trials to innovation and survivorship—they all pointed to the same conclusion: equitable cancer care depends not only on scientific progress, but also on political leadership, regional cooperation, and meaningful patient involvement.

Regions at the Heart of Europe's Cancer Care

The Annual Meeting opened with an institutional event hosted by the European Committee of the Regions, dedicated to "The Role of Regions in Safeguarding Equitable Care." The session highlighted the growing importance of regional authorities in ensuring that European health policies translate into tangible improvements for patients.

Europe's cancer care model, grounded in solidarity, equity, and universality, is under increasing pressure from economic constraints, workforce shortages, and territorial disparities. As Europe's Beating Cancer Plan moves from policy development to implementation, the focus turned to how regional leadership can bridge the gap between European ambitions and patients' everyday realities.

The event opened with welcoming remarks from Francisco Lozano (Chair of the Board, Cancer Patients Europe) and Dorota Tomalak (Deputy Head of Unit, European Committee of the Regions), followed by a keynote address from the event's host, Birgitta Sacredeus (Representative, Dalarna Region, Sweden), who underlined the essential role of regions in delivering equitable cancer care across Europe.

Tackling Cancer Inequalities

The challenge of regional disparities was explored further through evidence presented by *Stefano Giordani* (Scientific Director, Onconauti), who highlighted the inequalities experienced by cancer patients across Italy. Onconauti, a Bologna-based association providing integrated oncology rehabilitation in several Italian regions, illustrated how differences in specialist availability and access to innovative therapies continue to divide the country, reflecting broader inequalities seen across Europe.

These findings provided the foundation for a panel discussion bringing together *MEP Nicolás González Casares (S&D, Spain), MEP Elena Nevado del Campo (EPP, Spain), Marco Di Donato (EUREGHA), Anita Granero (Oscar's Angels, CPE Board Member), and Stefano Giordani.*

The discussion moved beyond healthcare delivery. It examined how socioeconomic conditions, workforce shortages, delayed diagnosis, and territorial disparities continue to shape cancer outcomes across Europe. Particular attention was given to the ongoing negotiations on the EU's next Multiannual Financial Framework (2028–2034). While welcoming the proposed increase in the health budget, *MEPs González Casares and Nevado del Campo* stressed the importance of preserving a strong role for regions in deciding how European funding is allocated. They also expressed concern that the European Commission's proposal for the next long-term budget could weaken regional decision-making, calling for this issue to be addressed during the European Parliament's negotiations.

Despite the challenges outlined, the discussion concluded on a constructive note. Speakers agreed that cancer inequalities are not inevitable but stem from policy choices, implementation gaps, and investment decisions. They called for stronger collaboration between regional authorities, European institutions, and patient organisations, while emphasising that patients should be recognised not merely as consultees but as equal partners in shaping cancer policy at every level of governance.

Turning Policy into Practice

The discussions on regional inequalities naturally led to a broader question: how can Europe turn ambitious cancer policies into meaningful improvements for patients? This question shaped the Annual Conference, held under the theme ***"Europe's Cancer Care Model: From Policy to Action."***

Against a backdrop of geopolitical uncertainty and evolving European health policy, participants explored

how Europe can translate political commitments into measurable improvements in cancer care. Expert presentations and interactive discussions identified practical priorities that will shape Cancer Patients Europe's future advocacy work.

Cancer Patients Europe Annual Meeting, 2026 | Credits: Elza Lőw (Event and Conference Photographer, Graphic Designer)

From Priorities to Action

Three priorities emerged repeatedly throughout the meeting: improving access to clinical trials, ensuring equitable access to care, and making personalised medicine a reality for every patient.

One of the strongest calls for action focused on clinical trials. The greatest barriers to participation are not scientific, but practical: limited awareness, insufficient personalisation, fragmented information, and unequal access across borders. Participants encouraged Cancer Patients Europe to strengthen patient information on ongoing clinical trials, contribute to shaping the forthcoming Biotech Act, and advocate for policies that facilitate cross-border participation in research.

Equitable access to cancer care emerged as another major priority. Access guaranteed by legislation does not always translate into timely or equal access in practice. Differences in pricing, reimbursement, healthcare resources, and national policies continue to create unequal outcomes across Member States. Among the recommendations were stronger European cooperation in health policy, a coordinated response to the US Most Favoured Nation pricing policy, and broader recognition of supportive care, including mental health services and return-to-work programmes, as essential components of comprehensive cancer care.

The discussions also reinforced that personalised cancer care extends well beyond genomic testing. Shared decision-making remains difficult to implement in routine clinical practice, despite broad recognition of its importance. Greater education for both patients and healthcare professionals, integration of shared decision-making into medical training, and wider adoption of successful models already in practice were identified as important steps towards more patient-centred care.

Achieving these goals, however, will depend not only on policy reform but also on Europe's ability to turn scientific innovation into routine clinical practice.

Cancer Patients Europe Annual Meeting, 2026 | Credits: Elza Lőw (Event and Conference Photographer, Graphic Designer)

Driving Innovation into Practice

Innovation alone is not enough. Speakers argued that Europe's next challenge is not developing new technologies, but ensuring they can be implemented consistently across healthcare systems.

The VOICE PM examined current barriers and best practices for involving patients in personalised medicine research, translating these experiences into recommendations for future policy and research.

A roundtable on Unlocking Cancer Innovation in Europe focused on the conditions needed to accelerate innovation, including sustainable investment, evidence generation, and health system readiness.

Another important focus was Mission Early, which argued that Europe already possesses much of the evidence and policy framework needed to improve early detection and treatment. The remaining challenge is consistent implementation and reducing inequalities in access to timely diagnosis and care.

Life After Cancer: From Survival to Equal Rights

Survivorship was another major focus of the meeting, particularly the growing European movement to establish a **Right to Be Forgotten** for cancer survivors. Despite growing momentum, only ten European countries had adopted binding legislation at the time of the meeting, highlighting the persistent inequalities in legal protection across the continent.

In his keynote address, *Hon. Robert Troy,* Ireland's Minister of State with special responsibility for Financial Services, Credit Unions and Insurance, confirmed that Ireland was on track to introduce Right to Be Forgotten legislation—a commitment fulfilled only weeks later when the Irish Oireachtas formally adopted the law.

Dr Françoise Meunier (EDACS), cancer survivor and patient advocate *Elordi Garcia, and Ingrid Krücken* (Europa Donna Luxembourg) emphasised that financial discrimination against cancer survivors is ultimately ***"a matter of dignity."*** Their discussion reinforced a shared conclusion: extending these protections across Europe is not primarily a financial challenge, but a political one.

Taken together, the meeting underscored that delivering Europe's cancer policy ambitions will require stronger patient involvement, more equitable access throughout the care pathway, and continued political commitment to removing the inequalities that patients continue to face.

Strengthening the Patient Voice

Beyond the policy discussions, the Annual Meeting also reaffirmed the importance of a strong and united patient community. During the CPE Annual General Assembly, member organisations reviewed the organisation's progress, discussed strategic priorities, and helped shape its future direction.

The Assembly reinforced Cancer Patients Europe's role as a patient-led organisation committed to ensuring that the experiences and perspectives of people affected by cancer continue to inform healthcare policy, research, and advocacy across Europe.

Looking Ahead

Across three days of discussion, a consistent message emerged: protecting Europe's cancer care model requires more than scientific innovation or ambitious policy alone. Delivering equitable cancer care depends on sustained political commitment, effective implementation, meaningful patient involvement, and close collaboration between European institutions, regional authorities, healthcare professionals, researchers, and patient organisations.

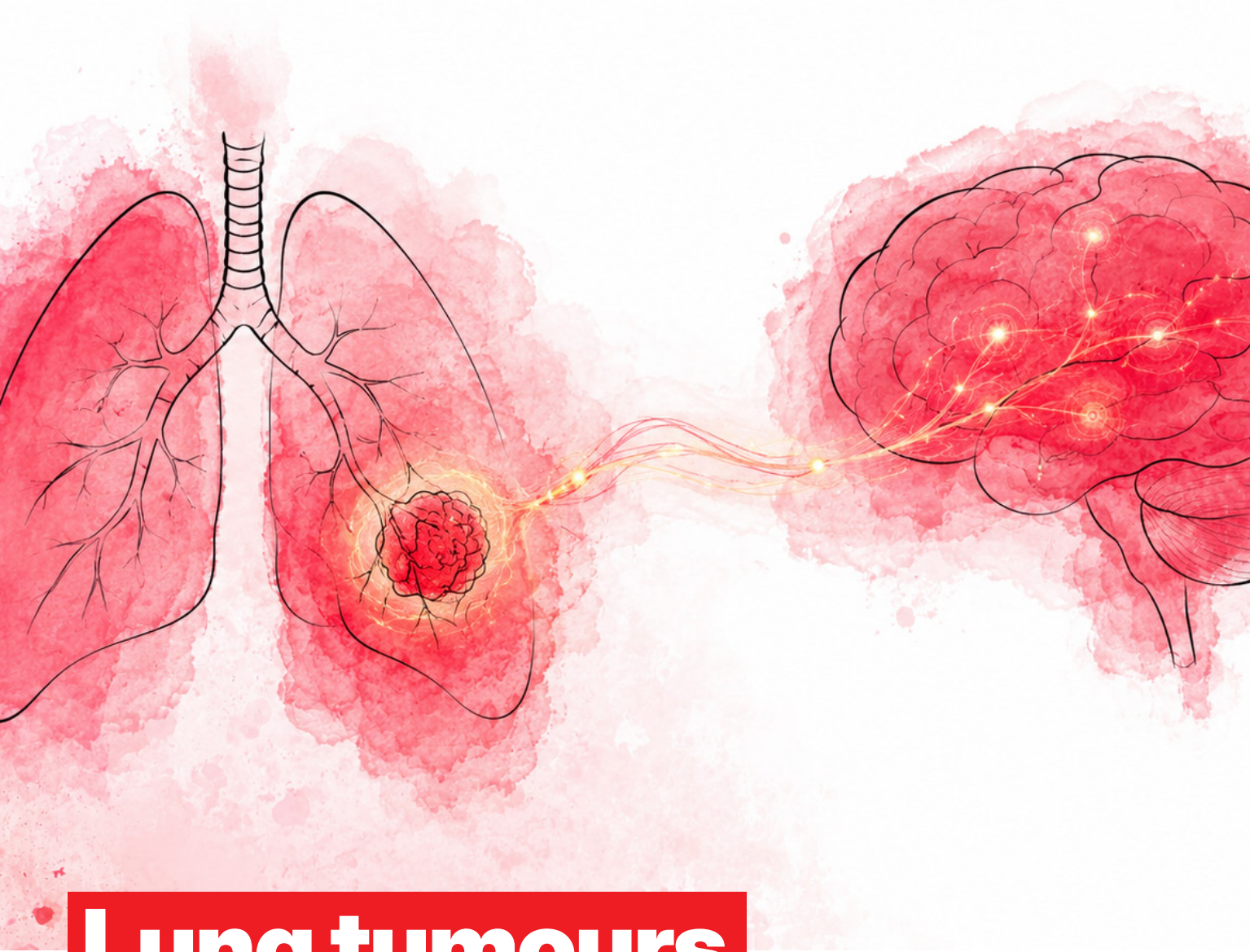
From addressing regional inequalities and expanding access to clinical trials, to advancing personalised care, accelerating innovation, and securing equal rights for cancer survivors, the discussions reflected a shared determination to translate policy into practice.

For Cancer Patients Europe, this work continues beyond the Annual Meeting. The organisation will maintain its advocacy for harmonised **Right to Be Forgotten** legislation across Europe, building on Ireland's recent progress while encouraging other Member States to adopt similar protections. It will also continue contributing to major European policy initiatives, including the forthcoming Biotech Act, ensuring that the patient perspective remains central as future legislation is developed.

Ultimately, the meeting reinforced that protecting Europe's cancer care model is not about preserving existing systems, but ensuring they continue to evolve in response to patients' needs.

Behind every statistic, policy proposal, or healthcare reform are individuals living with cancer, survivors rebuilding their lives, families providing support, and communities working to ensure that equitable, high-quality cancer care becomes a reality for everyone across Europe.

The next Cancer Patients Europe Annual Meeting will take place on 19–21 May 2027.



Lung tumours found to drive cachexia through direct brain signalling

By Janet Fricker

A mouse model of lung cancer has uncovered a potential new therapeutic strategy for treating cancer cachexia. The study, published in Science on 2 July, found that Lkb1-mutant lung tumours—a common subtype of lung cancer—can communicate directly with the brain through lung sensory neurons. The researchers showed that disrupting this tumour-to-brain signalling by silencing the sensory nerves reduced cachexia. Suppressing production of the lipid signalling molecule prostaglandin E_2 (PGE_2) through dietary intervention delivered similar benefits.

"In our study we've identified peripheral sensory nerves—not just circulating inflammatory factors—as a direct route through which tumours drive cachexia. We also found that PGE_2 acts as the local messenger, while dietary fat supplies the raw material needed to make it," senior author Thales Papagiannakopoulos tells CancerWorld.

"Together, these findings point to three potential ways to intervene with cachexia: targeting the nerves, blocking the signalling pathway with drugs, or modifying diet."

The study, he says, argues for a fundamental shift in thinking: cachexia should be reframed as a neuro-metabolic syndrome, rather than being regarded as a purely metabolic disorder.

Why Cachexia Matters

Cancer cachexia is a multifactorial syndrome characterised by progressive loss of skeletal muscle, often accompanied by fat loss, that cannot be fully reversed by conventional nutritional support. Affecting around 80% of patients with advanced cancer, it causes profound weakness, fatigue, and reduced tolerance of anticancer treatment, and is estimated to contribute to around 20% of all cancer deaths.

"As development of cachexia is associated with impaired quality of life, decreased tolerance to therapy, and reduced overall survival, there is an urgent need to understand the mechanisms that promote cachexia in translationally relevant animal models to develop effective treatments for this syndrome," write Papagiannakopoulos and colleagues.

Following the Tumour's Signals

To investigate how common genetic mutations influence the development of cachexia, the researchers created three genetically engineered mouse models of lung adenocarcinoma, a subtype of non-small cell lung cancer (NSCLC) in which cachexia is particularly common. They used CRISPR–Cas9, a gene-editing technology that enables scientists to precisely switch off specific genes, to inactivate either **Lkb1, Cdkn2a/2b,** or **p53** in mice with **Kras-**driven lung adenocarcinoma, thereby modelling the three major genetic subtypes of the disease.

Traditional cachexia models typically use tumours implanted beneath the skin, rather than in their natural environment, and often at sizes unlike those seen in patients.

"We used autochthonous lung cancer models, in which tumours develop naturally in the lung at clinically relevant sizes while preserving the local nerve supply. This enabled us to ask a question previous models couldn't: does the tumour communicate directly with neighbouring nerves?" says Papagiannakopoulos, who conducted the research while at the New York University (NYU) Grossman School of Medicine. He will move to the Salk Institute for Biological Studies in September.

The team found that only the **Lkb1**-mutant mice experienced cachexia. Since this variant did not produce substantially larger tumours than the other subtypes, they proposed that **Lkb1**-deficient tumours might be producing something that the other tumour types were not.

Hypothesising that reduced food intake was responsible for the weight loss, the researchers fed **Lkb1**-deficient mice a high-fat diet to investigate whether this would rescue their caloric deficit. For comparison, the other two mouse models were also given high-fat diets and quickly gained weight.

The researchers were surprised by the results.

Rather than correcting their energy deficit, mice with inactive Lkb1 in their tumours ate even less, lost more weight, and died sooner than those on the standard diet. Increased brainstem activation was also observed within days of starting the high-fat diet.

Instead of reversing cachexia, the findings suggested that dietary fat amplified a pathological signalling loop that exacerbated the syndrome.

A Direct Route to the Brain

To understand how high-fat diets might be exacerbating cachexia, the investigators collected fluid from the tumour-bearing lungs of mice with Lkb1-deficient tumours and measured levels of signalling molecules that they believed might be driving the syndrome.

Compared with Lkb1-deficient mice on a normal diet, those fed a high-fat diet had much higher levels of PGE_2—a signalling molecule known to amplify inflammation—as well as increased infiltration of immune cells into the lungs.

Since PGE_2 was elevated only in lung fluid and not in the bloodstream, the team hypothesised that it was exerting its cachexia-causing effects locally within the lungs.

At this point, Papagiannakopoulos recalled a 2023 Nature study by Stephen Liberles and colleagues showing that influenza infection triggers a dedicated nerve pathway from the upper airway to the brain. In that study, PGE_2 activated sensory neurons that induced sickness behaviours such as loss of appetite, lethargy, and reduced activity. Blocking this pathway reduced these symptoms and improved early survival without preventing infection, revealing a previously unrecognised mechanism through which the nervous and immune systems communicate during respiratory viral illness.

"We reasoned that if a virus can hijack this lung-to-brain sensory pathway, a tumour growing in the same tissue might exploit it too. That reframed the question away from blood-borne inflammatory factors, which is where the field had been looking, and towards local tumour–nerve interaction," says Papagiannakopoulos.

To investigate the role of sensory neurons, Papagiannakopoulos and colleagues used two complementary approaches: surgically disrupting the vagus nerve and chemogenetically silencing vagal sensory neurons that innervate the lungs.

Both interventions restored feeding behaviour in tumour-bearing mice.

When the team genetically modified mice to prevent PGE_2 production, the animals no longer developed cachexia. Similarly, in smaller studies, mice treated with aspirin or ibuprofen—drugs that inhibit the enzymes required for PGE_2 synthesis—were protected from cachexia.

Interrupting the Pathway

Cachexia could also be prevented through dietary intervention.

PGE_2 is derived from omega-6 fatty acids found in animal fats. By switching mice from a high-fat diet containing animal fat to one containing only omega-3 fatty acids, the body's ability to produce PGE_2 was limited. Without sufficient PGE_2, the tumours could no longer use the signalling molecule to communicate with the nervous system and brain to drive cachexia.

"Our study doesn't overturn the cytokine model—circulating inflammatory factors clearly matter in many contexts but it adds a parallel axis that the field has largely overlooked: local, anatomically restricted signalling between tumours and nearby sensory nerves that can independently drive systemic sickness behaviour," says Papagiannakopoulos.

"For lung tumours in particular, which lie adjacent to a dense sensory nerve network, this local pathway

should be considered alongside, not instead of, the systemic inflammatory one."

Towards New Therapeutic Strategies

The findings point to three potential therapeutic strategies: inhibiting PGE_2 production using inexpensive, already approved cyclooxygenase (COX) inhibitors; reducing the supply of PGE_2 precursors by shifting patients' diets from omega-6-rich fats towards omega-3 fatty acids; and, in the longer term, targeting the lung's sensory nerves through neuromodulation.

"The PGE_2 and dietary approaches are the most immediately actionable because they build on existing drugs and straightforward dietary counselling," says Papagiannakopoulos. "Neuromodulation of the sensory nerve pathway is likely to be the most precise long-term strategy, but we first need a much better understanding of the underlying neural circuits before it becomes clinically feasible."

The study was partly funded by the Cancer Cachexia Action Network (CANCAN), one of the Cancer Grand Challenges teams—a global initiative co-funded by Cancer Research UK and the US National Cancer Institute to tackle the toughest unanswered questions in cancer research.

As part of InteroCANCEption, a recently funded Cancer Grand Challenges team, Papagiannakopoulos is now focused on mapping the neural circuitry that underpins cachexia.

"We want to pinpoint exactly which sensory neuron subtypes and downstream brainstem and hypothalamic circuits are involved. We're also asking whether this same neural circuit contributes to other cancer-associated symptoms beyond appetite loss, such as depression and cognitive impairment."

Proximity to sensory neurons, adds Papagiannakopoulos, is not unique to lung cancer. "Tissues like the gut, pancreas, and liver are also richly innervated by peripheral and vagal sensory afferents, and tumours there are well positioned to exploit the same kind of local signalling. That's a direct, testable prediction, and one we want to follow up on."

A Broader View of Cachexia

In an accompanying commentary, Yetiş Gültekin and Matthew Vander Heiden, both from the Massachusetts Institute of Technology (MIT), write: "Recognising cachexia as a disorder of tumour, organ, and nerve communication rather than as a condition caused by specific circulating factors is also important when considering how to treat it in the context of cancer."

They add that how peripheral sensory neurons decode chemically diverse tumour-derived signals remains unknown and is likely to vary across tumour types and disease stages. Cachexia, they suggest, probably reflects a spectrum of mechanistically distinct but phenotypically convergent states rather than a single biological process.

Nevertheless, they conclude that defining how tumours recruit neural circuits to sustain their own metabolism and reshape host physiology will be important for understanding both cancer and cachexia biology.

About the Author

Janet Fricker is a UK medical writer with an MA in Physiology from the University of Oxford. She is the News Editor of CancerWorld. Janet has worked for the Cancer Drug Development Forum, Cancer Research UK, Lancet Oncology, European Journal of Cancer, Molecular Oncology, Ecancer Medical Science, and European School of Oncology (where she wrote the Oncopaedia sections on breast cancer). She has written for consumer publications including The Times, The Economist, The Daily Mail, The Independent and Marie Claire.

In Memoriam

Dr. Mary Buchanan

(1938–2026)

By CancerWorld

The European cancer community has lost one of its most influential voices for breast cancer advocacy. Dr. Mary Buchanan—physician, advocate, and one of the founding figures of Europa Donna – The European Breast Cancer Coalition—passed away on 18 June 2026.

For more than three decades, Dr Buchanan devoted her career to improving the lives of women and men affected by breast cancer. Those who had the privilege of knowing and working alongside her remember her unwavering dedication to Europa Donna, her remarkable energy for helping others, and her steadfast commitment to ensuring that the needs of people affected by breast cancer remained at the centre of healthcare, education, and public policy.

Building a European Movement for Breast Cancer Advocacy

Dr Buchanan was instrumental in establishing Europa Donna in 1993 alongside the late Gloria Freilich. Together, they laid the foundations for what would become Europe's leading breast cancer advocacy coalition.

From 2000 to 2003, Dr Buchanan served as President of Europa Donna, representing the Coalition in the European Parliament and helping strengthen its position as a leading voice for breast cancer advocacy across Europe. She also co-chaired the European Breast Cancer Conferences together with EUSOMA and EORTC, fostering collaboration between clinicians, researchers, and patient advocates.

Her presidency marked a period of significant growth for the organisation. Driven by her vision and commitment, Europa Donna expanded its reach across Europe and strengthened partnerships with numerous organisations and institutions, including the European Cancer League, the International Union Against Cancer, the Oncology Centre Antwerp, and the Breast International Group (BIG), among many others. Today, the Coalition brings together organisations from 47 countries, a testament to the foundations established during those formative years.

Dr Buchanan was equally committed to empowering

patient advocates. At the 5th Europa Donna Pan-European Conference, she helped inaugurate the Coalition's first pilot advocacy training programme.

Alongside sessions on diagnosis and treatment, participants attended workshops designed to develop effective communication skills, strengthen engagement with the media, improve dialogue with healthcare professionals, and build lobbying techniques for formal presentations to local governments. What began as a pilot initiative has since evolved into Europa Donna's established annual advocacy training course in Milan, continuing to prepare new generations of advocates across Europe.

In recognition of her outstanding contribution to women's health and advocacy, Dr. Buchanan received the European Woman of Achievement Award from the European Union of Women (UK) in 2001.

A Career Dedicated to Prevention, Education and Women's Health

Dr Mary Buchanan, MRCS, LRCP, DFSRH, worked in general medical practice from 1964 to 1989, with a particular interest in the health of women and adolescents. She was responsible for the Well Woman Clinic, the Adolescent Clinic, and the Cervical Screening Clinic, where she established cervical and breast screening programmes. Throughout her medical career, she remained committed to prevention, believing that health education, early detection, and screening were fundamental to reducing the burden of cancer.

Her special interest in women's cancers led her to hold numerous leadership positions throughout her distinguished career. She served as Chairman of the Women's Nationwide Cancer Control Campaign, advocating health education programmes for the prevention, early detection, and screening of women's cancers. She also chaired the Cancer Education Group of Great Britain and Ireland and served as the UK's National Representative to the European Commission's Europe Against Cancer Programme.

In 1997, Dr. Buchanan was appointed by the UK's Chief Medical Officer to the Cervical Screening Action Group to review all aspects of cervical screening. Later, she became a Member of the International Affairs Committee of the American Society of Clinical Oncology (ASCO), where she was recognised as an Emeritus Member in 2011.

Beyond her work in oncology, Dr. Buchanan remained deeply involved with a number of voluntary organisations. She was a Life Fellow of the Royal Society of Medicine and served as Chairman of the Soroptimist International Convention in 1991. Through Soroptimist International, she also became involved with the World Health Organization, further advancing women's health on the international stage.

An Enduring Legacy

Dr Buchanan was married to Dr John Scott Buchanan, JP, a physicist, who passed away in August 2022.

She will be remembered as a kind, inspiring, and formidable woman whose influence reached far beyond the organisations she served. Throughout her career, she championed prevention, education, screening, and patient advocacy, helping shape a stronger and more united breast cancer community across Europe.

The organisation she helped establish more than three decades ago continues to flourish. Through D. Buchanan's vision, leadership, and tireless dedication, Europa Donna's voice continues to grow, ensuring that the needs of women and men affected by breast cancer remain at the centre of advocacy, research, healthcare policy, and clinical care.

CancerWorld extends its deepest condolences to Dr Buchanan's family, friends, colleagues, and the entire Europa Donna community. Her legacy lives on through the generations of advocates she inspired, the partnerships she forged, and the enduring movement she helped build—one that continues to improve the lives of people affected by breast cancer across Europe.

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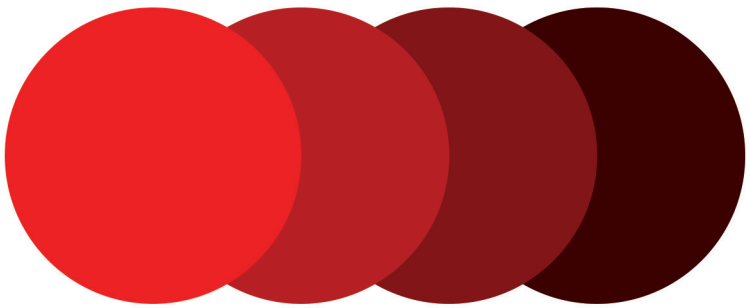
CANCER WORLD

Turning Pain into **Purpose**

Gloria Okwu



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Gloria Okwu

Turning Pain into Purpose

By Gevorg Tamamyan

When Gloria Chiniere Okwu discovered a lump in her left breast in 2016, she could not have imagined that the diagnosis would eventually make her one of the most influential patient advocates in Nigeria.

Today, Gloria is a cancer survivor, patient navigator, and advocate who spends her days helping patients navigate a journey she once faced alone. But her path to advocacy was neither planned nor straightforward.

"It happened by accident after my diagnosis in March 2017," she recalls.

The diagnosis came after months of scans, mammograms, and ultimately a biopsy confirming breast cancer. She underwent a mastectomy almost immediately.

What followed, however, would shape the rest of her life.

Fear, Misinformation, and Isolation

After surgery, Gloria was advised to undergo chemotherapy and radiotherapy. She refused.

"I was told chemo could kill me," she says. *"And so I was afraid of chemo."*

There were financial barriers as well. Fresh out of university, she could not afford treatment. The mastectomy became the end of her treatment plan.

For a while. Sixteen months later, the cancer returned. New tumors appeared on her chest wall.

Again, doctors recommended chemotherapy and radiotherapy. Again, she refused.

Looking back, Gloria says one of the biggest problems was not the disease itself—it was isolation.

"I didn't know anyone that could encourage me. I had not seen a cancer survivor."

The one survivor she met offered little hope.

"Talking to her caused me grief instead of relief."

Without guidance, she found herself making decisions alone.

"It was just me in my world, making all the decisions, making all the mistakes."

"Asking myself if I was in the right place"

Desperate for alternatives, Gloria followed her aunt, who was also battling cancer, into the world of herbal remedies.

Together they sought treatment from a local healer.

Then tragedy struck. Three months later, her aunt died.

"That was a wake-up call for me to start asking myself if I was in the right place."

As she reflected on her experience, she began noticing serious gaps in the care she had received outside the medical system.

Several tumors had been removed from her chest wall, but none had been sent for pathology.

"They don't even know what a biopsy is and do not have the facility for it."

The realization forced her to reconsider everything.

She returned to the hospital and finally agreed to chemotherapy.

"I made up my mind to do chemo, even though I was told it would kill me."

The decision came exactly two years after her mastectomy.

Becoming the Person She Needed

During treatment, Gloria had an important realization.

If she had struggled so much to find reliable information, support, and hope, thousands of others were probably facing the same challenges.

"I understood what some other patients might be

going through—not seeing patients like them to talk to, not knowing whom to advise them."

She decided to share her story publicly.

"I was going to be a relatable face."

She began posting on social media, openly discussing her diagnosis, treatment, fears, and lessons learned.

"I was going to share a relatable story so that people could see hope, could talk to me, share their burdens, and make better decisions."

That decision marked the beginning of her advocacy journey.

Making Sure Nobody Walks Alone

Today, Gloria's work centers around a simple philosophy: ***"Nobody walks alone."***

As a patient navigator and advocate, she provides peer support, psychosocial support, and practical guidance for patients and families.

"Because I have lived the experience, I understand a lot of the challenges cancer patients face."

She speaks frequently at conferences, community events, and awareness campaigns across Nigeria.

Prevention and early detection remain central to her mission.

"If I had the information I have now in 2017, I would have acted faster."

She believes many patients suffer unnecessarily because of delayed diagnosis, stigma, and lack of awareness.

"When we keep telling these stories, people understand that cancer is like every other disease and people should not be stigmatized because they have cancer."

When a Broken Machine Changes a Life

Gloria's advocacy is not limited to patients. She also speaks openly about health-system failures.

When she was diagnosed, radiotherapy equipment that could have offered breast-conserving treatment was unavailable.

"If there was that machine at the time, I wouldn't have a mastectomy. I wouldn't lose my breast."

For her, the issue is deeply personal.
Every missing machine, every delayed policy, every inaccessible treatment ultimately affects a real human being.

"I keep sharing this story to show our leaders how much they need to do and how much their lack of action can actually cost someone."

Why Survivors Must Speak

Many survivors prefer to leave cancer behind once treatment ends.

Gloria understands that instinct.

Yet she consciously chose another path.

"It is very difficult. It is very, very difficult. But in this case, silence is not golden."

She believes that reducing mortality, stigma, and emotional suffering requires open conversations.

"We must speak about it."

She wants cancer to become something people can discuss without fear.

"We should talk about cancer to the point that everybody becomes comfortable hearing about cancer."

Visibility matters.

"When they are diagnosed, they can easily say, 'I know someone that has cancer that lives in my street, or in my church, or in my office.'"

And then comes hope.

"And because this person is surviving cancer, I can survive."

Her personal philosophy is simple but profound:

"We should turn this pain to gain for other people. That is what makes suffering meaningful."

A Message to Policymakers

When asked what policymakers should prioritize, Gloria's answer is direct.

"There should be access to medicines. There should be universal health coverage."

Cancer treatment remains financially devastating for many Nigerian families.

"More than 65% are multidimensionally poor."

"I don't know how most of us are expected to treat cancer, myself included."

She calls for stronger infrastructure, better financing, and deliberate investments in cancer care.

"There should be deliberate efforts to provide funding for cancer."

A Message to Oncologists

Gloria also has a message for physicians.

First, she recognizes the enormous challenges they face.

"There were less than 90 oncologists" in Nigeria when she last checked.

Many continue leaving the country because of poor working conditions. But she also believes there is room for improvement.

"I would suggest placing a greater emphasis on empathy when interacting with patients."

She still remembers how her diagnosis was delivered.

"It didn't give me hope. It broke me."

For Gloria, communication matters as much as treatment.

"Doctors need to show more empathy, more respect, and more dignity for patients."

She also urges clinicians to listen more carefully.

"There are things we know that a doctor would never know. We live with this disease."

Patients may appear well while experiencing severe symptoms.

"A patient can look very healthy, look very happy, and still be managing pain at a very high level."

The Conversation Around Alternative Medicine

One of the most interesting points Gloria raises concerns alternative medicine.

She believes many patients use herbal remedies, but often hide this information from their doctors.

"They do not report these kinds of issues to the oncologists for fear of being scolded."

She argues that hospitals should create environments where patients can speak honestly.

"Even when patients make mistakes, they should be able to tell an oncologist."

Rather than ignoring these realities, she advocates for research.

"We should start having research to see how some of these medicines, roots, or herbs interact with mainstream treatment."

"There has to be a synergy between doctors and patients."

A Message to Patients

For patients currently facing cancer, Gloria's message is one of hope.

"No matter how bad the story is, there's always hope."

"Stage four, stage three, stage two, stage one—it doesn't matter. There's always hope."

She encourages patients to ask for help, remain connected, and continue living their lives.

"Don't isolate yourself."

"Keep doing what you love."

"Never stop living."

"You had a life before cancer. There is also life while battling cancer."

The Growing Power of Patient Voices

Gloria is encouraged by the growing recognition of patient advocates around the world.

"I am glad that patient voices are being amplified."

Increasingly, patients are being invited into discussions that shape research, policy, and care delivery.

"We are beginning to sit at the table."

Her hope is simple: *"The world could do more for patients so that everybody sits at this table to make decisions."*

For someone who once faced cancer alone, it is a fitting mission.

To ensure that the next patient never has to.

And perhaps that is the essence of Gloria Okwu's work.

Turning pain into purpose.

Turning survival into service.

And making sure nobody walks alone.


“Nobody walks alone.”
Every survivor who shares their story becomes hope for someone facing cancer today.

Oncology Couch

Questions, Answers, and the Space in Between

By Aleksandra Filipović

To patients and oncologists alike:

Are there questions living inside you that you have not been asking out loud?

Could it be that you do not even know what questions to ask?

Are there answers you have arrived at privately but never felt permission to share, for fear they might sound strange, naïve, unscientific, or somehow inappropriate?

Are you still searching for answers outside yourself?

These are the questions that gave birth to this series.

After years in oncology—and years of personal and professional transformation—I have come to believe that while questions and answers both matter, some of the most important moments in medicine happen in the space between them.

The pause before a patient answers. The hesitation before a doctor speaks. The story that almost gets told but doesn't. The sensation in the body that appears before language. The nervous system response is hidden beneath a symptom, a diagnosis, a treatment decision, or a prognosis.

This series is about that space.

It is called Oncology Couch: Questions, Answers, and the Space in Between because every clinical encounter contains far more than what appears in the medical record.

Long before a patient enters the consulting room, they have already arrived carrying an entire lifetime.

Every experience they have lived through has shaped

their nervous system, their biology, their beliefs, and their sense of identity. The same is true of the doctor sitting opposite them.

Patients do not arrive as scans and blood tests.
Doctors do not arrive as degrees and white coats.

Both arrive carrying lives that extend far beyond the consultation room.

Some of those experiences brought an oncologist into medicine.

Others brought a patient into a cancer clinic.

And then the two meet.

A patient walks through hospital corridors lined with wheelchairs and stretchers, hearing snippets of conversations, medical alarms, and the whispered advice of well-meaning strangers. They enter a room illuminated by artificial light, carrying fears about scan results, blood tests, treatment plans, and the life they are desperately trying to continue living.

The oncologist may arrive carrying fifty unanswered emails, multiple deadlines, administrative burdens, and only fifteen minutes for the consultation.

Yet somehow, within that compressed moment, something profoundly human is expected to happen.

More Than a Blood Test and a Scan

One of the most revealing questions in medicine is also one of the simplest.

How are you today?

Most of us ask it automatically.

Few of us are prepared to hear the long version of the answer.

Perhaps that is exactly where healing begins.

Not in the scan. Not in the blood result. Not even in the treatment plan.

But in creating enough safety for a person to tell the truth about what is happening.

My work gradually evolved beyond conventional oncology and into the exploration of nervous-system regulation, neurosomatic intelligence, and whole-health medicine. Readers familiar with my previous CancerWorld profile, "A More Excellent Way", will recognise this journey and the experiences that shaped it.

My own health challenges, my patients, and countless conversations gradually revealed a truth that medicine does not always teach us: treatment and healing are not necessarily the same thing.

Healing requires relationship.

Healing requires safety.

Healing requires meaning.

And all three begin with questions.

"I Hope I Never Need You"

People often say to me, "I hope I never need you."

It is one of the occupational peculiarities of being an oncologist.

People accept your business card with kindness and sincerity, then immediately tell you they hope never to call.

Of course, I would never wish illness upon anyone.

Yet my mother, who is also a breast cancer oncologist, taught me something important. She often says:

"You are not coming to me only when you are unwell. You come so that I can confirm that you are well."

Most people engage with medicine when the house is already on fire.

We wait until something is broken.

Until intervention becomes necessary.

Until symptoms become impossible to ignore.

But what if healthcare could also be a place where wellness is recognised, reflected, strengthened, and sustained?

What if we stopped waiting for catastrophe to grant ourselves permission to pay attention?

Many people tell me they are fine.

Often, they are fine in the way a swan is fine on a lake.

Graceful above the surface. Furiously paddling underneath.

Much of healing begins by helping the whole system settle.

The Nervous System and the Story

People often ask why I place such emphasis on the nervous system.

Because the nervous system and the story are inseparable.

Every experience leaves traces—not only psychologically, but biologically.

For some people, the doorway into healing is storytelling. For others, storytelling feels overwhelming, and practical tools offer a safer place to begin.

Eventually, both pathways meet.

The story shapes the nervous system, just as the nervous system shapes the story.

They are different expressions of the same reality.

This work is not mystical.

It is deeply practical.

It is about understanding why certain symptoms persist, why certain behaviours repeat, why some people find rest impossible, why uncertainty feels unbearable, and why safety can sometimes feel more frightening than stress.

One of the most surprising discoveries in this work is that rest is not always experienced as rest.

For a highly activated nervous system, rest may feel like vulnerability—a gap in protection.

Many people are not afraid of resting because they are lazy; they are afraid because stillness feels unsafe. Understanding this changes everything.

Care Is More Than Chemo

Cancer treatment focuses on the tumour. It should.

Chemotherapy targets cancer. Surgery removes it. Radiation destroys it.

Targeted therapies, immunotherapies, and countless advances in modern oncology save lives every day.

Yet treatment and care are not synonymous. Treatment focuses on the tumour. Care focuses on the person. That distinction matters.

A diagnosis often becomes the centre of gravity around which everything else revolves. Yet the diagnosis itself may be asking us to look deeper.

Not because cancer is caused by psychology.

Not because treatment should be replaced by introspection.

But because illness frequently exposes truths that have long remained hidden.

One of the most powerful questions I have encountered comes from the work of Dr Steve Bierman:

Why now?
Not why me.
Why now?

The question is not asked to assign blame.

It is asked to cultivate curiosity. To create space for reflection.

To wonder whether there are unmet needs, exhausted resources, unspoken truths, or long-neglected parts of ourselves asking for attention.

Sometimes a diagnosis grants people permission to acknowledge needs they have been unable to acknowledge for decades.

The diagnosis is not a gift. But occasionally it reveals where gifts have been missing.

The Power of Words

Medicine often underestimates the biological impact of language.

Yet every oncologist has witnessed words that changed a patient's life.

A prognosis. A diagnosis. A single sentence.

The science of noetic medicine explores something clinicians intuitively know: words are never just information.

Patients enter clinics during moments of vulnerability. They naturally assign authority to those caring for them.

What we say matters. How we say it matters. Tone

matters. Pace matters. Eye contact matters. Presence matters.

Even the question, *"How are you?"*, carries consequences depending on whether it is asked from obligation or genuine curiosity.

Communication is not an accessory to treatment. Communication is part of treatment.

The goal is not merely to deliver information. The goal is to empower healing.

The Questions Patients Rarely Ask

One question I wish more people would ask is:

How good can it get?

Patients are often encouraged to prepare for the worst. To anticipate complications. To expect challenges.

Few are invited to imagine the best possible outcome.

Few ask: "What if it all works out?"

Another question lies beneath many consultations, though it is rarely voiced.

Do I still have permission to live? Can I travel? Can I fall in love? Can I plan a future? Can I book a holiday? Can I laugh? Can I still be myself?

Too often, a diagnosis becomes synonymous with putting life on hold.

Yet sometimes the experience of illness becomes the very thing that finally teaches people how to live.

Identity and Healing

Perhaps the deepest question of all is:

Who am I?

Most people answer with roles.

I am a doctor. I am a mother. I am a husband. I am an engineer. But these are roles.

Over time, identities form around them.

Identities also form around illness, perfectionism, over-functioning, self-sacrifice, caretaking, achievement, and suffering.

Eventually, we stop responding to life itself. We respond through those identities.

Healing therefore involves more than reducing symptoms. It involves examining who we have become around those symptoms.

When identity shifts, entire areas of life often begin to reorganise themselves.

The symptom may be the visible expression.

The identity is often the deeper architecture beneath it.

The Space in Between

As medicine becomes increasingly technological, an unexpected opportunity is emerging. Artificial intelligence will remember more facts than any of us. Algorithms will analyse more data than any individual clinician.

The future does not require doctors to become better databases. It invites us to become more human.

Technology can help us diagnose, analyse, and make decisions. But it cannot replace presence. It cannot replace curiosity. It cannot replace compassion.

And it cannot replace what happens in the space between two human beings sitting across from one another in a consultation room.

That space remains sacred.

It is where stories are told.

Where identities shift.

Where meaning emerges.

Where healing begins.

That is the space this series will continue to explore.

About the Author

Aleksandra Filipović, MD, PhD, is a medical oncologist, cancer cell biology scientist, drug developer, and educator. She earned her PhD at Imperial College London and now serves as Head of Oncology and Chief Medical Officer within the biotech sector. Dr Filipović practices and teaches integrative oncology internationally and hosts the OncoDaily TV podcast "Into the Body, with Dr Aleks".

Life After Cancer Has No Borders: Is Moving Abroad as an AYA a Good Idea?

What moving across eight countries taught me about survivorship, resilience, and the hidden barriers facing young adult cancer survivors.

By Carmen Monge

When Cancer Changes Everything

Having cancer means that the life you know—your dreams, hobbies, relationships, and plans for the future—may suddenly be put on hold or changed forever.

In 2013, I was 24 years old, living in Costa Rica, newly engaged, and working at my first real job when a painless little bump that suddenly appeared on my neck led to a diagnosis of Hodgkin lymphoma. I was shocked and found it difficult to accept that this would completely change the plans I had made for my future.

My life came to a standstill during the ten months of treatment. I felt betrayed by my body, and because my only reference for cancer came from films, I thought this was the end—party over. Yet even during treatment, I found myself planning and imagining what life would look like afterwards. One of those dreams was moving abroad.

Choosing to Leave Home

Luckily, my partner received a scholarship to study abroad, and that marked the beginning of our post-treatment adventure. We weren't afraid of moving to another country after cancer. At that age, we were fearless—perhaps even a little irresponsible. Not many people would choose to leave behind a familiar healthcare system and the support of their entire family. What if the cancer came back?

We simply wanted to live life to the fullest because, after experiencing cancer, you realise that anything can happen.

At the time, I didn't know that surviving cancer would be only one part of the journey. Learning how to navigate life and healthcare across different countries would become another.

When Survivorship Crosses Borders

Since my diagnosis, I have lived in eight countries. Along the way, I encountered challenges I had never anticipated, particularly how drastically healthcare systems differ and what it takes to access care for the long-term effects of cancer treatment.

Ironically, I have often found it more difficult to access survivorship care than cancer treatment itself.

Every hospital, support group, and even doctor's office operates within its own culture, and local patients are often expected to know how the system works. As a newcomer, I rarely did.

Each move taught me something different—not only about healthcare systems but also about what it means to be a cancer survivor far from home.

Australia: My First Lesson in Survivorship

My first experience living abroad after finishing chemotherapy was in *Australia*. I felt reassured to be moving to a country with a modern healthcare system and expected that continuing my follow-up care would be straightforward.

Instead, I immediately encountered problems with my port-a-cath.

In Costa Rica, ports are generally removed five years after treatment, whereas in Australia, they were routinely removed immediately after chemotherapy. Because I had been treated overseas, there was no clear pathway for maintaining or removing my port. I worried about developing a blood clot because I couldn't have it flushed regularly.

On top of that, my student health insurance excluded pre-existing conditions, including my cancer history. As a result, none of my follow-up care was covered, and I had to fly back to Costa Rica for routine check-ups—a significant financial burden for a young couple living on a single student income.

It was my first lesson that surviving cancer and accessing survivorship care are not always the same thing.

Europe: A New Dream, New Challenges

My next destination was Europe, where I joined my dream Erasmus Mundus programme, which allows students from around the world to study at several universities across Europe over two years.

Before leaving Costa Rica, I decided to have my port-a-cath removed, even though my doctors advised against it. In the end, I signed a waiver releasing the hospital from

responsibility.

Although removing the port solved one problem, new challenges quickly emerged.

My student health insurance remained limited, and I was not eligible for social security benefits in either Italy or France. I also faced language barriers and varying levels of support from the universities I attended. With every move, I found myself learning a new healthcare system from scratch while trying to continue my survivorship care.

IRELAND: The Hidden Burden of Survivorship

Ireland brought an entirely different challenge.

Several years after finishing treatment, I developed severe anxiety and depression and became convinced that my cancer had returned. Looking back, I recognise many of these feelings as fear of recurrence—a common but often invisible experience among cancer survivors.

At the time, however, I didn't have the words to describe what I was experiencing.

I kept my fears to myself. I didn't tell my classmates, and I didn't tell my family.

Fortunately, I found the support I needed through my university's health service. For the first time, I had access not only to mental health care but also to a cancer support group—something I had never experienced in my home country.

That experience opened my eyes to the importance of mental health care during treatment and, perhaps even more importantly, after it. It changed the way I understood survivorship, teaching me that recovery is not only about physical health but also about learning to live with the emotional impact that cancer leaves behind.

NETHERLANDS: When Support Exists—But You Don't Know It

My final stop in Europe was the Netherlands. There, I encountered a healthcare system that was not always easy to navigate as a foreign national, despite the fact that around 20–25% of the population has an international or migration background.

Specialist appointments were expensive, and many support groups and important health information were available only in Dutch. What surprised me most was that, despite informing both my GP and oncologist from the moment I arrived that I had previously been treated for cancer, I was never told that services such as psychological support, follow-up care, or fertility counselling were available.

It was only seven years later that I discovered there was a support group specifically for adolescent and young adult (AYA) cancer survivors.

That experience made me realise that access to care is not only about whether services exist, but also about whether patients know they are available.

Cancer Doesn't End with Treatment

Over the past two years, I returned to Latin America and lived in Costa Rica, Chile, Peru, and Colombia.

Once again, I encountered new challenges, this time related to health insurance.

Because I was moving between countries, I needed health insurance that would cover me across the region. My husband and I applied for the same policy in Costa Rica. His application was approved within hours.

I knew mine would be different.

Although I had been cancer-free for 12 years, I knew that the question about my cancer history would become an issue. A week after submitting my application, I was asked to provide all of my medical records related to my diagnosis and treatment.

I sent everything they requested.

Months later, I am still waiting for a response.

That experience reminded me that, for many survivors, cancer continues to shape their lives long after treatment has ended.

What Living in Eight Countries Taught Me

These experiences have taught me that healthcare systems are still not designed with migrants in mind. This is particularly relevant for adolescent and young adult (AYA) cancer survivors, as this stage of life often includes studying abroad, starting a career, building relationships, and, for many, moving to another country.

Despite paying for healthcare, I often felt like an outsider.
At the same time, I recognise my privilege as someone who migrated by choice. The barriers I experienced are often much greater for people who are forced to leave their countries because of conflict, economic hardship, or other circumstances beyond their control.

Every cancer patient and survivor deserves equitable access to follow-up care, support, and respect, regardless of where they come from.

Living in different countries also transformed the way I understand cancer care and survivorship. I realised that survivorship is not the same everywhere, and getting to know advocacy initiatives in different countries inspired me to find my own voice as both an advocate and a researcher. Today, my work focuses on improving cancer care for everyone, particularly people from underrepresented and underserved populations, including migrants and those living in low- and middle-income countries.

Finding My Voice Through Advocacy

These experiences eventually inspired the creation of the ***OncoDaily Lived Experience Advocacy Hub,*** with the goal of sharing knowledge, resources, and opportunities so that advocates everywhere can strengthen cancer care in their own countries.

For me, advocacy grew naturally from lived experience. Every healthcare system I encountered taught me something new—not only about survivorship, but also about the inequalities that still exist for people affected by cancer. Those lessons continue to shape both my research and my work as an advocate.

Would I Do It Again?

Would I make the same decision to move abroad after cancer again?

Absolutely.

I am grateful for the resilience and adaptability I gained along the way. Living in different countries introduced me to resources that were unavailable in my home country, including dedicated mental health services and strong survivor communities. It also gave me a deeper understanding of different cultures, healthcare systems, and the many ways people experience cancer around the world.

Moving abroad after cancer was not always easy. There were moments of uncertainty, frustration, and isolation. Yet every challenge taught me something valuable about myself and about the importance of equitable survivorship care.

As more young people study, work, and build lives across borders, healthcare systems must recognise that cancer survivors do the same. Survivorship should not stop at national borders.

No young person should have to choose between pursuing opportunities abroad and accessing the care they need to live well after cancer.

The Missing Link in Cancer Care

Can AI-supported patient navigation close the gap in LMICs?

By Uddiptya Goswami

For many people with cancer in low- and middle-income countries (LMICs), the greatest barrier is not that treatment is unavailable. It is that the path to treatment is fragmented, difficult to navigate, and easy to fall out of. A person may notice a symptom, see a primary-care provider, travel for imaging, wait weeks for a biopsy, carry reports from one hospital to another, and then return repeatedly for surgery, chemotherapy, radiotherapy, or follow-up. Each step makes clinical sense on its own. Yet patients can quietly disappear between those steps—and in LMICs, many do.

Artificial intelligence (AI) is increasingly being explored as a way to identify these patients before they are lost, not by replacing the people who support them, but by helping overstretched navigation teams recognise problems earlier and intervene sooner.

The Problem is Coordination

A patient can be registered at a clinic, a laboratory, and a tertiary cancer centre, and still not truly belong to any of them. A missed appointment, a pathology report that takes too long to reach the right desk, or a family that cannot afford the next trip to hospital can bring a patient's journey through the system to an end without anyone noticing. By the time they resurface, if they do, the disease has often progressed to an incurable stage.

Longer intervals between diagnosis and treatment have been linked to poorer outcomes across several common cancers. Fragmentation also breeds anxiety, distrust, avoidable expense, and treatment abandonment.

Patient Navigation as an Access Intervention

Patient navigation is a coordinated approach to helping people overcome the practical, informational, financial, and emotional barriers that interrupt cancer care. A navigator may be a nurse, social worker, or trained community health worker who ensures that clinical decisions are translated into timely care by booking appointments, tracking reports, explaining care plans in plain language, arranging referrals, helping with insurance paperwork, and routinely following up with patients who miss a critical visit.

The evidence base in LMICs is still limited. One review identified only a small number of studies evaluating cancer-navigation interventions across Asia, Africa, and South America, most of them focused on women's cancers. A more recent systematic review concluded that navigation programmes can meaningfully reduce barriers to treatment and improve access for underserved populations.

India Offers a Practical Example

Tata Memorial Centre's KEVAT programme is the first model in India to focus on an emerging navigation approach that can be applied across cancer institutions. It is built around barriers commonly encountered in LMICs, including language, low health literacy, economic hardship, and the logistical challenges of travelling for specialised care.

KEVAT also runs a one-year postgraduate diploma in oncology patient navigation, mentored by national and international experts. To date, 130 navigators working across nine Tata Memorial Centre hospitals have supported approximately 600,000 patients over five years.

In patients with advanced lung cancer, navigation was associated with a median nine-day reduction in the time taken to start cancer-directed therapy. During the COVID-19 pandemic, navigators also helped patients secure financial support, accommodation, and transport, demonstrating that navigation extends well beyond appointment scheduling.

While programmes such as KEVAT illustrate what organised navigation can achieve, they also highlight an important challenge. As patient numbers continue to grow, even experienced navigation teams cannot manually track every referral, pending investigation, or missed appointment. This is where AI-supported tools may provide valuable support—not by replacing navigators, but by helping them identify which patients need attention first.

Where AI Can Help

Limited navigation teams cannot manually track every referral, pending test, or missed appointment across

large patient volumes. AI-supported tools can help identify who needs attention first, and several early models illustrate how.

One approach scans clinical records or radiology reports for language suggestive of malignancy and flags patients who have not yet reached a biopsy or specialist review within an agreed timeframe. In the United States, one such programme used natural-language processing to identify imaging reports suggestive of possible pancreatic cancer, after which a human navigation team coordinated biopsy and referral. Mean time from imaging report to biopsy fell from 22 days to seven, mean time to an outpatient oncology visit decreased from 32 days to 15, and mean time to treatment initiation fell from 56 days to 34.

A second approach uses predictive modelling to identify patients most likely to miss an upcoming appointment, based on prior attendance patterns, travel distance, and clinic history. A study from Massachusetts General Hospital and Harvard Medical School, Boston, found that patients identified as being at high risk of a no-show were prioritised for a telephone call from a navigator shortly before their appointment. The no-show rate fell to 10.2% compared with 17.5% under usual care, with the greatest benefit seen when the navigator successfully reached the patient.

A third approach involves AI-supported chatbots and remote symptom-monitoring tools that check in with patients between visits and escalate concerning symptoms to a human navigator, rather than requiring every patient to be followed manually. A review by German researchers described the dual-edged role of AI chatbots, highlighting their potential to support patient education and reduce clinical workload, while also emphasising the risks of inadequate algorithmic transparency, misinformation, and the ethical challenges posed by AI-driven interactions. Algorithmic transparency—the ability to understand the data and reasoning behind AI-generated decisions—is particularly important because a lack of transparency can make it difficult for clinicians to evaluate recommendations or take appropriate action.

However, some patients still prefer to speak directly with a person, and poorly designed digital triage systems can increase workflow burden rather than reduce it. This is an important consideration for LMICs, where simple, well-tested tools that are tailored to the intended patient population and supported by a responsive human navigation team are likely to be more effective than complex technological solutions.

Roadblocks to Avoid

Many LMIC health systems continue to face fragmented medical records, unreliable electricity and internet connectivity, and too few staff to respond to digital alerts. An algorithm that identifies delayed care has little value if no one has the time, resources, or authority to address the underlying problem.

AI systems trained predominantly on data from high-income countries may not perform reliably in settings where disease patterns, languages, healthcare infrastructure, and care pathways differ. In addition, adherence-prediction models still face limited external validation and remain vulnerable to bias.

The World Health Organization (WHO) has warned that AI could widen existing health inequities unless systems are developed with human rights, privacy, transparency, and local context at their core. Likewise, tools that depend on smartphones, English-language interfaces, or continuous internet access risk excluding the very populations most likely to benefit, including people living in poverty, socioeconomically disadvantaged communities, and those with limited literacy.

These challenges reinforce an important principle: AI cannot compensate for weak health systems. Rather, it is most effective when introduced into services that already have the people, governance, and infrastructure needed to respond to the needs it identifies.

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or authority to address the underlying problem.

AI systems trained predominantly on data from high-income countries may not perform reliably in settings where disease patterns, languages, healthcare infrastructure, and care pathways differ. In addition, adherence-prediction models still face limited external validation and remain vulnerable to bias.

The World Health Organization (WHO) has warned that AI could widen existing health inequities unless systems are developed with human rights, privacy, transparency, and local context at their core. Likewise, tools that depend on smartphones, English-language interfaces, or continuous internet access risk excluding the very populations most likely to benefit, including people living in poverty, socioeconomically disadvantaged communities, and those with limited literacy.

These challenges reinforce an important principle: AI cannot compensate for weak health systems. Rather, it is most effective when introduced into services that already have the people, governance, and infrastructure needed to respond to the needs it identifies.

What Should Change?

For policymakers, three priorities matter more than any single technological tool.

First, patient navigators should be recognised as a core part of the cancer workforce, not as a charitable add-on. Their roles should be clearly defined, supported by formal training pathways, and funded through sustainable health-system budgets.

Second, governments should invest in the infrastructure that AI depends on: interoperable health records, reliable digital connectivity, and high-quality local-language data. Without these foundations, even the most sophisticated algorithm is little more than a technical demonstration.

Third, AI should be introduced into cancer care only with appropriate human oversight, robust privacy safeguards, and local validation. These should be prerequisites for implementation, not afterthoughts once pilot programmes have already expanded.

From Pilot Projects to Cancer Policy

Patient navigation is not an optional courtesy layered on top of cancer services; it is the connective tissue that determines whether diagnostic capacity, treatment protocols, and referral networks actually reach the people they were designed to serve.

For many patients, the greatest obstacle is not the absence of treatment but the difficulty of reaching it. Every missed appointment, delayed biopsy, or failed referral represents another opportunity for someone to disappear from care.

LMICs can no longer afford to treat navigation as a pilot project when, in practice, it is often the difference between a health system that treats cancer and one that merely diagnoses it.

AI can help make those gaps visible and help navigation teams respond to them earlier. But technology alone cannot coordinate care, build trust, or guide patients through increasingly complex health systems. Those responsibilities remain fundamentally human.

The future of cancer care in LMICs will depend not on choosing between AI and patient navigators, but on combining the strengths of both. AI can help navigation teams work more efficiently, identify patients at greatest risk of being lost to follow-up, and prioritise limited resources. Human navigators, in turn, provide the judgement, empathy, and continuity of care that no algorithm can replace.

Investing in patient navigation should therefore be recognised as an essential component of cancer control.

In cancer care, the smartest technology will never replace the value of someone making sure a patient reaches the next step.

About the Author

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The Patient's Voice

May Be One of Oncology's Best Prognostic Tools

Large meta-analysis suggests patient-reported outcomes complement traditional clinical assessment.

By Victoria Forster

Despite advances in imaging, molecular profiling, and biomarkers, accurately estimating how long a patient with cancer is likely to survive remains challenging. Now, a large analysis involving data from more than 44,000 patients suggests that an important additional source of prognostic information may come directly from patients themselves.

"We wanted to look beyond conventional factors that patients usually associate with illness, such as disease stage, blood work, and biomarkers," said Dr Ryan Huang, first author of the study from the Temerty Faculty of Medicine at the University of Toronto.

Clinical teams typically consider numerous variables—including tumour type and stage, biomarkers, and patient characteristics such as age, sex, and comorbidities—when estimating prognosis after diagnosis. Even so, providing an accurate prediction remains notoriously difficult.

Listening to the Patient

Patient-reported outcomes (PROs) are health measures provided directly by patients, without interpretation by a clinician. Questionnaires used to collect PROs ask about symptoms such as pain or fatigue, but also about emotional, social, and physical wellbeing, as well as how effectively patients are able to fulfil important roles in their lives, including work and family responsibilities.

"We wanted to see if the patient voice could tell us more about their prognosis, how they may cope with illness, and ultimately their outcomes," said Dr Huang, now a resident physician at the University of British Columbia in Vancouver.

The study, published in JAMA Oncology[1], involved a systematic review and meta-analysis of data from 69 prospective randomised clinical trials, including 44,030 adults with cancer. The analysis found that higher self-reported physical functioning and role functioning were associated with improved overall survival.

"We found that a patient's subjective reports of their functioning—their ability to fulfil roles such as their jobs and family life—as well as their physical functioning, including their ability to perform everyday activities, were associated with survival," said Dr Huang.

What the Study Found

A subset of 31 trials that used the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) was analysed to explore associations between specific patient-reported outcomes and survival.

Higher scores for global health status, a measure of overall quality of life and wellbeing widely used in clinical research, were consistently associated with improved overall survival.

"The main score of the questionnaire, the global health status, how patients feel overall regarding their health, was associated with better survival for patients with all sorts of different tumours and cancers," said Dr Huang.

Conversely, patients who reported a greater burden of symptoms—including pain, fatigue, loss of appetite, nausea, vomiting, and shortness of breath—generally had poorer overall survival.

"Patients may subjectively feel certain symptoms before they even manifest as results on laboratory tests or imaging. PROs could therefore provide earlier insight into prognosis, and when added to cancer staging and biomarkers, they may provide additional information," said Dr Huang.

Why Patient Voices Matter

The study found that these PROs provided prognostic information across a broad range of cancers represented in the included trials, including lung, head and neck, pancreatic, colorectal, and prostate cancers. The findings suggest that patients' own reports of their health and wellbeing may capture important aspects of disease and function that are not fully reflected by traditional clinical assessments.

"Our study really shows how important it is to listen to patients and not be fixated on CT imaging, MRIs, or biomarkers," said Dr Huang. *"It's important to see the patient in front of us, really listen to them compassionately, and systematically collect these PROs using validated and accessible tools."*

The researchers emphasised, however, that PROs are not intended to replace existing approaches to cancer prognosis. Rather, they should be viewed as an additional source of information that complements established clinical factors, tumour characteristics, and biomarkers.

"Patients may recognize changes in how they feel before those changes become apparent on laboratory tests or imaging," said Dr Huang. *"When combined with cancer staging and biomarkers, PROs may provide additional information that helps clinicians better understand a patient's prognosis."*

Building Better Prognostic Models

The researchers now hope to determine whether incorporating PROs into existing prognostic models improves their predictive performance.

"In the future, we would like to compare a model based only on clinical factors with one that combines clinical factors and patient factors to see whether there is additional prognostic benefit," said Dr Huang.

Such studies could help establish whether integrating PROs into predictive models provides a more accurate estimate of outcomes than relying solely on traditional clinical information.

"Our study supports the systematic collection of these PROs in healthcare institutions," said Dr Huang. *"It is important to use validated tools, provide accessible options, and listen carefully when patients describe concerning symptoms, because their experiences may reveal changes earlier than laboratory testing."*

Beyond Predicting Survival

Although the current study focused on prognosis, the researchers suggest that routinely collecting PROs could have broader clinical value. Beyond helping estimate survival, these measures may enable clinicians to identify patients who could benefit from additional supportive care or closer monitoring during treatment.

"At a time when healthcare is rapidly embracing AI, biomarkers, and precision medicine, our findings highlight an equally important message: patients themselves remain one of the most informative sources of clinical data," said Dr Huang.

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About the Author

Victoria Forster, PhD is a cancer research scientist, childhood leukemia survivor and health writer. Passionate about engaging patients in research and healthcare systems, she earned her PhD in cancer biology in the U.K. and now works as the head of Patient Engagement at an academic hospital in Toronto, Canada.

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Emerging research suggests that understanding psychological wellbeing in people affected by cancer requires looking beyond traditional diagnostic categories.

Beyond Anxiety and Depression

A New Framework for Mental Health in Cancer Care

By Adrian Pogacian

A cancer diagnosis is far more than a medical event. It can disrupt every aspect of a person's life, reshaping relationships, work, identity, and future plans almost overnight. While remarkable advances in prevention, early detection, and treatment have transformed outcomes for millions of people, the psychological consequences of cancer remain among the most complex and often underestimated aspects of care.

More than 20 million people are diagnosed with cancer every year, and that number continues to rise. As survival improves, the focus of oncology has expanded beyond treating disease alone towards supporting people throughout survivorship. Increasingly, clinicians recognise that recovery is not defined solely by tumour response or years gained, but also by emotional wellbeing, resilience, and quality of life.

Yet understanding mental health in people affected by cancer remains challenging.

Many symptoms commonly associated with psychiatric disorders—including fatigue, sleep disturbance, appetite changes, cognitive difficulties, and reduced energy are also common consequences of cancer itself or its treatment. This overlap can make it difficult to distinguish psychological distress from the physical effects of illness. At the same time, many patients experience emotional difficulties that extend beyond anxiety and depression, but these may go unnoticed when assessment focuses on only a limited number of psychological conditions.

These challenges have prompted researchers to ask an important question: are current approaches to assessing mental health broad enough to capture the full psychological experience of people living with cancer?

Looking Beyond Traditional Diagnosis

For decades, psychiatry has relied on two internationally recognised classification systems: the *Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD)*. These frameworks have shaped clinical practice worldwide and

remain essential tools for diagnosing mental illness.

However, both systems were designed primarily for the general population rather than for people living with complex medical conditions such as cancer, where physical symptoms and psychological distress frequently intersect.

In recent years, researchers have increasingly explored alternative ways of conceptualising mental health. One of the most promising is the **Hierarchical Taxonomy of Psychopathology (HiTOP)**, a dimensional framework that seeks to describe psychological difficulties as interconnected spectra rather than as separate diagnostic categories.

Instead of asking whether someone meets the criteria for a particular disorder, HiTOP examines the full range, severity, and relationships between psychological symptoms. This approach acknowledges that mental health rarely fits neatly into isolated diagnoses and that many conditions share overlapping features.

For psycho-oncology, where emotional experiences are often multifaceted and influenced by both illness and treatment, such a perspective may provide a richer understanding of patients' psychological wellbeing.

Dr Darren Haywood, whose recent research explored the application of HiTOP in people affected by cancer, believes this broader approach could address important limitations in current practice.

"Most psycho-oncology care still relies on approaches that focus primarily on traditional diagnosis using tools like the DSM or only distress, anxiety and depression," he explains.

According to Dr Haywood, this presents a significant challenge.

Many symptoms used to identify psychiatric disorders—including fatigue, appetite changes, sleep disturbance, and concentration difficulties are also direct consequences of cancer and its treatment. At the same time, people living with cancer often experience psychological challenges that extend beyond what are traditionally considered internalising disorders.

"Together this may suggest the potential for misdiagnosis using tools like the DSM and potentially missing important mental health challenges beyond common internalising difficulties," he says.

Rather than replacing established diagnostic systems, HiTOP offers an additional lens through which clinicians and researchers can understand psychological wellbeing.

By focusing on dimensions of psychopathology rather than discrete diagnoses, it may provide a more comprehensive picture of patients' experiences and highlight needs that conventional assessment approaches can overlook.

More Than Anxiety and Depression

The central aim of Dr. Haywood's study was to determine whether existing psycho-oncology assessments adequately reflect the complexity of psychological experiences among people living with cancer.

Historically, psycho-oncology has focused largely on distress, anxiety, and depression. These remain critically important aspects of patient care, informing routine screening and many psychosocial interventions. However, the researchers questioned whether this relatively narrow focus might overlook other clinically meaningful psychological difficulties.

Their findings suggest that it does.

People living with cancer reported elevated difficulties across a much broader range of psychological domains than those routinely assessed in oncology settings. As expected, symptoms associated with anxiety and depression were more common among participants with cancer. However, researchers also identified substantial increases in somatisation and thought-related symptoms, alongside elevations across several additional dimensions of psychopathology that receive comparatively little attention in routine cancer care.

These findings paint a more complex picture of psychological well being than conventional assessment tools typically capture.

"We found that people with current cancer experienced elevated difficulties across a much broader range of psychological domains than those routinely assessed in cancer care," says Dr Haywood.

"This suggests that a narrow focus on distress, anxiety and depression may overlook clinically meaningful aspects of patients' experiences. A broader assessment framework could help identify needs that might otherwise go unrecognised and untreated."

For clinicians, this distinction matters. Identifying distress is only the beginning. Understanding how that distress manifests and recognising when it extends beyond traditional diagnostic categories may allow support to become more personalised and clinically meaningful.

A broader assessment framework could help healthcare professionals detect psychological needs earlier, tailor interventions more effectively, and ultimately provide more holistic care throughout the cancer journey.

Can One Mental Health Framework Work for Everyone?

Applying a framework developed within psychiatry to people affected by cancer naturally raises an important question. Does cancer create such a unique psychological context that it requires an entirely separate model of mental health, or can existing evidence-based frameworks still accurately describe patients' experiences?

This was one of the study's central questions.

The researchers examined whether the structure of psychological difficulties measured by the HiTOP Self-Report remained consistent among people affected by cancer and compared these findings with individuals from community and mental health populations.

The results were striking.

Across all groups, the researchers identified eleven broad dimensions of psychopathology that closely mirrored patterns previously observed in psychiatric research. In other words, the fundamental architecture of mental health appeared remarkably consistent regardless of whether someone was living with cancer.

For Dr Haywood, this represents one of the study's most important findings.

"We found that the overall structure was remarkably similar across people affected by cancer and people drawn from community and mental health populations," he explains.

"This means that many of the same building blocks of mental health appear to exist both within and outside cancer populations."

At the same time, the study identified meaningful differences in how some psychological dimensions interacted within cancer populations.

Experiences related to bodily symptoms and blood-injection fears, for example, showed stronger associations with broader psychological domains among people living with cancer than in comparison groups. These findings suggest that while the underlying structure of mental health remains stable, the experience of cancer can shape how different psychological difficulties emerge and interact.

Rather than requiring an entirely separate classification system, the findings indicate that dimensional models such as HiTOP can be applied within psycho-oncology while remaining sensitive to the unique realities of living with cancer.

"We do not need an entirely separate model of mental health for cancer care," says Dr Haywood. *"Instead, we can use the same evidence-based framework while recognising that cancer-related experiences influence how some psychological difficulties present and interact."*

This connection between psycho-oncology and broader psychiatric research has important implications. It allows cancer researchers to build on decades of evidence from mental health science while adapting assessment and interventions to the realities of cancer diagnosis, treatment, and survivorship.

From Research to Clinical Practice

Beyond validating the use of HiTOP in people affected by cancer, the study raises broader questions about the future of psychosocial oncology.

Cancer care is becoming increasingly personalised, with treatments tailored to tumour biology, genetics, and individual patient characteristics. Dr Haywood believes psychological care should evolve in the same direction.

A broader understanding of psychopathology could help clinicians move beyond identifying distress alone to recognising the diverse psychological profiles that patients experience. Earlier recognition of these needs may enable more targeted interventions and improve support throughout the cancer continuum.

The framework may also benefit researchers.

Rather than relying exclusively on traditional diagnostic categories, HiTOP provides an opportunity to study psychological wellbeing in greater depth, offering more nuanced ways of measuring outcomes in psycho-oncology research and evaluating the effectiveness of psychosocial interventions.

Importantly, adopting a common dimensional framework also strengthens collaboration between psycho-oncology and the wider field of mental health research. Instead of developing cancer-specific models in isolation, researchers can build on existing psychiatric knowledge while refining it for oncology populations.

Seeing the Whole Person

One of the strengths of HiTOP is that it reflects the reality that psychological experiences rarely exist in isolation.

People living with cancer often experience uncertainty about the future, fear of recurrence, changes in identity, financial concerns, physical symptoms, treatment-related side effects, and disruptions to family and professional life—all at the same time. These experiences frequently overlap, influence one another, and evolve throughout treatment and survivorship.

Traditional diagnostic systems remain invaluable for identifying mental disorders and guiding treatment decisions. However, they are not always designed to capture the full complexity of psychological wellbeing in people managing a life-changing illness.

HiTOP does not seek to replace these systems. Instead, it complements them by providing a broader perspective on how psychological symptoms cluster and interact.

For clinicians, this means looking beyond a checklist of diagnoses and considering the wider pattern of emotional and psychological functioning. For patients, it represents an approach that acknowledges the complexity of their lived experience rather than reducing it to a single diagnostic label.

As Dr Haywood's research suggests, understanding mental health in cancer care may require shifting the question from *"Which disorder does this patient have?"* to *"What psychological challenges is this person experiencing, and how do they relate to one another?"*

Looking Ahead

Advances in cancer treatment have transformed outcomes for millions of people, allowing more patients than ever to live long after diagnosis. As survivorship continues to improve, the quality of that survival has become an equally important measure of success.

Providing high-quality cancer care means addressing not only the disease itself but also the emotional, psychological, and social consequences that accompany it.

The findings from Dr. Haywood and colleagues suggest that this may require broadening the way mental health is understood in oncology. Looking beyond anxiety and depression alone may help clinicians identify psychological needs that have long remained hidden, allowing support to become more personalised, timely, and responsive to individual experiences.

HiTOP is unlikely to replace established diagnostic frameworks in the immediate future. However, by offering a more comprehensive understanding of psychopathology, it has the potential to strengthen both psycho-oncology research and clinical practice.

Ultimately, improving mental health care in oncology is not about replacing one classification system with another. It is about ensuring that every person living with cancer is seen in the full complexity of their experience—because behind every diagnosis is an individual whose emotional wellbeing deserves the same attention as their physical health.

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