THE STATE OF PATIENT EMPOWERMENT REPORT

2023 Edition

Outcomes4Me

Dear Reader

Last year, we published the first State of Patient Empowerment Report, a first-of-its kind study aimed at understanding barriers to patient empowerment in order to develop strategies to address them. The study, which was conducted among breast cancer patients and focused on representative moments within the continuum of patient experience from pre-diagnosis to remission—stages common to many conditions—set out to define and measure the state of patient empowerment across the United States. It revealed that breast cancer patients were, on the whole, not fully informed of the evidence-based treatments that could influence their care, many lacked necessary access to a consultative care team that shared timely and relevant information about treatment options, and the integration of patient goals was low.

This year, in addition to assessing some of the areas we measured last year, we set out to dive deeper into patients' use of technology to navigate the healthcare system, their views on privacy, and their evolving relationships with their care teams. This focus was driven by some of the emerging trends of the past year, including:

- The launch of ChatGPT and excitement around generative AI, including insights we heard from patients at the Future of AI and Cancer Care symposium we held at the American Society of Clinical Oncology (ASCO) annual meeting.
- The increase in provider burnout with a quarter of academic oncologists reporting burnout in 2023 and forty-five percent of ASCO's membership, including community practitioners, saying they experienced burnout.
- Continued shortage of healthcare workers with recent estimates of a nursing shortage of up to 450,000 nurses by 2025 in the United States.
- New costs for patients driven by some health insurers and hospitals that have started to charge patients for sending messages via patient portals. Even with insurance, a message to the doctor or nurse might carry up to a $75 co-pay.
- The focus of the new National Cancer Plan on patient navigation and the inclusion of reimbursement of navigation in CMS's 2024 physician fees.
- President Biden's Executive Order on AI–designed to ensure "safe AI".

These trends collectively will fundamentally reshape healthcare as we know it. It is therefore of utmost importance that we continue to focus on patient empowerment. We cannot change what we do not manage, and we cannot manage what we do not measure, which is why we reinforce our commitment to this multi-year effort.

Thank you to all of the breast cancer patients who took the time to respond to this year's survey and for sharing your perspective and experiences. You deserve to be at the center of this discussion, and to be the guiding force in how we continue to recenter the healthcare system around the patient.

Maya Said

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Founder and CEO, Outcomes4Me

Background

Patient empowerment measures how informed and enabled patients are to take an active role in their care and ultimately achieve better outcomes consistent with their own personal life goals. A clear understanding of the state of patient empowerment will help healthcare organizations better incorporate patients' ability to act on their health and life goals in their development of patient touchpoints and transactions, and to adopt measures of empowerment among key metrics for success in care delivery. It will also ensure patients' informed voices are heard. Our framework for assessing patient empowerment across a comprehensive cancer treatment plan focuses on capturing representative moments of patient experiences at three distinct phases: (1) Diagnosis and plan creation, (2) treatment, and (3) survivorship:

DAYS **DIAGNOSIS**	DAYS – 1 MONTH **CREATING A PLAN**	3 – 12 MONTHS | ONGOING **TREATMENT**	5 YEARS – LIFETIME **SURVIVORSHIP**
Detection and Diagnosis Detection of cancer through routine imaging or symptoms	**Complete Diagnosis Decision Making** Combining diagnostic details to create a plan	**Following the Treatment Plan** Receiving anti-cancer treatment and assessing response, navigating financial, healthcare realms	**Follow-up** Recovering from treatment, managing side effects, finding a "new normal"
• What should I expect next? • What tests will I need to undergo? • Where do I find information?	• What do my test results mean? • What are my treatment options? • How do I prepare for symptoms/treatment? • Who/where is my care team?	• What side effects might I get? • How do I manage side effects? • How long will I get this treatment? • What do I do if my treatment fails? • Do I need to change my lifestyle (work, diet, activities)? • Should I enroll in a clinical trial?	• How do I find my "new normal"? • How do I decrease my risk of recurrence? • How do I cope with long-term side effects? • How can I get involved to help other patients?

Based upon this care continuum, these prerequisites are required for comprehensive patient empowerment:

01 Easy, timely, and actionable access to medical records

02 Trusted, multidisciplinary care team

03 Evidence-based standards

04 Grounding of patients' health and overall life goals

Research effort

In 2023, we again focused on a direct-to-patient survey of breast cancer patients from the general population, coupled with anonymized patient data, as well as survey responses from the Outcomes4Me patient member community.

We continue to believe that breast cancer is a representative disease for measuring empowerment because the diagnosis, treatment, and survivorship period associated with breast cancer is similar to many conditions. Additionally:

- Breast cancer is a condition where treatment decisions are vast and complex–and precision medicine has only made optionality more prominent.
- Precision diagnostics and treatments are available within breast cancer at various points within a patient's care. Additionally, genetic testing is available and important.
- Breast cancer is a highly disruptive disease that can affect patients' lives for long periods of time.
- Within breast cancer, fear around one's prognosis is prevalent.
- Patients are forced to learn a lot about their illness in order to navigate it; at the same time, purveyors of misinformation prey upon breast cancer patients.
- Survivorship within breast cancer can be a lonely period; treatments can create additional health problems that neither the active care team or general practitioner are equipped to manage.

With our annual measurement of the state of patient empowerment, our goal is to influence healthcare organizations to begin to consider patient empowerment as distinct – and distinctly important – from engagement, and begin adopting measures of empowerment that are critical to patient-centered care. We also want patients to have the ability to be in control of their own care, engaging in evidence-based decision-making together with their providers, taking into consideration the latest science and innovations, based on their individual health goals. Therefore, empowered patients must have:

- **Easy, timely,** and **actionable access** to their **full medical records**
- A **trusted, multidisciplinary care team** acting in a consultative manner during key decision points and available to answer questions when they arise
- Access to care based on **evidence-based standards** and presentation of those standards as part of treatment discussions, including clinical trial options
- **Grounding of their health and overall life goals** to guide their care teams' perspectives, including regular conversations about, documentation of, and integration of their preferences into the treatment plan

Study methodology

Outcomes4Me fielded a direct-to-patient online survey, recruiting patients via Facebook advertising and Outcomes4Me's own database. The survey was active between August 10, 2023 and September 10, 2023 and yielded 452 responses, with 61% coming from the Outcomes4Me platform and 39% representing patients who are not current members of the Outcomes4Me platform. We augmented survey data regarding medical institutions' compliance with patient-directed medical records requests with anonymized, proprietary data from the Outcomes4Me platform, reporting on 861 medical requests across 667 medical centers across every U.S. State.

THE CHARACTERISTICS OF THE SURVEY POPULATION ARE AS FOLLOWS:

71% of respondents are being treated at a community hospital. **29%** are being treated in an academic setting.

80% of respondents reported having early-stage breast cancer (Stage I or Stage II at the time of diagnosis). 20% were diagnosed with advanced or metastatic breast cancer (Stage III or Stage IV).

19% of respondents describe where they live as urban, **49%** suburban, and **27%** as rural

24% reported high school as the highest level of education completed; **35%** reported bachelor's degrees as the highest level of education completed, and **23%** reported having a Master's degree or Ph.D.

56% of respondents report a total annual household income of less than $75,000 USD

12% of respondents reported a total annual household income over $150,000 USD

12% of respondents are under 50 years old; **39%** are between 51 and 65; **49%** are 66+

45% of survey respondents are on Medicare, **30%** have employer-sponsored insurance, **10%** have individual health insurance, **6%** are on Medicaid, and **less than 1%** are uninsured

76% of respondents are white/non-Hispanic, **13%** are Black or African American and non-Hispanic, and **4%** are Hispanic

94% of respondents have access to broadband internet; only **6%** do not

Study findings

The data shows that there has been limited progress, if any, on the issues that we identified in last year's report and surfaced a number of new challenges and opportunities.

As highlighted last year, patients today:

- Have limited timely and actionable access to their health records
- Many lack a trusted, multidisciplinary care team to help navigate through their disease and needs
- Do not have sufficient presentation of evidence-based standards and treatment choices
- Have very limited, if any, integration of their health and life goals to drive treatment choices and plan

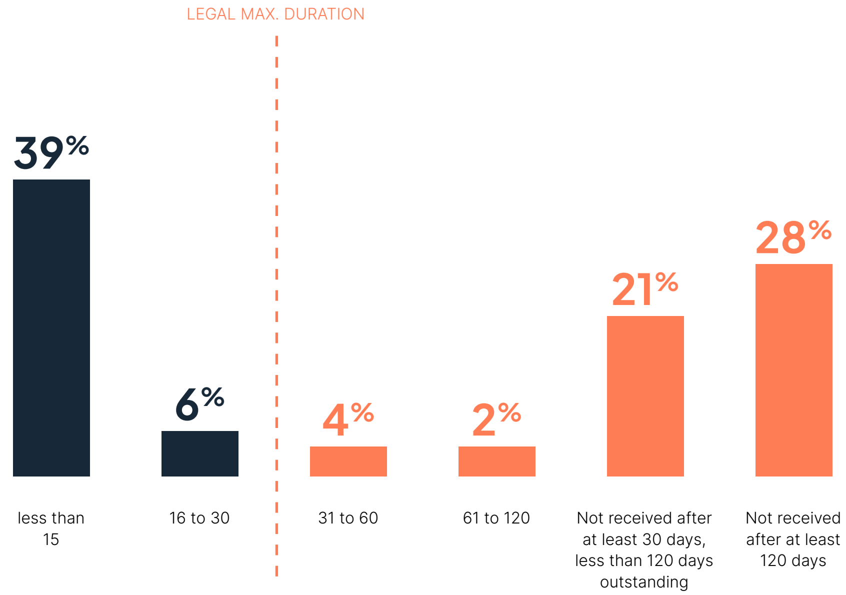
This year we identified additional challenges and opportunities where patient empowerment can have an impact.

Specifically, the data show that patients today:

- Are expecting more information from their care team and the majority are not fully satisfied with the information they receive
- Lack the tools to proactively engage with their providers
- Are increasingly turning to online tools for health information and using that as a mechanism to advocate for themselves
- Most are willing to opt-in to share their health information with evidence-based digital health tools in order to benefit from a more personalized approach and support

45% of medical records requests are fulfilled in a timely manner and only 42% of all institutions are fully compliant with patients’ requests

Time from request to receipt of medical records (number of days)



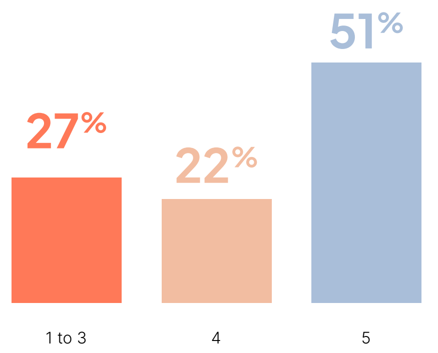
N=861 record requests across 667 institutions

42%

of all institutions are fully compliant with individuals’ right under HIPAA to access their health records

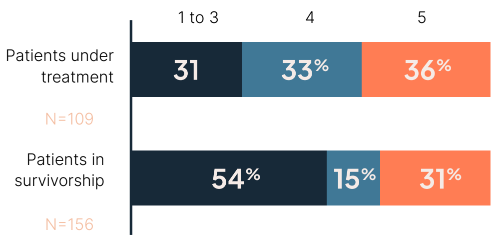
51% of patients felt their care team was fully accessible to answer questions during treatment and almost a third were fully satisfied with the information they got from their care team in treatment and survivorship

How accessible is your care team to answer questions during your treatment? (1=least, 5=most)



N=109

How satisfied are you with the information you receive from your care team? (1=least, 5=most)

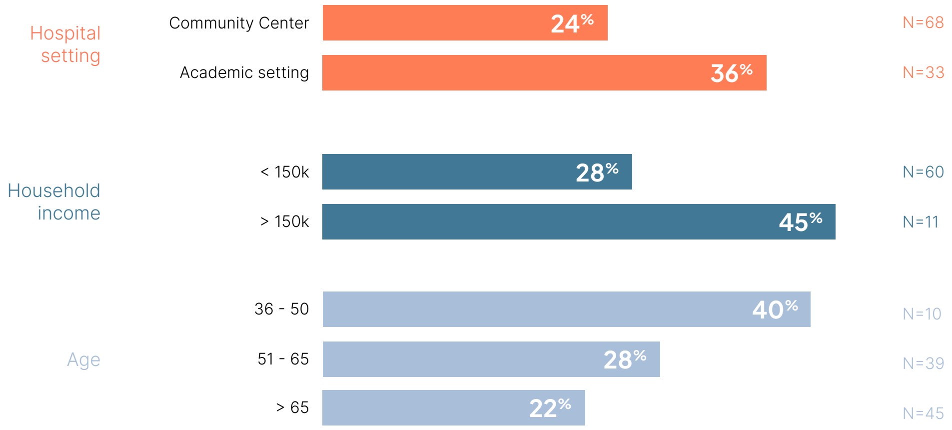


> *Every encounter is a different person who spends time catching up rather than moving me forward.*

> *I've had to work hard to find information.*

> *They just go by protocol, not your personal information.*

28% of patients are presented with clinical trials as a treatment option and patterns vary by hospital setting, income, and age



> ***NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.***
>
> *— The National Comprehensive Cancer Network® (NCCN®) Clinical Practice Guidelines in Oncology®*

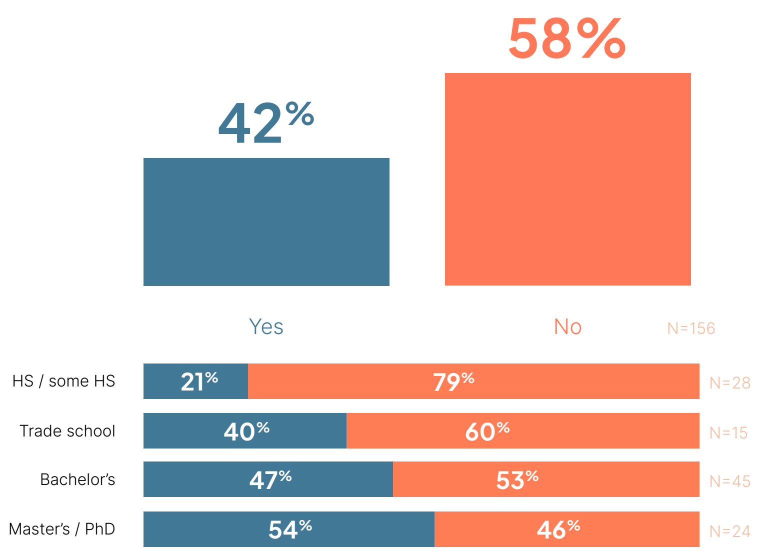
28%

of patients presented with a clinical trial as a treatment option

N=109

28% of patients in survivorship are offered a care plan and more than half of patients are not aware of survivorship care plans, with varying patterns by education level

Do you know what a care plan (sometimes called a survivorship care plan) is?



28%

of patients in survivorship offered a care plan

Patients' goals are not systematically discussed during the delivery of care

18%
of patients informed how treatment may impact pain management

36%
of patients informed how treatment may impact breast reconstruction options

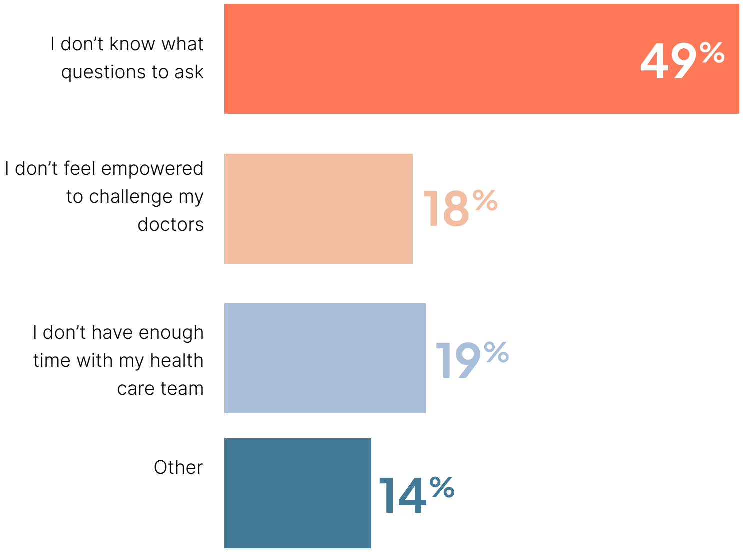
42%
of patients informed how treatment may impact lymphedema

N=109

> *All he said was chemo won't do you any good. Have the surgery. I'll see you again after that.*

67% of patients who are not fully satisfied with the information they get from their care team do not have the tools to have the appropriate conversation with their provider while 87% of patients in treatment are seeking information from sources other than their care team

If you are not fully satisfied with the information you receive from your care team, what is preventing you from getting the information and explanation that you need?



N=175

87%

of patients in treatment are seeking further information about their cancer from sources other than their care team

N=109

34% of patients in treatment pursued a second opinion while 69% of patients rely on online resources to get information about their cancer, and patterns are similar irrespective of age

34%

of patients in treatment pursued a second opinion

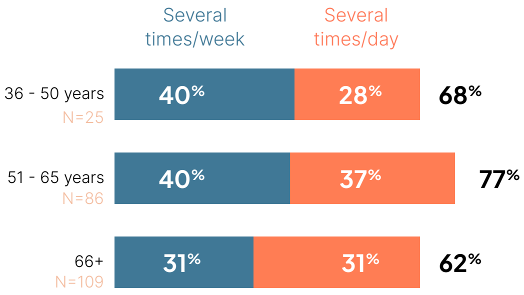
N=109

69%

of patients use online resources at least several times a week to manage their care

N=220

How frequently do you use online resources (e.g. an app, the internet, peer communities) to manage your cancer care?



Digitally active patients feel more comfortable advocating for themselves with their healthcare providers

If you do not feel like your care team listens to your preferences, do you feel comfortable advocating for yourself? (1 = least, 5 = most)

44%

of patients using online resources **rarely** to manage their care gave a score of 5

N=32

50%

of patients using online resources **weekly** to manage their care gave a score of 5

N=40

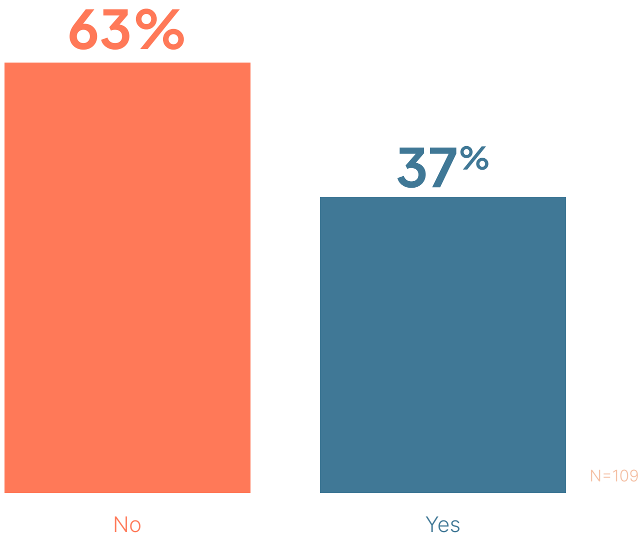
70%

of patients using online resources **daily** to manage their care gave a score of 5

N=37

More than a third of patients learned about clinical trials through online resources and 1 in 4 of discussions between patients and physicians about clinical trials was initiated by the patient

Did you learn about a clinical trial from online sources that your doctor never told you about?



1 in 4

discussions between patient and physician about clinical trials was initiated by the patient

N=31

However, 60% of patients will not ask questions to their doctors if they have to pay for the service

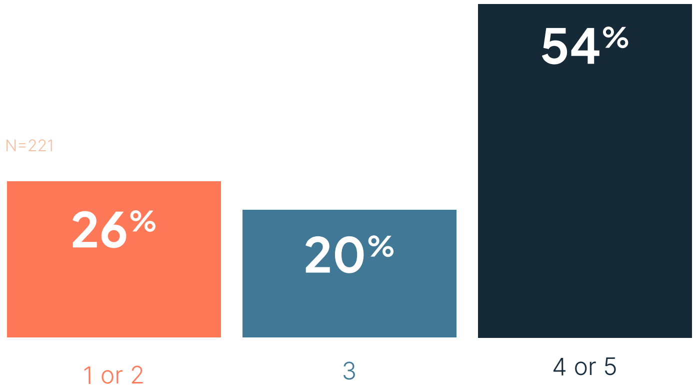
60%

of patients would be prevented from asking questions to their doctor via a health portal if charged a cost

N=109

More than half of patients are willing to share their medical records/health history with a digital health tool, if it could support their cancer care

Would you feel comfortable sharing your medical record/health data with a digital health app if it could support your care? (1 = not comfortable, 5 = very comfortable)



> *Guarantee of protection of private identifying information.*

> *I would love for any other options. I do not want to go with this surgery at that hospital or see my cancer doctor at all anymore.*

65%

among Master's Degree / PhD

N=51

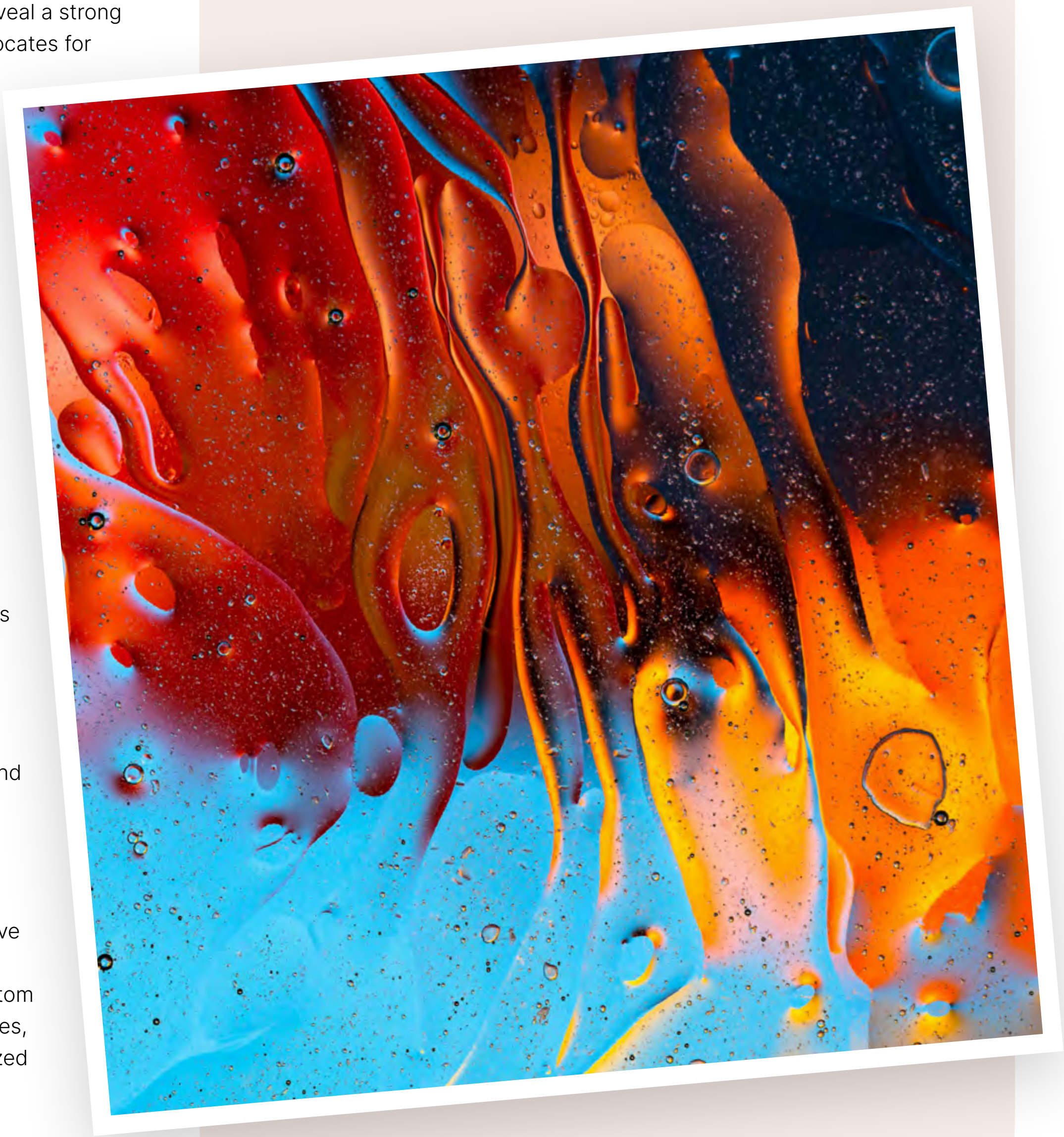
63%

among patients using online resources daily to manage their care

N=83

A call to action

While distinct information gaps, identified last year, remain—with many patients not having full access to their medical data and not fully informed of the evidence-based treatment options that could influence their care—this year's results reveal a strong willingness for patients to be greater advocates for themselves, and a desire to leverage technology to do so.



This year's study highlights opportunities for healthcare providers to partner with digital health companies to enhance patient empowerment by delivering patient-facing solutions that provide:

- Evidence-based navigation incorporating the latest science and innovation
- Access to timely and actionable medical data providing patients the agency and power to act upon them and share them with the technologies of their choice
- Identification of patients' personal health goals and integration of those goals into a personalized care plan and follow-up
- Bringing the care plan 'alive' through two-way information-sharing and actions that enable patients to achieve better outcomes in line with their personal health goals, through symptom monitoring, patient-reported outcomes, clinical-trial matching, and personalized treatment matching
- Customized resources to address every patient's unique financial and logistical barriers

Cancer patients are online and searching for ways to be more proactive in their care and achieve better outcomes. Now, we must act upon this need so that we deliver on the promise of the latest cancer innovation–and, most importantly, so that every cancer patient, whomever and wherever they are, has the best chance for the very best health outcomes.

Outcomes4Me

Outcomes4Me is an AI-driven patient empowerment platform that helps cancer patients take a proactive approach to their care, gaining access to personalized, evidence-based treatment options and information. The company is on a mission to democratize healthcare by providing real-time, evidence-based clinical information to cancer patients, ensuring they can effectively navigate through their disease and improve their outcomes. In doing so, Outcomes4Me is working to promote health equity by generating deeper insights that improve care, and accelerating research and access to innovation. Based in Boston, Massachusetts, Outcomes4Me is a woman-led company of seasoned healthcare, oncology, pharmaceutical, consumer and technology veterans. For more information, visit **www.outcomes4me.com**