June 2025

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The Collective Action Roadmap for GI Cancers

A practical multi-stakeholder tool for improving outcomes across the patient journey

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Letter from Martha Raymond

Mobilizing the Gastrointestinal (GI) Cancer community for collective action

Supporting individuals with GI cancer requires an inclusive and coordinated approach to ensure access to the best care and the best outcomes. The GI cancers community is comprised of diverse stakeholders and each play an instrumental role in improving outcomes for people living with, or at risk of, GI cancer and their loved ones.

Patient advocacy groups (PAGs) play a unique role by taking a "for patients, by patients" approach – grounding their support for people with, or at risk of, GI cancer and their caregivers in the lived experiences of navigating a GI cancer diagnosis. Likewise, community-based organizations (CBOs), professional medical associations, governmental agencies and other health system stakeholders play an equally critical role in improving how GI care is accessed, delivered and experienced across diverse communities. Both PAGs and CBOs work to reach historically underserved populations who often face higher prevalence and poorer outcomes related to GI cancers. **To enact positive change in partnership with the GI cancers community, we must harness our collective power to create an equitable, responsive and coordinated system of care.**

The GI Cancers Alliance, a coalition of patient communities, advocacy organizations, healthcare professionals, industry, academic, media and corporate partners, was established in 2015 with this goal in mind – to build a strong, unified voice and collective approach to prevent, treat and cure GI cancers.

In January 2025, with support from AstraZeneca, the GI Cancers Alliance convened a robust array of PAGs focused on improving outcomes in cholangiocarcinoma, colon, liver, pancreatic, gallbladder, rectal, esophageal and gastric cancer to define the key challenges in GI cancer care and how best to solve them to co-create a path for better care and support for people living with GI cancer.

Our Vision

The result of this effort is the Collective Action Roadmap for GI cancers – a framework to guide multi-stakeholder action and drive systemic improvements for people living with GI cancer. We hope this roadmap functions as a practical resource for healthcare stakeholders to identify critical challenges, prioritize action and work in partnership across the GI cancers community.

We are deeply grateful to every partner who contributed their voice to this effort. Together, we believe that meaningful change is not only possible but is already in motion.

Sincerely,

Martha Raymond

Chief Executive Officer (CEO),
GI Cancers Alliance

Thank you to our PAG partners

This Collective Action Roadmap for GI Cancers would not have been possible without our Patient Advocacy Group partners who generously contributed their time, expertise, personal stories and experiences to bring this report to life.

This roadmap is intended to be used by all stakeholders across the GI cancers community to support all patients – regardless of their GI cancer or tumor diagnosis – through every stage of their care journey.

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NO STOMACH FOR CANCER

AMERICAN LIVER FOUNDATION®

HOPE FOR STOMACH CANCER

PANCREATIC CANCER ACTION NETWORK

GLI GLOBAL™ LIVER INSTITUTE

Community Liver Alliance

Blue Faery The Adrienne Wilson Liver Cancer Association

GALLBLADDER CANCER FOUNDATION

Debbie's Dream Foundation CURING STOMACH CANCER

Cholangiocarcinoma Foundation®

GASTRIC CANCER FOUNDATION

GUTHY JACKSON® Charitable Foundation

MAN UP TO CANCER · OPEN HEART · WARRIOR SPIRIT ·

RAYMOND FOUNDATION

ECAN Esophageal Cancer Action Network

paf Patient Advocate Foundation

The Challenge

The Burden of Oncology & GI Cancers in the United States

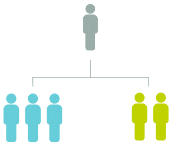
Cancer remains the **second-leading cause of death in the U.S**, with approximately **two million** new diagnoses and more than **618,000 deaths** expected in 2025 alone.[i] Despite significant innovation in prevention, screening and treatment, the overall burden of cancer continues to rise – driven by an aging population and systemic disparities in care.

Notably, GI cancers collectively account for ***approximately one-fourth of all cancer-related deaths*** *in the U.S.*[ii]

GI cancers include many different cancer types, including rare cancers, that may originate in any part of the digestive tract, including: cholangiocarcinoma (CCA), colon, rectal, esophageal, gallbladder, gastric, liver and pancreatic cancers.

Racial and ethnic minorities face an outsized burden related to GI cancers – with Native American and Black and Latino communities experiencing mortality rates that are approximately

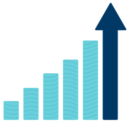
three and two times higher, *respectively, compared to white communities.*[iii]



Veterans also face significant disparities across GI cancers:

41 percent *of gastric cancer diagnosis among veterans are stage IV (late-stage).*[iv]

The incidence rate of liver cancer, specifically, is ***5 times higher*** *than the general U.S. population.*[v]



Challenges contributing to GI cancer burden

GI cancers are associated with some of the poorest prognoses. A primary reason includes the often indistinct and non-specific nature of early symptoms, which are often incorrectly attributed to less serious types of GI distress. As a result, GI cancers can take far longer than other cancer types to diagnosis accurately and are frequently diagnosed at advanced stages. Moreover, the path from diagnosis to treatment is rarely straightforward – often marked by delayed referrals to a GI specialist, fragmented care, lack of multidisciplinary care teams and patient navigation services, as well as limited access to information to support therapeutic decision-making. These challenges have an outsized effect on people from low socioeconomic backgrounds and racial and ethnic minority groups, resulting in the mentioned disparities.

People facing rare GI cancer types such as CCA and gallbladder cancer experience added challenges related to significant detection delays and difficulty accessing GI specialists who are familiar with the latest treatments and care standards for these cancers. The average time from onset of symptoms for CCA to diagnosis is almost two years, compared to as low as two months for hepatocellular carcinoma, a more common liver cancer.[vi,vii]

Our Call to Action:

Create multi-stakeholder partnerships to support patients, streamline pathways to diagnosis and quality treatment and improve the quality of life for people with GI cancer.

Driving progress in GI cancers requires a collaborative and strategic approach – one that unites patients, caregivers, hospital systems and broader multi-level healthcare stakeholders around urgent and clear priorities and coordinated action. By aligning on common goals and leveraging strengths of stakeholders across disciplines, the GI cancers community can accelerate sustainable progress, scale impact, and deliver equitable outcomes across the patient care journey.

The Collective Action Roadmap
for Gastrointestinal (GI) Cancers

What it is and **how** to use it

The Collective Action Roadmap for GI Cancers is a framework that aims to provide practical guidance and best practices for improving GI cancer care. The roadmap was created by Patient Advocacy Groups focused on GI cancers and leads with the patient perspective on the key challenges and solutions throughout the patient journey – including **Awareness, Testing & Diagnosis, Treatment and Wellbeing**. Additionally, the roadmap outlines the specific stakeholders that have a critical role to play in addressing these challenges and; therefore, are important to engage and collaborate with to drive progress and improve GI cancer care as a collective.*

Stakeholders are encouraged to iteratively revisit this roadmap as organizational, healthcare and patient challenges evolve over time to select and collaboratively implement activities that most align and respond to patient community needs.

Collective Action Roadmap: Summary

CHALLENGES

Awareness

Low health seeking behavior and delayed care due to:

- Limited public and provider awareness of GI cancer risk factors and early symptoms
- High stigma associated with lifestyle-based risk factors
- Socioeconomic (SES) barriers to accessing care

Testing and Diagnosis

Delayed pathways to diagnosis due to:

- Low and fragmented use of biomarker testing
- Limited coverage of biomarker testing
- Lack of standardized diagnostic practices
- Lack of screening and early detection tests for some GI cancers

Treatment

Limited access to tailored treatment due to:

- Low use of biomarker testing
- Complex and fragmented patient navigation resources
- Low provider awareness of tailored options
- High reliance on outdated care standards
- Unequal access to clinical trials
- SES barriers to accessing care

Well-being

Poor access to well-being services due to:

- Limited clinical guidelines on supporting patient well-being during and after treatment
- Limited access to multi-disciplinary teams and allied health workers
- SES barriers to accessing care

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Short-term solutions

Inclusive of individual and community-level activities that can be implemented within 1 to 2 years by building on existing programs and best practices

Awareness	Testing and Diagnosis	Treatment	Well-being
• Public awareness campaigns • National & regional conferences	• Accessible GI cancer risk assessment tests and risk management tools • Patient care navigation and advocacy tools	• Patient education toolkits • Peer counselling on treatment options • Clinical trial navigation tools	• Peer-to-peer navigation and emotional support • Patient awareness of well-being support options

PRIMARY STAKEHOLDERS TO ENGAGE

PAGs

Awareness	Testing and Diagnosis	Treatment	Well-being
with CBOs, cancer coalitions, industry, trusted media and community leaders	with academic cancer centers, CBOs and national guideline-setting bodies (e.g. NCCN)	with CBOs, cancer coalitions, industry, trusted media and community leaders	with multidisciplinary healthcare providers, including allied health workers

Long-term solutions

Includes health system and policy-level interventions that require significant coordination, investment and engagement from a diverse set of stakeholders over 3+ years

Awareness	Testing and Diagnosis	Treatment	Well-being
• PCP and GI specialist training on risk factors and early signs • Comprehensive medical school education • Standardized GI cancer terminology • Standards-aligned education tools	• Standardize biomarker testing as routine care • PCP and GI specialist training on quality diagnosis • Advocate for greater coverage of biomarker testing • Data-informed interventions using patient registries	• Provider training on personalized care • Connect rural oncologists to cancer centers of excellence • Advocate for coverage of clinical trials and second opinions	• Virtual and in-person physical therapy and nutritional services • Integration of psychosocial and navigation services into care guidelines • Standardized post-treatment guidelines • Greater coverage of well-being services

PRIMARY STAKEHOLDERS TO ENGAGE

Awareness	Testing and Diagnosis	Treatment	Well-being
• **Professional medical associations** • **PAGs** • **Medical schools** • **National guideline-setting bodies**	• **Professional medical associations** • **PAGs** • **Academic cancer centers** • **Insurers**	• **Professional medical associations** • **PAGs** • **Academic cancer centers** • **Insurers**	• **Professional medical associations** • **PAGs** • **Insurers** • **Hospital systems**

**Please reference the 'Glossary of Stakeholders Roles' in the appendix for a list of key influential stakeholders and their principal role in advancing coordinated, equitable and effective GI cancer care.*

Improving Outcomes Across the Patient Journey

The following sections are built using insights and input from the GI Patient Advocacy Group community and provide additional detail on the priority activities and solutions – awareness, testing & diagnosis, treatment and well-being.

While some activities can be implemented in the near term (within 1 to 2 years) by building on existing programs or best practices, others represent longer-term priorities (3 years or more) that will require significant coordination, investment and engagement across stakeholders. **Across the phases, all activities will require diverse expertise and lived experiences, especially the voices of patients and caregivers, to design and implement interventions that create meaningful and sustainable change in GI cancer care.**

Awareness

***Goal 1:** increase public and healthcare provider awareness of GI cancers – including potential risk factors, signs and symptoms – to improve health seeking behaviors and increase access to essential GI cancer prevention and risk reduction services early*

SHORT-TERM PRIORITIES

- Public awareness campaigns
- National & regional symposiums or conferences

LOOKING FORWARD

- Provider awareness training
- Comprehensive medical school education
- Standardized GI cancer terminology

SHORT-TERM PRIORITIES

***Sub-goal 1.1:** Encourage health seeking behaviors for early cancer detection and risk management, especially communities at higher risk, and reduce personal stigma associated with GI cancers*

ACTIVITY:

Public Awareness Campaigns

Focus: Increase awareness of GI cancers broadly – including genetic, lifestyle and non-lifestyle related risk factors, early signs and potential symptoms – and amplify patient stories

WHAT THIS COULD LOOK LIKE:

- National campaign to increase general awareness of risk factors and early symptoms of GI cancers that may be more than "ordinary" GI distress
- Regional liver or esophageal cancer campaign ads targeting at-risk communities in the South amid high burden
- De-stigmatization social media campaigns for veterans and other populations who face lifestyle-related GI cancer risk factors
- Compelling patient story marketing campaign amplifying the health-critical impact of managing cancer risk factors early

LED BY:

Patient Advocacy Groups in partnership with **community-based organizations, cancer coalitions, trusted media partners and community leaders and influencers**

Sub-goal 1.2: *Enhance provider capacity to recognize risk and diagnose all GI cancers*

ACTIVITY:	WHAT THIS COULD LOOK LIKE:	LED BY:
GI cancer symposiums & conferences **Focus:** Build awareness of GI cancers, including research updates and the latest medical innovations Amplify patient stories for healthcare professionals	• National convenings of researchers, health professionals and patients to catalyze collaboration, learning and innovation for rare GI cancers • Regional conference to educate providers on local GI cancer disparities, risk factors and healthcare challenges • Small, community-level medical symposia to build GI cancer knowledge and capacity among rural primary care providers (PCPs), GI specialists and community oncologists	**Patient Advocacy Groups** in partnership with **community-based organizations, cancer coalitions and industry partners**

Awareness Spotlights

Blue Faery's 'Love Your Liver' digital campaign

Raising awareness of liver disease and cancer among at-risk populations

World Pancreatic Cancer Coalition 'Hello Pancreas' digital campaign

Empowering individuals to engage with their health and recognize symptoms and risk factors of pancreatic cancer to enhance earlier detection

Esophageal Cancer Action Network's 'Heartburn Can Cause Cancer' campaign

Raising awareness on the link between persistent heartburn and esophageal cancer to promote early detection

Cholangiocarcinoma Foundation Annual Conference & Regional Symposia

Bringing together leading researchers, healthcare professionals, patients and caregivers to share patient stories and advance learning on the latest diagnostic techniques and treatments for Cholangiocarcinoma, a rare cancer

LUNGevity Foundation Pan Cancer Consortium

Developing recommendations on how to streamline terminology related to biomarker, genetic and genomic testing to coordinate how providers talk to their patients, unify educational resources and simplify care navigation for all patients

LOOKING FORWARD

Sub-goal 1.3: *Enable PCP, GI specialists and the next generation of healthcare providers to diagnosis GI cancers early*

ACTIVITY:	LED BY:
Enhance capacity of PCPs and GI specialists to recognize risk and diagnose GI cancers early **by creating and disseminating patient-informed training and continued medical education materials**	**Professional Medical Associations and Patient Advocacy Groups,** with input from industry partners and healthcare providers
Train the next generation of providers to recognize GI cancer risk and streamline pathways to diagnosis **by integrating comprehensive GI cancer education into medical school curricula**	**Medical School Accreditation Bodies** and **Medical Schools,** with input from patient advocacy groups and professional medical associations

Sub-goal 1.4: *Streamline and align GI cancer terminology to support patient understanding, care navigation and decision-making*

ACTIVITY:	LED BY:
Standardize terminology for all GI cancers across the health system **by building consensus of standard terms among medical societies and integrating standards into clinical guidelines, coding systems and educational materials**	**Professional Medical Associations and National Guideline-Setting Bodies,** with implementation and regulatory support from governmental agencies, public payers and hospital accreditation bodies

Testing and Diagnosis

Goal 2: *Biomarker testing is a standardized and accessible step in the GI cancer care journey to streamline care and referrals pathways for accurate and timely GI cancer diagnoses*

SHORT-TERM PRIORITIES

- Risk assessment tests and management tools
- Patient navigation & advocacy tools

LOOKING FORWARD

- Integrate biomarker testing into routine care
- Provider training on quality diagnosis
- Advocate for greater coverage of biomarker testing
- Data-informed interventions using patient registries

SHORT-TERM PRIORITIES

Sub-goal 2.1: Encourage health seeking behaviors to detect and manage cancer risk early, especially communities at higher risk

ACTIVITY:

At-home risk assessment tests and management tools

Focus: Increase awareness of the genetic and lifestyle factors associated with increased risk of GI cancers

Equip individuals with tools to detect and respond to GI cancer risk early

WHAT THIS COULD LOOK LIKE:

- Online survey to assess individual risk for all GI cancers, based on family history, health status and lifestyle behaviors, with outlined actions to take if at higher risk
- Local health service events to deliver liver cancer risk assessment tests and risk management tools for populations with higher risk (e.g. Latino men in California)

LED BY:

Patient Advocacy Groups in partnership with **academic cancer centers, community-based organizations and trusted media and community leaders**

Sub-goal 2.2: Increase patient capacity to understand and navigate complex GI cancer information and access their desired care options

ACTIVITY:

Patient navigation & advocacy tools

Focus: Increase individual capacity to understand and navigate the GI cancer care system

Equip individuals at risk of GI cancers with tools to advocate for their health concerns and desired care

WHAT THIS COULD LOOK LIKE:

- Patient-provider discussion tool to help individuals advocate for testing or risk reduction services
- Educational tools clarifying GI cancer terminology
- Diverse patient storytelling campaign illustrating cancer journey and elevating value of testing across racial and ethnic minority communities
- Patient stories about biomarker testing shared broadly, including on industry websites
- Online provider locator tools to help patients find accessible, PAG – and patient – recommended GI specialists

LED BY:

Patient Advocacy Groups in partnership with **industry, community-based organizations, insurers, and national guideline-setting bodies**

Testing & Diagnosis Spotlights

Pancreatic Cancer Action Network ‘Talk, Test, Take Control’

Education and resource campaign emphasizing three key actions – “talk” about genetic and biomarker testing with your providers, “Test” to understand your cancer risk and treatment options and “take control” by making informed clinical care decisions

GI Cancers Alliance ‘Test Your Biomarkers’

A resource hub linking patients to key biomarker testing information and access tools for each GI cancer

CCF ‘Biomarkers Matter’

A resource hub featuring information on biomarker testing for cholangiocarcinoma and other cancers, alongside patient testimonials to illustrate the role of testing in personalizing treatment decisions

LOOKING FORWARD

Sub-goal 2.3: *Make biomarker testing a routine step in the cancer care journey*

ACTIVITY:

Integrate biomarker testing into clinical guidelines and routine care protocols **by amplifying clinical evidence and the patient voice to justify and advocate for its inclusion and incentivizing providers via value-based care reimbursement**

LED BY:

Professional Medical Associations, with input from academic cancer centers, patient advocacy groups and implementation support from national guideline-setting bodies, governmental agencies and insurers

Sub-goal 2.4: *Ensure primary diagnosing providers regularly use the latest diagnostic techniques to improve referrals, early diagnosis and delivery of tailored care plans*

ACTIVITY:

Train providers – especially PCPs, GI specialists and community providers – on quality diagnostic techniques, including testing and care protocols **through medical conferences, provider-to-provider learning and continued medical education (CME) trainings**

LED BY:

Professional Medical Associations and **Academic Cancer Centers,** with implementation support from hospital systems and patient advocacy groups

Sub-goal 2.5: *Reduce out-of-pocket costs and increase access to tailored GI cancer care*

ACTIVITY:

Support greater insurance coverage of biomarker testing **through advocacy campaigns rooted in patient impact and health outcomes, patient voices and cost-effectiveness data**

LED BY:

Patient Advocacy Groups, with clinical and cost-effectiveness data provided by academic cancer centers, health economists and NCCN Policy Program

Sub-goal 2.6: *Leverage patient registry data to inform targeted GI cancer interventions and enhance care delivery strategies*

ACTIVITY:

Develop data-informed interventions to improve access to quality and timely care **by using patient registry data on disease incidence, diagnostic hotspots, provider and specialist access and beyond**

LED BY:

Patient Advocacy Groups, with implementation support and input from academic cancer centers and Cancer Centers of Excellence

Testing & Diagnosis Spotlights

Pancreatic Cancer Action Network – increased coverage of pancreatic cancer-related biomarker testing

Elevating patient outcomes, impact metrics and peer-reviewed data from the "Know Your Tumor" service, with clinical research from Memorial Sloan Kettering Cancer Center, to advocate for inclusion of testing in national guidelines

Treatment

***Goal 3:** People with GI cancer have access to tools and the necessary support from their multidisciplinary care team to engage in their care and receive tailored, quality treatment*

SHORT-TERM PRIORITIES			LOOKING FORWARD		
Patient education toolkits	Peer-to-peer counselling on treatment options	Patient navigation & advocacy tools	Provider training on tailoring treatment	Connect rural oncologists to academic medical centers	Advocate for greater coverage of clinical trials and second opinions

SHORT-TERM PRIORITIES

***Sub-goal 3.1:** Equip patients with culturally appropriate resources to advocate for their desired care and access personalized treatment*

ACTIVITY:	WHAT THIS COULD LOOK LIKE:	LED BY:
Patient education toolkits **Focus:** Support care navigation and understanding of treatment options	• Online repository of best-in-class educational resources and tools (diagnosis overviews, treatment pathway maps, patient-provider discussion tools, links to supportive access programs) • Digital document with the latest information on GI cancer risk factors, signs and symptoms, treatment and clinical trial options and care engagement tools • Partner with local tribal leaders and organizations to co-develop a culturally competent, One Health-focused, toolkit for indigenous peoples diagnosed with liver and other GI cancers that have a disproportionate burden on the community • Educational resources translated into multiple languages to reach diverse populations living with GI cancers	**Patient Advocacy Groups** in partnership with **community-based organizations and allied healthcare professionals**

***Sub-goal 3.2:** Help individuals with GI cancer navigate care and identify and advocate for the best treatment option, including clinical trials*

ACTIVITY:	WHAT THIS COULD LOOK LIKE:	LED BY:
Peer-to-peer counselling **Focus:** Build supportive patient communities that help individuals navigate their treatment choices Increase awareness of existing peer counselling options	• Scale patient treatment and clinical trial navigation hotlines to cover all GI cancers • Create secure and HIPAA-compliant patient platforms where recently diagnosed individuals can ask peers or expert mentors about care options and managing their treatment • Patient conferences to help individuals diagnosed with rare GI cancers connect and learn from other patient peers, providers and cancer survivors	**Patient Advocacy Groups** in partnership with **community-based organizations and allied healthcare professionals**
Patient navigation & advocacy tools **Focus:** Increase individual capacity to understand and navigate complex GI cancer and clinical trial information Equip and raise awareness of patient self-advocacy tools among individuals with GI cancer	• Regional and community-level awareness campaigns on AI-powered clinical trial matching tools (Antedote, Massive Bio and Genomic Focus) targeting individuals and their providers, especially community oncologists • Localized rural education program amplifying the option to virtually work with academic cancer centers of Excellence to optimize GI cancer treatment plans	**Patient Advocacy Groups** in partnership with **community-based organizations**

Treatment Spotlights

PCAN “Right Track” Model

Provides personalized support across the care journey by connecting patients to specialists and improving awareness about testing, clinical trial and treatment options to enhance shared decision making

PCAN “Clinical Trial Finder” Program

Connects patients to appropriate clinical trials based on type of pancreatic cancer, staging, treatment history and region of residence, with support from dedicated patient services case managers

GO2 for Lung Cancer “LungMatch” Program

Connects patients to dedicated navigators who provide support with biomarker testing referrals, clinical trial matching and follow up across the care journey

Hope for Stomach Cancer “Hope in a Bag” Program

Equips newly diagnosed patients with resources, including educational materials, comfort items and “My Companion Guidebook” to support patients across the care journey

CCF “Newly Connected” Program

Comprehensive resource hub for patients newly diagnosed with cholangiocarcinoma and their caregivers to support engagement in shared decision making across the care journey

LOOKING FORWARD

Sub-goal 3.4: *Strengthen provider capacity to deliver quality personalized care – improving treatment outcomes, especially for rare cancers and late-stage cases*

ACTIVITY:

Train providers – especially GI specialists and community oncologists – on tailoring treatment and coordinating with academic cancer centers **through comprehensive medical school education, medical conferences, CME trainings as well as amplifying the unique stories of rural patients**

LED BY:

Professional Medical Associations and **Academic Cancer Centers,** with input and implementation support from patient advocacy groups, hospital systems and healthcare providers

Sub-goal 3.5: *Reduce out-of-pocket costs and broaden patient access to other provider opinions and clinical trial participation*

ACTIVITY:

Support greater insurance coverage of second opinions and clinical trials **through advocacy campaigns rooted in patient outcomes, patient voices and cost-effectiveness data**

LED BY:

Patient Advocacy Groups with clinical and cost-effectiveness data provided by academic cancer centers, health economists and NCCN policy program

Well-being

Well-being focuses on overall patient wellness - supporting their physical health as well as their mental and social health - from diagnosis through survivorship to connect, support and empower patients and improve their quality of life across the GI cancer journey.

***Goal 4:** Individuals diagnosed with GI cancer can access well-being services during and after treatment to improve quality of life and increase adherence to care*

SHORT-TERM PRIORITIES

- Peer-to-peer counselling

LOOKING FORWARD

- Access to physical therapy, rehabilitative and nutrition services
- Routine access to psychosocial and care navigation services
- Standardize post-treatment care guidelines
- Advocate for greater coverage of well-being services

SHORT-TERM PRIORITIES

Sub-goal 4.1: Build supportive patient communities to enhance overall quality of life during and after treatment

ACTIVITY:	WHAT THIS COULD LOOK LIKE:	LED BY:
Peer-to-peer counselling **Focus:** Build supportive patient communities that provide or connect individuals to well-being services during and after treatment Build individual awareness of existing peer counselling options	• Identify and vet existing peer counselling programs for quality, relevance and alignment with patient needs • Diverse patient chatrooms where individuals diagnosed with GI cancer can connect with care navigation mentors and other survivors • Enhance awareness among providers, allied health workers and supportive services staff to facilitate referrals to peer counselling resources as part of standard care protocols • Grief support programs for those navigating loss—whether of a loved one or personal identity—designed to foster healing, reflection and connection	**Patient Advocacy Groups** in partnership with **community-based organizations, providers, allied health workers and supportive services staff**

Well-being Spotlights

Man Up to Cancer 'Gathering of the Wolves' Retreat'

Helping men living with cancer connect and access peer-to-peer support to strengthen their capacity and confidence to advocate for their health and actively engage in their cancer care journey

Esophageal Cancer Action Network's educational webinar series

Featuring expert-led sessions on mental health, nutrition and the importance of survivorship to raise visibility of post-treatment needs and enable broader integration of well-being services across the care journey

University of Miami "Survivorship Symposium"

By bringing together leading healthcare providers, patients and caregivers, the symposium educates and raises visibility on the latest research and initiatives focused on survivorship and improving patient well-being across the cancer care journey

GI Cancers Alliance Patient Navigators

Bringing together dedicated patient navigators who provide personalized support to help patients navigate care and access resources across the care journey

LOOKING FORWARD

Sub-goal 4.2: Drive whole-person health approaches during and after treatment, enhance adherence to care and improve treatment outcomes

ACTIVITY:	LED BY:
Support broader physical health and rehabilitative needs of individuals during and after GI cancer treatment **by enabling access to virtual or in-person physical therapy and nutritional services**	**Patient Advocacy Groups,** with implementation support from community-based organizations and hospital systems
Enhance access to allied health workers – oncology social workers, mental health counsellors and nurse navigators – **by advocating for the integration of psychosocial and navigation services into care guidelines and standards**	**Patient Advocacy Groups,** with evidence generation support from professional medical associations and academic cancer centers

Sub-goal 4.3: Coordinate and standardize post-treatment care protocols to ensure equitable access to quality care and health management support for all individuals

ACTIVITY:	LED BY:
Standardize post-treatment care guidelines **by amplifying clinical evidence, outcomes data and the patient voice to justify and advocate for its inclusion and incentivizing providers via value-based care reimbursement**	**Professional Medical Associations,** with input from academic cancer centers, patient advocacy groups and implementation support from national guideline-setting bodies, governmental agencies and insurers

Sub-goal 4.4: Reduce out-of-pocket costs and increase access to well-being services to improve individual outcomes and quality of life during and after treatment

ACTIVITY:	LED BY:
Enable greater insurance coverage of well-being services **through advocacy campaigns rooted in patient impact and health outcomes, patient voices and cost-effectiveness data**	**Patient Advocacy Groups,** with clinical and cost-effectiveness data provided by academic cancer centers, health economists and NCCN Policy Program

Cross Journey

There are activities that are critical to **prioritize at each phase of the patient journey** to drive consistency in care delivery, strengthen alignment among stakeholders and support patient-centered approaches to GI cancer care.

AWARENESS | BIOMARKER TESTING | DIAGNOSIS | TREATMENT

SURVIVORSHIP/PATIENT WELL-BEING

CROSS JOURNEY PRIORITIES

Standardizing guidelines | Establishing and implementing clinical standards – including consistent terminology, care protocols and quality benchmarks – to ensure evidence-based care delivery practices, enhance provider decision-making and strengthen care coordination.

Provider trainings | Training and building capacity of providers, including the next generation of GI doctors, across the care journey – from early risk recognition and diagnostic protocols to treatment planning and survivorship care – to support timely, tailored and coordinated clinical decision-making.

Peer-to-peer counselling | Embedding peer and mentorship support across the care journey – from diagnosis through post-treatment – to facilitate shared learning, improve navigation of care and strengthen patient advocacy and engagement in care planning.

Patient education | Developing and disseminating patient-friendly, accessible educational resources across the care journey – focused on risk recognition, awareness, treatment navigation, advocating for care and well-being – to improve health literacy and empower individuals to engage confidently in their care decision-making.

Community healthcare access programs | Scaling public-private partnerships and community-based initiatives to address socioeconomic barriers – including transportation, financial burden of cancer care and GI specialist deserts – to reduce disparities and improve access to quality care for all individuals.

Multi-disciplinary teams (MDTs) access | Equipping providers, allied health professionals and individuals with GI cancer with practical resources to build, utilize and optimize the clinical benefits of coordinated multidisciplinary teams for more personalized and integrated patient care.

Cross-Journey Spotlights

GI Cancers Alliance Patient and Caregiver Advisory Board

Bringing together patients and caregivers to serve as a collective voice for the GI cancers community and shape the development of patient-centered initiatives across the care journey.

The Path Forward

Improving outcomes for people living with, or at risk of, GI cancer requires a shared commitment from all corners of the health system and the broader community. Each stakeholder brings a unique perspective and role, and by advancing collective action through collaboration and knowledge sharing across disciplines, we can close long-standing gaps and lay the groundwork for a coordinated, inclusive and patient-centered system of GI cancer care.

We envision a future where every individual living with any GI cancer has access to timely, tailored and high-quality care. The Collective Action Roadmap for GI Cancers is grounded in that belief and offers a shared foundation for progress. It reflects the insights of the GI cancers community and sets forth a vision for what coordinated, sustained action can achieve.

Our hope is that it serves not only as a guide, but as an invitation – to foster meaningful collaboration, champion equity at every step and help shape a system of care that is responsive to those it serves. We invite all stakeholders to carry this roadmap forward – not as a one-time initiative, but as an ongoing commitment to improving GI cancer care. **Together, we can reimagine what is possible.**

Acknowledgements

We are deeply grateful to our Patient Advocacy Groups who helped inform and shape this report. Their contributions, rooted in lived experience, compassion and commitment were essential in making this a community-informed effort. This roadmap aims to reflect the needs of all those living with GI cancer, and we hope it serves as a meaningful tool to support the work to advance equitable, patient-centered care and improve outcomes for patients and their caregivers.

AstraZeneca

This report was supported by AstraZeneca.

Appendix of Resources

Pancreatic Cancer Action Network (PanCAN) – Know your tumor service

Overview of Challenge

There are few standard-of-care treatments available for patients diagnosed with pancreatic cancer and the treatments harbor limited success in improving survival outcomes. Furthermore, when Know Your Tumor launched:

- There were zero approved targeted therapies for pancreatic cancer that were based on matched alterations
- Biomarker testing, despite its potential to match patients to more successful precision medicine treatment options by identifying tumor alterations, was not widely used nor recommended in national guidelines

Know Your Tumor was created to increase delivery of and access to precision medicine for patients diagnosed with pancreatic cancer by increasing access to biomarker testing and providing doctors and patients with tailored clinical trial and off-label therapy treatment options based on the identified alterations.

Project Description

The goals of the 'Know Your Tumor' service was to:

- Match patients to tailored treatment options based on tumor biopsy biomarker testing results in the academic and community settings
- Gather data on the impact of biomarker testing and increased access to precision medicine services for patients with pancreatic cancer

Success Factors

The success of Know Your Tumor is attributed to:

- The existence of PanCAN's robust Patient Services program and targeted and inclusive messaging for patients and caregivers on the importance of biomarker testing
- Buy-in from key opinion leaders who championed biomarker testing for pancreatic cancer
- Partnerships with leading companies and laboratories in the biomarker testing space
- Spotlighting Know Your Tumor patient success stories to underscore the human impact of the program on their life
- Publishing results from the Know Your Tumor service at national conferences and peer-reviewed journals

In more recent years, as biomarker testing became a standard of care for most patients with pancreatic cancer, the Know Your Tumor service shifted to prioritizing access to biomarker testing services for patients who are vulnerable to geographic or socioeconomic healthcare access barriers.

Through the Know Your Tumor Service, biomarker testing was provided to patients free of charge. PanCAN partnered with commercial testing companies and labs to create a care pathway for referring patients and their doctors directly to biomarker testing, guiding them through obtaining tumor tissue and sending it to the lab. Once a patient received their testing report, the PanCAN Patient Services team helped walk patients through their results and navigate and identify options to molecularly tailored clinical trials and targeted therapies.

Project Impact

The goals of the 'Know Your Tumor' service was to:

- **Reach:** Provided over 1700 biomarker testing reports to patients with pancreatic cancer
- **Policy influence:** Leveraging publications and impact data from Know Your Tumor, along with other impact and precision medicine research from academic institutions such as Memorial Sloan Kettering, biomarker testing for pancreatic cancer was integrated into the National Comprehensive Cancer Network (NCCN) treatment guidelines for pancreatic adenocarcinoma and coverage for some biomarker testing services increased for those diagnosed with pancreatic cancer.
- **Patient outcomes:** In a retrospective analysis of Know Your Tumor, patients who received treatment tailored for an actionable alteration live longer (2.58 years versus 1.51 years) than patients who did not receive treatment based on an identified alteration[viii]

In collaboration with pancreatic cancer researchers, PanCAN has published over 10 peer-reviewed publications and abstracts at national conferences with learnings from Know Your Tumor.

Hope for Stomach Cancer – Ask the experts virtual peer support groups

Overview of Challenge

Patients diagnosed with gastroesophageal cancers – especially those who are newly diagnosed, facing surgery, or living with advanced-stage disease – often lack access to clear, timely information about treatment options, surgical procedures and how to manage side effects. While peer support groups offer emotional connection, they often lack the clinical guidance needed to support informed decision-making.

Recognizing a need for trusted clinical navigation support, Hope for Stomach Cancer (Hope), in collaboration with the Esophageal Cancer Education Foundation, launched the *Ask the Experts Support Groups* virtual series to bridge access to clinical knowledge to empower patients to advocate for the best treatment.

Project Description

Hope for Stomach Cancer's Ask the Experts series is a monthly virtual Zoom support group that connects patients and caregivers with leading GI oncologists, surgeons and other patients. The program includes two tracks:

1. For those who are facing, or have undergone, a total or partial gastrectomy as their primary curative cancer treatment
2. For those with Stage IV (advanced) or recurrent stomach, esophageal, or gastroesophageal junction (GEJ) cancer

Hope's internal team and medical advisors curate content for each session based on emerging treatment trends and participant needs. Participants can ask the medical professionals questions related to their treatment options, learn about new clinical insights and connect with peers to share experiences and build a community. Each session is promoted nationally and internationally, with an emphasized focus on underserved communities.

Success Factors

The success of *Ask the Experts* stems from:

- Building trusted partnerships with a rotating set of GI oncologists and surgeons to help clarify clinical information
- Complementing clinical support with emotional peer-to-peer support
- Co-creating sessions with patient advocates to ensure the session is relevant to patients, leverages a patient-centered tone and prioritizes topics that are patients-driven
- Providing the sessions for free and through accessible digital platforms like Zoom
- Promoting series through social media as well as clinical networks

Foundationally, the program's hybrid of clinical clarity and emotional support is central to its continued impact.

Project Impact

- **Reach:** Over 1,000 patients and caregivers across 40+ U.S. states and internationally
- **Patient outcome:** Increased understanding of treatment pathways, surgical strategies and biomarker relevance among session participants
- **Patient outcomes:** Reduced feelings of anxiety and isolation, increased confidence and trust in medical decision-making and improved care plan adherence, especially for underserved communities

Cholangiocarcinoma Foundation (CCF) – CholangioConnect and peer-to-peer support

Overview of Challenge

When supporting patients and caregivers affected by cholangiocarcinoma, a rare GI cancer, emotional isolation remains a significant challenge. While many resources exist to educate and guide individuals medically, there is also a need for a meaningful human connection. Patients often navigate their diagnosis without meeting someone else with the same disease, leaving them feeling isolated and alone in their treatment journey. At the same time, caregivers report feeling unsupported and ill-equipped to fully support those they are caring for.

As a result, there was a clear opportunity for individuals to create a structured, empathetic way to connect with others who truly understand what they're going through. CholangioConnect is a focused mentoring program that connects patients and caregivers to mentors that have firsthand experience in cholangiocarcinoma.

Success Factors

The success of CholangioConnect is attributed to its personalized matching process, which considers diagnosis details, treatment journeys and lived experiences to ensure relevant, empathetic support. Mentors undergo comprehensive training and many encourage their mentees to become mentors when ready – creating a natural cycle of support.

CCF staff collaborate with program participants to create an ongoing recruitment strategy through social media posts and advertisements targeted towards members of the CCF community, newsletter articles, blog posts and press releases.

Project Description

CholangioConnect was developed to provide structured mentorship support to individuals impacted by cholangiocarcinoma. This program matches patients and caregivers with trained mentors with lived experience – forming one-on-one connections grounded in shared treatment journeys, roles, and personal backgrounds. Specifically, the program seeks to connect people with mentors who share their age, gender, location, treatment history and more to ensure more personalized support.

The program extends the Foundation's support model beyond patient education, resource development and research, serving as a key relational touchpoint that helps participants feel seen, heard and less alone. This peer-to-peer platform helps anyone touched by cholangiocarcinoma, at any stage of their journey, find a mentor to ask questions and get support from someone with personal experience with the disease.

Project Impact

In the past year (2023 – 2024)

- **Reach:** 339 matches facilitated
- **Patient reach:** 22% increase in support requests – indicating growing awareness and trust in the program
- **Geographical reach:** Reduced feelings of anxiety and isolation, increased confidence and trust in medical decision-making and improved care plan adherence, especially for underserved communities
- **Mentors trained:** 56% increase in new mentors – expanding the program's reach and diversity

Glossary of Stakeholder Roles

Patients & Caregivers

- Act as advocates, decision-makers and partners across the GI cancer journey
- Share stories of their lived experience to inform solutions and support other individuals with GI cancer

Patient Advocacy Groups (PAGs)

- Design and implement patient-centered education campaigns, care navigation resources and policy & advocacy initiatives
- Amplify and integrate the patient voice and lived experience into healthcare provider trainings, clinical care protocols, policy change and programs focused on addressing socioeconomic barriers to care to improve access to quality GI cancer care

Community-Based Organizations (CBOs)

- Act as trusted leaders and educators – faith-based organizations, community event centers, minority and intercultural resource centers – among the communities they serve
- Directly engage with communities to deliver and scale culturally competent and locally-tailored awareness programs, educational resources and navigation tools

Healthcare providers, including allied health workers and supportive service providers

- Deliver quality and standards-aligned care, build trust, support patient navigation and translate clinical guidance into accessible information for individuals diagnosed with GI cancer and their caregivers

Professional Medical Associations

- Inform and support development of clinical guidelines and care standards for GI cancers
- Deliver continuing medical education (CME) training to healthcare providers, including raising awareness of evolving standards in GI cancer care and emerging cancer innovations

National Guideline Setting Bodies

- Inform and support development of clinical guidelines and care standards for GI cancers and translate updated standards into clinical decision-making tools and care protocols for providers, hospitals and payers

Academic Cancer Centers & Cancer Centers of Excellence

- Conduct and disseminate research to inform clinical guidelines and quality care standards, medical education curricula and approaches to advocacy and education campaigns
- Provide cutting-edge care to accelerate improvements in GI specialty care

Hospital systems

- Integrate guidelines and standards of care into care delivery practices, including monitoring adherence and building capacity of healthcare providers to follow new care protocols
- Build multidisciplinary cancer care teams – inclusive of mental health counsellors, nurse navigators and oncology social workers – to deliver whole-person-healthcare

Governmental agencies, public payers & regulatory bodies

- Establish the policy and payment landscape for accessing GI cancer care, including setting reimbursement models and quality standards, to influence commercial insurer coverage decisions and hospital care delivery practices

Industry partners

- Conduct research to drive innovation in GI cancer diagnosis and treatments and educate stakeholders on upcoming innovations

Medical schools

- Develop and implement standards-aligned curriculum to train the new generation of healthcare providers on recognizing, diagnosing and effectively treating GI cancers

Commercial insurers

- Determine which GI cancer services are accessible and affordable to patients as well as influence provider behavior and care practices through coverage policies, reimbursement rates, provider payment models and utilization management

Trusted Media Partners and community leaders and influencers

- Act as trusted community advocates, messengers and educators to support local amplification of GI cancer-related support tools and resources to increase credibility and visibility among key audiences

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! We acknowledge that **designing, implementing and evaluating all recommended activities to enable meaningful progress, at scale, depends on sustained public and private investment** from **funding organizations** – including philanthropic organizations, private foundations, industry and government agencies. While funding partners are not detailed in the roadmap, it is critical for funders to understand the critical role they play in supporting stakeholder efforts.

Program Evaluation Framework

This evaluation framework is designed to offer guidance on measuring the impact of prioritized activities over time – outlining short-term indicators related to reach and uptake as well as longer-term outcomes tied to behavior and policy change.

Measuring impact and tracking progress is not only critical for evaluating program success but also serves as a mechanism for adapting program strategies to deliver more value and impact to the GI cancers community. Stakeholders should tailor these indicators to align with the scope, focus population and intended outcomes of the prioritized activity.

FOCUS AREA	SHORT-TERM IMPACT	LONG-TERM OUTCOMES
Patient awareness campaigns **Examples include:** national and regional GI cancer campaigns	• # of people reached through media impressions • # or percent reach among populations at high risk • Percent increase in PAG website traffic	• Increased awareness of [*specific GI cancer*] – e.g. risk factors and early symptoms or care options • **Increase in individual health seeking behaviors for specific GI cancer services** • Increase in high-risk individuals seeking specific GI cancer care services • Increased individual confidence in navigating GI cancer care and resources • Improved patient confidence to advocate for health concerns and care • Increased access to quality services and providers as a result of self-advocacy – *e.g. biomarker testing, quality specifics and oncologists*
Patient education events **Examples include:** GI cancer symposiums	• # of people who attended event • # of resources disseminated • Post-event satisfaction or feedback scores • Percent of attendees who report improved understanding of GI cancers and the care pathway	
Patients advocacy & care navigation tools **Examples include:** at-home risk assessment tests, provider-patient discussion tools, patient education toolkits	• Rate of engagement with tools and resources (clicks, shares, downloads) • # of people using discussion and education tools • # or percent of 'at-risk' users that access GI cancer resources • Percent increase in PAG website traffic • Social media engagement (likes, shares, comments) • Percent of users who report improved understanding of GI cancers and the care pathway	
Peer-to-peer counselling **Examples include:** care navigation hotlines, patient chatrooms	• # of individuals connected to peer-to-peer counselling initiatives • Percent increase in individual understanding of care options – *e.g. treatment, clinical trials, well-being services – post-peer engagement* • Post-peer engagement satisfaction or feedback scores	• Improved patient confidence to advocate for care • Increased individual confidence in navigating GI cancer care • **Percent increase in access or uptake of services** – *e.g. testing, clinical trial enrollment*

FOCUS AREA	SHORT-TERM IMPACT	LONG-TERM OUTCOMES
Provider capacity building **Examples include:** national and regional GI cancer campaigns	• # of providers reached with training materials *[stratify by provider type – PCP, GI specialist, community oncologist]* • Percent increase in pre- and post-training knowledge assessment scores • Percent increase in provider's confidence on related to training focus area • # of institutions adopting training	• Increased [*specific GI cancer*] risk detection among providers • Improved practice change [quality care assessment score] among providers • Increased provider adherence to quality care practices • Increased use of biomarker testing results to inform treatment plan development • Increased referrals to specific services *– e.g. testing, specialist care or clinical trials* • **Reduced average time to diagnosis**
Medical school education	• # of medical schools incorporating GI cancer training • # of students receiving updated GI cancer curricula • Percent increase in pre- and post-competency scores among medical students • # of continuing medical education options related to GI cancers	• Increased competency in GI cancer risk detection and care pathways among medical school graduates • **Improved early risk detection among new PCPs and GI providers**
Standardizing care guidelines **Examples include:** routine care protocols for biomarker testing; clinical standards for post-treatment care	• # of clinical guidelines or protocols updated • # of publications developed to inform guideline updates • # of hospital or health systems that have updated protocols to align with new guidelines • # of providers trained on updated protocols	• **Increased access to quality and comprehensive GI cancer care** – *e.g. biomarker testing, multidisciplinary treatment, well-being services* - among patients ◦ Improved access to services among underserved communities (e.g. racial and ethnic minorities, un- and under-insured populations) • Increased use of biomarker testing results to inform treatment plan development • Increased integration of guidelines into hospital's routine care protocols • Increased provider competency in updated care protocols
Policy and advocacy **Examples include:** advocating for greater insurance coverage of testing or well-being services	• # of policymakers reached with advocacy tools and evidence • # of decision-makers reached with evidence related to the cost-effectiveness of GI cancer services – *e.g. biomarker testing, clinical trials, well-being services, second opinions*	• Increased payer coverage of specific GI cancer services • Increased access to specific services through updated insurance coverage ◦ Improved access to services among underserved communities *(e.g. racial and ethnic minorities, un- and under-insured populations)* • **Decreased out-of-pocket costs associated with biomarker testing**

Citations

[i] American Cancer Society. (2025). Cancer Facts & Figures 2025.

[ii] CDC. (2025, February). Cancer data and statistics.

[iii] Siegel, R. L., Kratzer, T. B., Giaquinto, A. N., Sung, H., & Jemal, A. (2025). Cancer statistics, 2025. *CA: a cancer journal for clinicians, 75*(1), 10–45. https://doi.org/10.3322/caac.21871

[iv] Fansiwala, K., Qian, Y., & Liang, P.S. (2024). Gastric Cancer Risk Factors in a Veteran Population. *NIH, Military Medicine. 189*(3-4). doi: 10.1093/milmed/usad319.

[v] Patel, N., Yopp, A. C., & Singal, A. G. (2015). Diagnostic delays are common among patients with hepatocellular carcinoma. Journal of the National Comprehensive Cancer Network: JNCCN, 13(5), 543–549. https://doi.org/10.6004/jnccn.2015.0074

[vi] Ju, M.R. et al. (2022). Variation of Hepatocellular Carcinoma Treatment Patterns and Survival Across Geographic Regions in a Veteran Population. *NIH, Annals of Surgical Oncology. 29*(13), 8413-8420. doi: 10.1245/s10434-022-12390-7.

[vii] Bibeau, K., Bachini, M., Lindley, A.A., et al. (2021). Exploring the Diagnostic Journey and Life Impact of Patients with Cholangiocarcinoma. 2021 Gastrointestinal Cancers Symposium, Abstract 277.

[viii] Pishvaian M.J. et al. (2020). Overall survival in patients with pancreatic cancer receiving matched therapies following molecular profiling: a retrospective analysis of the Know Your Tumor registry trial. *The Lancet Oncology. 21*(4): 508 – 518. doi: 10.1016/S1470-2045(20)30074-7.

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