SDIRSACR

Official Journal of the Serbian Association for Cancer Research
Schelle A., Kapitein P., Oncol Insights 2026 No. 4
Manuscript received on: June 18, 2026
Manuscript revised on: July 3, 2026
Manuscript accepted on: July 6, 2026

613/614:616-006.04-051
https://doi.org/10.66552/OI202641

Oncology Insights

PATIENT ADVOCATE POINT OF VIEW

Open access

Inspire2Live: Advancing the Global Voice of Patients with Cancer

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Abstract
Cancer remains a profound global health challenge, disproportionately affecting populations in low- and middle-income countries who frequently lack representation in decision-making processes. Inspire2Live is an international advocacy movement committed to amplifying the patient voice and fostering collaboration across the healthcare ecosystem. This article outlines the mission, vision, and operational framework of Inspire2Live, with particular emphasis on equitable access, patient-centred innovation, and global solidarity in cancer care.

Introduction

Each year, millions of individuals across the globe receive a cancer diagnosis. Yet, the burden of mortality falls overwhelmingly on those living in low- and middle-income countries (LMICs), where access to care, early detection, and treatment remains severely limited. Despite being most affected, these populations are often excluded from meaningful participation in the discussions that shape policy, research agendas, and healthcare delivery.

Inspire2Live stands as a corrective force within this inequitable landscape. It is founded upon a simple yet uncompromising principle: '**If about us, not without us.'** The organisation exists to ensure that the lived experiences of patients are not marginalised, but rather placed at the centre of global oncology discourse.

Mission and Vision

Inspire2Live identifies itself unequivocally as **the patient's voice in cancer**. Its mission is to inspire and empower patients, alongside all stakeholders in healthcare, to collaborate in preventing, treating, and ultimately eliminating cancer.

The organisation's vision is both ambitious and necessary: a world in which cancer care is equitable, inclusive, and driven by the priorities of patients themselves. It recognises that global progress must not be measured solely by advances in wealthy nations, but by improvements in outcomes for the 7.8 billion people worldwide—particularly those currently underserved.

Patient Advocacy as a Structural Imperative

Central to Inspire2Live's philosophy is the assertion that ethical and effective healthcare policymaking must include patients as equal partners. Patient advocates within the organisation are not token representatives; they are professionals drawn from diverse backgrounds, including research, clinical practice, policy, and industry.

This multidisciplinary expertise enables advocates to engage at the same level as stakeholders within what is often termed the "medical-industrial complex"—including governments, pharmaceutical companies, regulators, and payers.

By fostering a **"coalition of the willing"**, Inspire2Live promotes collaborative action rooted in shared responsibility and mutual respect.

The World Campus: A Global Community of Practice

At the heart of Inspire2Live is its international network, known as **The World Campus**. Comprising approximately 120 members from over 55 countries, this community embodies both diversity and unity in confronting the realities of cancer. Members meet regularly to exchange knowledge, develop initiatives, and strengthen relationships. Monthly sessions feature global experts addressing pressing health topics, while bi-weekly working group meetings focus on practical action. These interactions cultivate not merely professional collaboration, but a shared sense of purpose and solidarity. The Annual Congress further consolidates this bond, transforming the network into a cohesive movement committed to systemic change.

In the paragraphs below, some tangible examples can be found, with more details available on our website about our projects and achievements; our advocates sometimes perform very small and sometimes very large projects locally, which are not always known at the central level.



Figure 1. Internal session roundtable during the Inspire2Live Annual Congress in Amsterdam.

Strategic Areas of Action

Inspire2Live's work is organised into several thematic priorities, each addressing critical gaps in global cancer care:

1. Awareness

Early detection significantly improves outcomes and reduces costs. Inspire2Live's awareness initiatives aim to build trust within communities and encourage both symptom recognition and participation in screening programmes. Cultural sensitivity is central to these efforts. Said NGO in Lebanon, for example, has very strong advocacy on colorectal cancer screening. Every year, they campaign with a walkathon in Beirut under the patronage of the Ministry of Public Health and supported by WHO Lebanon.

Breast Care International in Ghana has a yearly breast cancer awareness walk with thousands of people walking for the cure of cancer.



Figure 2. Inspire2Live at a yearly breast cancer awareness event in Ghana.

2. Empathy
Understanding the lived experience of patients with cancer, particularly in resource-limited settings, is essential. Tools such as *Real Lives Games*, developed by members, provide immersive educational experiences that foster empathy and awareness across diverse audiences.

3. Prevention
With up to 50% of cancers preventable through lifestyle changes, education is paramount. Initiatives include promoting healthy living and supporting vaccination programmes, such as HPV vaccination, which has already demonstrated life-saving potential in regions like Africa. Our members played an important role in the awareness campaign and in convincing, together with the WHO, the government to adopt the one-dose-policy.

4. Early Diagnosis
Timely diagnosis remains a major challenge in LMICs. Inspire2Live supports innovations such as affordable multi-cancer blood tests. Through its not-for-profit social enterprise, **OncoInv** (www.oncoinv.org), the organisation works to make early detection accessible to all.
The first implementation of the product(s) started in 2023. It is already used in Bulgaria, Brazil, China, Costa Rica, Mexico, Nigeria and Poland.



Figure 3. Inspire2Live promoting cancer prevention measures in Africa.

5. Palliative Care
The lack of adequate pain relief in many countries represents a profound humanitarian failure. Inspire2Live advocates for improved access to palliative care, emphasising that relief from suffering is a fundamental human right. One of our members, professor Christian Ntizimira, is travelling around the globe to advocate his approach: 'The Safari Concept.'

6. Access to Treatment
Global disparities in treatment access are ethically indefensible. Inspire2Live actively campaigns to reduce these inequalities, asserting that inaction in the face of suffering is itself a form of injustice. To get the medicines to the people who need them, we have our local people (often physicians) work together with reliable organizations like the Access to Medicines Foundation, IDA Foundation and Medicines Patent Pool. A new initiative is to get more trials for patients with cancer into Africa and Latin America.
In Europe, the Dutch Parliament has unanimously approved the Whole Genome Sequencing diagnostic method for patients with a Cancer of Unknown Primary, as part of the basic healthcare package, as a result of hard scientific work and lobbying by Inspire2Live. By bringing together top researchers from around the world who co-designed organoid projects for breast, colon, lung, pancreatic and prostate cancers, Inspire2Live participated in the introduction of organoids to many cancer research labs like the Cold Spring Harbour Lab, MSKCC and Sanger, to name just a few.

Methodology and Approach
Inspire2Live operates through a combination of advocacy, collaboration, and innovation:

- **Representation**: Ensuring patient voices are present in healthcare boards, research initiatives, and policy discussions.
- **Participation in Research**: Enhancing the relevance and quality of scientific studies through patient involvement.

- **Project Initiation**: Pioneering initiatives such as organoid-based drug screening and personalised treatment approaches.
- **Knowledge Exchange**: Facilitating global learning through expert dialogue and working groups.



Figure 4. Inspire2Live promotional event in Africa.

Impact and Ongoing Work

- The organisation's tangible impact is reflected in its projects, partnerships, and initiatives, including:
- The establishment of **OncoInv**, expanding access to early detection technologies.
- A wide portfolio of advocacy projects and global collaborations. We are very proud of our initiative with organoids. We were the first to set up projects with human tumour tissue.
- Inspire2Live was, in 2011, the first organization that set up research with institutes from the Europe and North American continent. This is now normal, but we were the catalysts.
- A growing network of patient advocates, ambassadors, and partners dedicated to systemic change.

Further details can be found via:
Achievements: https://inspire2live.org/our-impact/achievements/
Projects: https://inspire2live.org/our-work/projects/

Conclusion

Inspire2Live represents a vital shift in global cancer advocacy—from a system that speaks about patients to one that speaks **with** them. Its work highlights a stark reality: inequality in cancer care is not inevitable, but a consequence of collective inaction.

The organisation's message is both urgent and clear: **justice in medicine demands participation, equity, and courage**. As disparities continue to widen, the responsibility to act is shared by all stakeholders. In the fight against cancer, silence is not neutrality—it is complicity.

We look forward to establishing new collaborations with interested associations and individuals in your countries and region.

Contact and Further Information

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Patient Advocates:	https://inspire2live.org/about-us/patient-advocacy/meet-our-patient-advocates/
Ambassadors:	https://inspire2live.org/our-impact/ambassadors/
Heroes of Cancer:	https://inspire2live.org/about-us/patient-advocacy/heroes-of-cancer/
Partners:	https://inspire2live.org/about-us/the-patients-voice/partners/