EU PROJECTS

EU-CiP
Part of the European Cancer Patient Digital Centre

Funded by the European Union

Building a Trusted and Accessible Cancer Information Ecosystem in Europe

AN EU-CIP STAKEHOLDER CO-CREATION FORUM REPORT

Executive summary

Despite the growing availability of digital health information, access remains fragmented, inconsistent and unequal across Europe. Barriers related to language, health literacy, misinformation and the complexity of healthcare systems continue to affect patients, particularly those with rare cancers and underserved populations. The European Cancer Information Portal (EU-CIP) is being developed to improve access to trustworthy, patient-centred cancer information by connecting and strengthening existing resources rather than replacing them.

Discussions during the Stakeholder Co-Creation Forum highlighted broad support for a coordinated European approach that aggregates and harmonises evidence-based information from trusted sources and presents it in clear, accessible language. Participants consistently identified trust, transparency, quality assurance and regular content updates as essential foundations for the platform.

The Forum also emphasised the importance of designing EU-CIP around users' needs. Information should be easy to navigate, accessible across different levels of health literacy, and integrated into clinical practice to support communication between patients and healthcare professionals.

Participants recognised that the platform will operate within a rapidly evolving digital environment shaped by search engines and AI-driven tools. Its long-term success will depend on remaining visible, accessible, multilingual and responsive to changing user behaviours, supported by strong governance and ongoing stakeholder collaboration.

Methodological note

This report presents a qualitative synthesis of discussions held during the EU-CIP Stakeholder Co-Creation Forum. Contributions were collected through plenary discussions and facilitated breakout sessions involving patients, caregivers, healthcare professionals, researchers, policymakers and other relevant stakeholders. Inputs captured during the sessions were reviewed and analysed by the report authors to identify recurring themes, shared concerns and key considerations raised by participants.

The findings presented in this report reflect the perspectives and insights expressed during the Forum and represent a synthesis of stakeholder contributions. They do not reflect a formal voting process, consensus procedure, or formal validation by participants. The resulting recommendations and implications for EU-CIP design and implementation were developed by synthesising these discussions alongside the objectives and context of the initiative.

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Key findings of the stakeholder forum

Access to cancer information remains fragmented and uneven across Europe
Clear, reliable cancer information is not consistently accessible across countries.

Trust, quality and transparency are essential foundations
The platform's credibility depends on rigorous quality assurance, clear sourcing, regular updates and visible endorsement from trusted institutions.

Health literacy and misinformation are persistent challenges
There is a need to support users in identifying reliable sources and strengthening digital health literacy alongside evidence-based content.

Patient-centred, accessible design is critical
Information must be clearly structured, easy to understand, and responsive to user needs across the cancer journey.

Accessibility and inclusion require deliberate action
Barriers related to language, literacy, digital skills and socio-economic factors must be addressed to ensure equitable access and avoid reinforcing disparities.

AI presents opportunities and risks
Artificial intelligence can support scalability, particularly in multilingual content delivery, but requires strong governance and validation to ensure accuracy and cultural appropriateness.

Visibility and discoverability are strategic priorities
Ensuring content is easily found through search engines and AI-driven tools is critical to the platform's effectiveness.

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Introduction

Access to clear, reliable and understandable information is a fundamental component of high-quality, patient-centred cancer care. Across the cancer journey, from prevention and diagnosis to treatment, survivorship and palliative care, information plays a critical role in supporting informed decision-making, patient empowerment and overall quality of life. Patients, caregivers and families need accessible and trustworthy information to navigate complex healthcare systems, understand treatment options, and engage meaningfully with healthcare professionals. Despite the increasing availability of cancer information, access across Europe remains fragmented, inconsistent and often difficult to navigate. Patients frequently encounter information that is overwhelming, not tailored to their needs, or outdated, with disparities in health literacy and digital skills further reinforcing inequalities. At the same time, the growing reliance on digital tools, including search engines, social media and artificial intelligence, is reshaping how information is accessed. While this expands access, it also raises challenges related to misinformation and trust, reinforcing the need for clear, reliable, and patient-friendly information.

The European Cancer Information Portal (EU-CIP) is being developed as a response to these challenges. As part of Europe's Beating Cancer Plan and a key component of the future European Cancer Patient Digital Centre (ECPDC), EU-CIP aims to provide a coherent framework for delivering high-quality cancer information across Europe. The initiative seeks to aggregate and adapt evidence-based content from trusted sources and make it accessible in a clear, non-technical and user-friendly format. By doing so, it aims to strengthen health literacy, support informed decision-making, empower patients and caregivers, and reduce inequalities in access to information.

A central feature of the initiative is its co-creation approach, involving patients, healthcare professionals, researchers and other stakeholders to ensure that the platform reflects real needs and is usable across diverse contexts. Within this context, a Stakeholder Co-Creation Forum was convened to gather perspectives on the development and implementation of EU-CIP. The forum brought together 136 unique participants from across Europe, including patients, caregivers, healthcare professionals, researchers, representatives of cancer organisations, policymakers, national parliamentarians, representatives of European Union institutions and members of the Cancer Mission Board. Through plenary discussions and breakout sessions, participants explored current challenges in accessing and using cancer information, as well as expectations for this European-level initiative.

This report summarises the main messages emerging from these discussions. It presents the key findings of the Stakeholder Forum and outlines the implications for the design and implementation of EU-CIP, with the aim of supporting its development as a trusted, accessible and impactful resource within the European cancer ecosystem.

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Trustworthy and high-quality information as the foundation

EU-CIP's value depends on being a credible, evidence-based and up-to-date source of information. This includes strong quality assurance, transparency of sources and visible institutional endorsement.

The portal is designed to aggregate reliable information from European and international sources and present it in clear, non-technical language tailored to patients, survivors, caregivers and relatives.

A central theme in the discussion was the importance of continuous monitoring and improvement. The platform could integrate user feedback mechanisms, such as simple evaluation tools and open channels for information requests, alongside usage analytics, to help inform future developments and support its long-term relevance and sustainability.

Ensuring trust and addressing misinformation were also identified as important priorities. Beyond providing evidence-based content, the portal could contribute to helping users better assess the reliability of online information and strengthen their digital health literacy. Maintaining accurate and regularly updated content will also be important to support credibility and minimise the risk of outdated or misleading information.

EU-CIP could be seen as a central entry point for cancer information, complementing rather than duplicating what already exists at national and local level. Its added value would also lie in helping guide users towards the most relevant sources where needed, including through clear pathways for further support when information requirements cannot be fully met directly on the platform.

Artificial intelligence can support scalability, particularly for multilingual content, but requires careful validation to ensure accuracy and cultural sensitivity. At the same time, the evolving digital landscape means that visibility will depend on content being discoverable and referenced across platforms.

The scope of the portal should remain clearly defined, focusing on general, validated information rather than detailed listings of clinical trials or specialised services. Clear communication about its purpose will help manage expectations.

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Integration within healthcare systems and existing ecosystems

EU-CIP should be designed as a complementary resource that fits within existing national and European cancer information environments, rather than replacing them. Its role is to reinforce and extend what is already available, supporting continuity between institutional information, clinical care and patient needs across different settings.

A key function of the platform is to support clinical interactions by offering patients reliable information they can consult before and after appointments. This can help strengthen understanding, facilitate shared decision-making and improve the quality of discussions between patients and healthcare professionals.

To support usability across diverse needs and moments in the care pathway, content should follow a structured, layered format. This allows users to access concise core information first, with the option to progressively explore more detailed content when required. The structure should reflect the full cancer journey, ensuring continuity and coherence across stages of care, while maintaining a clear and empathetic tone throughout.

Healthcare professionals, including cancer nurses, patient navigators, general practitioners and other care providers, will be essential in promoting the platform and integrating it into routine practice. Their role in introducing and contextualising the tool can significantly enhance uptake and ensure it is used effectively within care pathways.

Successful implementation will also depend on addressing practical challenges, including maintaining a balance between comprehensiveness and clarity, adapting content to national and linguistic contexts, and securing strong institutional endorsement to reinforce credibility and encourage consistent use.

Scalability, visibility, and long-term sustainability in a digital Europe

EU-CIP must be designed to operate effectively within a rapidly evolving and increasingly complex digital environment. This requires ensuring multilingual scalability, responsible and well-governed use of AI, strong online discoverability, continuous monitoring of content and alignment with EU digital health and policy frameworks to ensure long-term relevance.

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A key consideration is visibility at the point of need. Patients often experience information overload, particularly at diagnosis or during emotionally difficult moments, when their ability to process complex material is limited. In these situations, it is important that EU-CIP is easily discoverable through common search behaviours and integrated digital pathways, so that users can reliably reach clear and trustworthy information when they actively seek it.

EU-CIP is positioned as a strategic component within the broader European cancer and digital health ecosystem. Building on the European Knowledge Centre on Cancer, it aims to consolidate scientifically robust and harmonised content while translating it into accessible, patient-friendly formats. In doing so, it helps bridge the gap between complex evidence and everyday understanding, supporting both patients and carers.

The platform also contributes to wider EU priorities, including the Digital Decade 2030, by supporting inclusive digital services and data-driven innovation in health. At the same time, it aligns with the European Code of Cancer Practice, reinforcing the importance of clear and reliable information as part of patient-centred care.

In terms of long-term sustainability, it would be important to ensure that appropriate structures are in place to support the ongoing maintenance, governance, and evolution of the platform over time, so that it remains relevant, trusted, and fit for purpose in the long run.

Conclusion and next steps

EU-CIP has the potential to strengthen access to trusted, patient-centred cancer information across Europe by complementing existing national resources and making evidence-based knowledge easier to find and understand. Stakeholder discussions confirmed broad support for a coordinated European approach built on trust, accessibility and collaboration.

Successful implementation will depend on strong governance, transparent quality assurance, meaningful integration into healthcare pathways and the responsible use of digital technologies, including AI. Continued collaboration with patients, healthcare professionals and national stakeholders will be essential to ensure the platform remains relevant and responsive to evolving needs.

The next phase should focus on establishing governance and quality standards, refining the platform's scope and content, strengthening accessibility and co-creation, and implementing continuous monitoring and feedback mechanisms to support long-term sustainability.

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