



Policy Brief

The Manifesto of the Oncology Focused Living Labs

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Policy Brief:

The Manifesto of the Oncology Focused Living Labs

Co-authored & supported by:

- Thessaloniki Active & Healthy Ageing Living Lab (Thess-AHALL) (<https://thessahall.com/>)
- AUTH Lab of Medical Physics & Digital Innovation (AUTH iMedPhys) (<https://imedphys.med.auth.gr/>)
- European Network of Living Labs (ENoLL) & the ENoLL Health & Well-Being Action-Orientated Task Force (H&W AOTF) (<https://enoll.org/>)
- LifeChamps: A Collective Intelligent Platform To Support Cancer Champions (H2020 Project) (<https://lifechamps.eu>)
- European Cancer Patient Coalition (ECPC) (<https://ecpc.org/>)
- International Society of Geriatric Oncology (SIOG) (<https://siog.org/>)

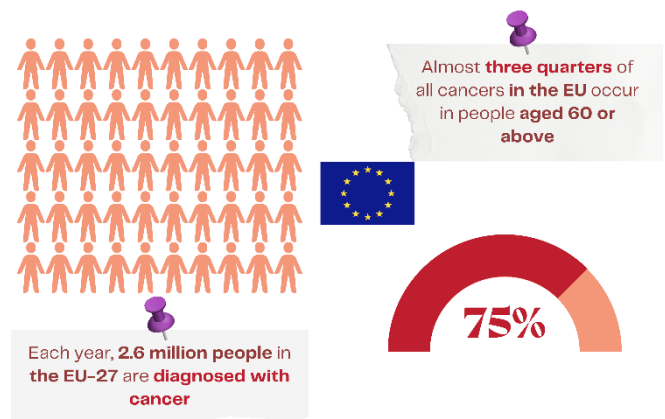
Executive Summary



Cancer has become one of the main priorities of the EU public healthcare. Within the context of Europe's Beating Cancer plan, and the EC's Mission Board for Cancer several recommendations and action points have been identified towards the effective understanding & tackling of cancer in the whole care continuum. It is estimated that the digital transformation of the current cancer clinical practice and care models will improve the provision of service & support to patients, while they will lead to the transition of the oncology workforce into a new up-skilled era. This Policy Brief explores the potential role and added value of the Oncology-Focused Living Labs, both as technology & open innovation accelerators, as real-life experimentation & stakeholder empowerment enablers, providing key recommendations, as stemmed from a series of public consultation events and initiatives, led by the co-authoring organizations.

Introduction

Cancer consists one of the biggest healthcare challenges worldwide. Considering that Europe has a quarter of all cancer cases and less than 10 % of the world's population, it is evident that cancer is a huge threat for Europe's citizens and health systems. Each year, 2.6 million people in the EU-27 are diagnosed with cancer. Without strong action, the number of cancer cases in Europe will increase by 25 % by 2035¹. Given that the challenges that arise from cancer for European citizens and countries are vast, conquering cancer



¹ https://ec.europa.eu/info/publications/conquering-cancer-mission-possible_en

in Europe calls for multiple actions by many stakeholders.

On the occasion of the World Cancer Day (3rd of February 2021), the European Commission officially launched its promising and long-awaited **Europe's Beating Cancer plan**², a key EU Public Health priority for the next coming years. In June 2020, the Mission Board for Cancer of the Directorate-General for Research and Innovation (DG RTD), published **its interim progress report towards the definition of a Mission in the area of Cancer**³. Both initiatives set out actions & recommendations to support and implement research & innovation activities in the Member States.

Cross-cutting recommendations highlighted the need for the **digital transformation** of the clinical practice for cancer, **personalised treatment & care** models, as well as actions to **reduce cancer inequalities** across the EU. Among the cross-cutting recommendations, the following idea was highlighted:

RECOMMENDATION 12:
Accelerate innovation and implementation of new technologies and create **Oncology-focused Living Labs** to conquer cancer

The idea behind the recommendation and the establishment of thematic living labs, focused on cancer research & innovation actions is summarized as below:

“The Oncology-focused Living Labs will enhance cross-sector research, knowledge-sharing and implementation of new technologies. Through increasing mutual understanding, and creating efficient and effective collaborative approaches to driving innovation, job creation and industrial competitiveness in healthcare and health-related industries, innovation will be steered (e.g. facilitated, protected and rewarded) in the direction of solving the societal challenge

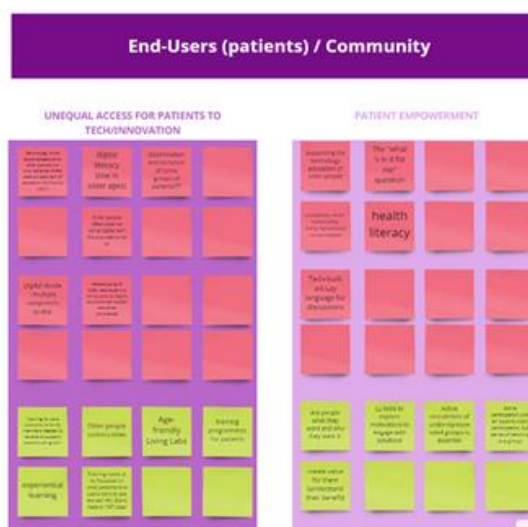
of the cancer burden, as well as generating economic growth, wellbeing and technological spill-overs. (Interim Report: Conquering cancer, mission possible – DG RTD/Mission Board for Cancer)

Towards this end, an open dialogue had to be facilitated between involved stakeholders (cancer patients, healthcare professionals etc.) and the Living Lab community in order to better define and match the demand and supply of innovative solutions for combating cancer. A series of interactive sessions was delivered where stakeholders’ needs were analyzed, prioritized and mapped to proposed Living Lab action points. Living Lab experts actively participated and offered their insights that helped shape the vision for the first version of Oncology-focused Living Labs. In what follows, details of the key findings and a first interpretation is offered to set the basis for opening the dialog further among the EC and the Living Lab community.

Background Overview

A. Digital Living Lab Days 2021⁴

Back in September 2021, in the framework of its annual gathering, the Digital Living Lab Days (DLLD21), a special thematic debate, entitled **“Oncology-focused Living Labs: a new challenge to be addressed”**, took place, giving the opportunity to both medical oncologists (represented by SIOG) & cancer



² https://ec.europa.eu/commission/presscorner/detail/en/ip_21_342

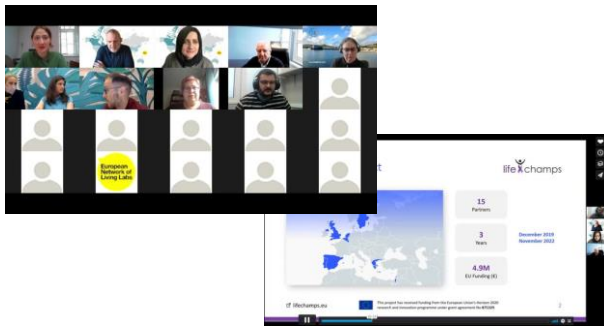
³ https://ec.europa.eu/info/publications/conquering-cancer-mission-possible_en

⁴ <https://openlivinglabdays.com/oncology-focused-living-labs/>

patients (represented by ECPC) to define current challenges, regarding the digital transformation of the solutions' acceptance.

Participating Living Labbers & Social Innovators listened to clinicians & patients' requirements, envisioning together, how they could effectively meet & address the emerged needs within the framework of the future Oncology-focused Living Labs. Both SIOG & ECPC presented the topics for discussion in advance and then, Living Labbers & Innovators were requested to provide their feedback in an open discussion & a hands-on exercise orientated around the following four pillars:

- Up-Skilling of the Oncology Workforce (soft & digital skills)
- Addressing the Emerging Needs for Multi-Disciplinarity (in clinical practice & cancer care)
- Unequal Access for Patients to Tech/Innovation (underrepresentation of patient groups & level of digital literacy)
- Stakeholders' Empowerment (“What’s in it for me?”, regarding involvement in digital service design & implementation of new tech-based care models)



Key Findings:

A summary of the main key findings, as they emerged from the debate discussion & the interaction among all the participating stakeholder groups is provided:

Key Finding #1 - Up-Skilling of the Oncology Workforce (soft & digital skills) & support its multi-disciplinarity: as highlighted by the SIOG, although there is much progress during the last years, regarding the digital transformation of the cancer care & clinical practice, there is still an important gap in the proper training and skills' acquisition of the Oncology Workforce, as well as

a remarkable lack in knowledge transfer among clinicians, experts in-field and researchers from different specialties.. As open innovation ecosystems, the Oncology-Focused Living Labs could operate *as tech-enhanced learning environments* for clinicians and professional caregivers to enhance & upgrade their digital skills, within the LL **real-life experimentation & tech infrastructures**, as well as **experiential learning environments** including patients as co-learners, better understand their needs & finally improve their soft skills.

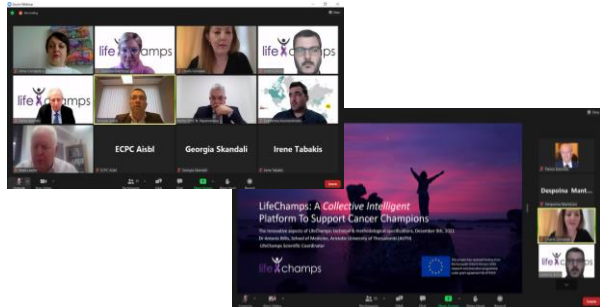
Key Finding #2 - Ensuring Equal Access for Cancer Patients to Innovative, Technology-based health & care services: on its side, **the ECPC** focused on the underrepresentation of some cancer patient groups in clinical research, in service & care models' design, e.g. aged individuals, or socio-economically deprived ones. In order to improve the support & quality of life of all the cancer patients and their smooth transition to digital health & care services, their technology uptake should be enhanced, through targeted training programmes, experiential learning & co-validation activities with professionals. The support of the “digital literacy” of cancer patients and the improvement of their technology acceptance & adoption in everyday care can be improved through the Living Lab real-life experimentation settings & their active -and not opportunistic- and standardized involvement in the clinical practice and the digital service design.

Key Finding #3: Enhancing Stakeholders' Empowerment & Active Involvement in research & innovation: Following the previous finding, an umbrella topic of the debate was the importance of **the stakeholder's empowerment**, of both clinicians & cancer patients, to ensure their active participation & long-term engagement in research and innovation initiatives & their involvement in the clinical practice. The Living Labs can provide the mechanisms and tools to explore motivation and active engagement of all the involved stakeholders, based on their different priorities, culture values & needs. In other words, just like in various other fields of implementing participatory research & social innovation actions, a Living Lab can provide the fertile ground to its stakeholders to find their pathways within their involvement in conquering cancer and create value

for them, answering the always “hot” question: “What’s in it for me?”.

B. Lifechamps H2020 - Parliamentary event⁵

As a follow-up event, in December 2021, the Thess-AHALL, through its LifeChamps H2020 project organised an open discussion event with the support of the ECPC, SIOG & ENoLL, again, under the general host of the European Parliament BECA Committee. The event was entitled “**The role of Research & Innovation**



in the enhancement of older cancer patients care & treatment options, accessibility, and Quality of Life during survivorship” and was part of the whole series of events of the European Parliament, regarding the Europe’s Beating Cancer Plan.

EU-level policymakers, with an active role in the field of conquering cancer, participated in a new round of discussions with clinicians & patients’ representatives, as well as the Living Lab & research community, regarding the evolvement of the cancer health & care models in the new tech-advanced era and the role of the Oncology-focused Living Labs as promoters of responsible, participatory research & open innovation accelerators. The participants of the Parliamentary Event co-validated & extended -in some cases- the findings from the previous DLLD21 debate, setting the basis for the further exploration of the Living Lab settings & methodologies as vehicles to maximize the EU Cancer Mission impact.

The main pillars of the discussion are summarized, as following:

- Equal access to clinical research/practice data (to ensure equal access to cancer health & care services)

- Need for personalized cancer treatment & care technologies (tech-based solutions: telehealth / telemedicine)
- Establishment of European Reference Networks (ERNs) for Cross-border Healthcare and Regulatory on Cancer (promotion consultation & increase of awareness)

Key Findings:



Key Finding #1 - *Re-use Data for Personalized Treatment & Care Models:*

Personalized treatment & care is a key priority for the EU healthcare service provision, including cancer, and a main pillar towards the digital transformation of the healthcare system. However, one major “driver” towards this direction is the (re)use of data, coming from clinical research and practice. However, the lack of interoperability of data between different EU member states, the problem of different protocols, different legal and ethical rules of how to use the data, different interpretations of the GDPR in most of the cases operate as a deterrent to the mutual exchange of knowledge & information. The Living Labs are currently working towards the harmonization & standardization of all these issues, as well as of research infrastructures, methodologies & tools to foster innovative, person-centred, tech-advanced & open research in the Health & Well-being fields ([VITALISE H2020 project](#)).




Key Finding #2 - *User-driven tech-based solutions (telecare / telehealth):*

There is a need to improve research, the relevance of clinical trials, embed genetic assessment in trial design, and use personalised medicine technologies. There are opportunities with telehealth to improve the care & the support of everyday living of cancer patients, who are still underrepresented in research & have limited access to clinical practice, by providing them the mechanisms & opportunity to receive proper treatment, monitoring, advice & care, remotely ([LifeChamps H2020](#)). Living Labs can operate, as alternative European Reference Networks (ERNs) -networking enablers & consultation intermediaries- exploiting their capacity building & awareness approach to promote cross-border


⁵ <https://lifechamps.eu/index.php/2021/12/22/lifechamps-ep-event-on-the-digital-transformation-of-the-cancer-health-care-services/>


cancer healthcare & collaboration models, in which, for instance, knowledge and best practices transfer among stakeholders of different EU regions can occur favoring the underserved ones.


 **Key Finding #3 - Active Stakeholder involvement in Research & Innovation:** just like in the DLLD21, participants in the Parliamentary Event highlighted the importance of the active & equal involvement of both cancer patients and clinicians in the development & approval of new clinical models & digital service design. The active participation and engagement of stakeholders should be recognized in every stage of the R&I and solutions should be based on the principles of the Living Lab approach, stemming for the creation of a new relationship, perception & acceptance of citizens towards technology & innovation, allowing them to design & deploy solutions based on their own everyday living needs & challenges. This approach could also work towards the acceleration of technology and innovation in the battle against cancer just like it has worked through a wide range of participatory research, experimentation & applications in different fields, so far.


Recommendations & Vision

Based on the findings from the two events the Recommendation #12 of the EU Mission Board for Cancer on the Oncology-Focused Living Labs is primarily confirmed & partially extended, opening the way to further discussions & deliberation on the proper exploitation of the Living Labs as technology & innovation accelerators and capacity building & networking enabler. In summary, the Oncology-Focused Living Labs may:

 introduce **real-life experimentation settings**, including cancer social & healthcare care structures, to promote **responsible research & open innovation in clinical practice**

 operate as intermediaries to **increase the knowledge transfer, new technology uptake and better understanding** of patients & clinicians' needs towards **more inclusive cancer treatment & care solutions**

 operate as **tech-enhanced learning environments** for clinicians to acquire **soft & digital skills** towards cancer understanding, prevention, treatment & care (**LL tech infrastructures**)

 increase **networking, mutual collaboration & trust** among all the stakeholders & the **equal representation** of all the cancer patients in **clinical practice, research & service design**

The added value of the Living Labs in the field of the EU Cancer Mission is its methodological approach: There are a lot of examples where clinical studies have proven the effectiveness of an intervention, but patients do not follow it in real life, either because they do not see the value or it does not meet their real needs. The unique advantage that Living Labs as real-life experimentation ecosystems and open innovation accelerators have is that they create and increase the value not only for the end-user -cancer patient, but for all the involved stakeholders, relatives, hospitals, academia, policymakers, industry and the targeted funding. And this is primarily, because Living Labs preserve innovation open and inclusive, by conducting user-driven research & innovation, not just testing & validation, and they embrace what exists outside, beyond their organizations by engaging all the stakeholders throughout the innovation & development process & providing them with all the necessary methodological, organizational frameworks & tools to build new solutions & to transform old ones, so as to always meet the real needs of the society to the maximum extent.

To this end, **our vision** for the Oncology-Focused Living Labs is to create:

 ***“not another test-bed, but open innovation & research, mutual collaboration & real-life experimentation ecosystems to foster the digital transformation of the clinical practice & make innovative health & care services equally accessible & inclusive to ALL cancer patients”.***

Discussion & Next Steps

The current Policy Brief on the Oncology-Focused Living Labs has derived as a result of a series of consultation workshops, as part of open discussion events among the different involved stakeholders' groups. This is a first attempt to map the key discussion & action points towards the identification of the role of Living Labs, thematically focused on the field of cancer (prevention, treatment, care & quality of life support). Although the preliminary findings confirm the added value that the Oncology focused Living Labs can provide in conquering cancer, there are still many things to be done for their effective establishment & successful implementation. Some of the priorities of the coming period, as defined by the leading actors of the initiative are the following:

- **Expansion** of the Oncology LL **network** & establishment of **local open innovation cancer ecosystems**
- Formalization of **collaboration with EU-level** cancer-care policymakers
- **Standardization of Patient Involvement** in digital cancer care service design & deployment
- Exploration of the **LLs' role in the Digital Transformation** of the Public Healthcare Services
- **Sustainability** of the Oncology LL network and its positioning in the **business ecosystem**

***Disclaimer:** This file includes information & findings coming from the LifeChamps Project. This project has received funding from the European Union's H2020 Research & Innovation Programme under Grant Agreement No. 875329.*

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