

Unprecedented Living Lab Approach: Technological Innovations for Paediatric Cancer Support System

Natacha Rosa^{1,2}, Angela Carvalho^{1,2}, Flavia Santos^{1,3}, Ana Monteiro⁵, Filipe Santos-Silva¹, Barbara Macedo^{1,3}, Hugo Prazeres^{1,4}

¹ i3S - Instituto de Investigação e Inovação em Saúde, Universidade do Porto, Porto, Portugal

² INEB - Instituto de Engenharia Biomédica, Universidade do Porto, Porto, Portugal

³ IBMC - Instituto de Investigação e Inovação em Saúde, Universidade do Porto, Porto, Portugal

⁴ IPATIMUP - Instituto de Patologia e Imunologia Molecular da Universidade do Porto, Portugal

⁵ ACREDITAR - Associação de Pais e Amigos de Crianças com Cancro, Porto, Portugal

Natacharosa22@gmail.com

angela.carvalho@i3s.up.pt

flavias@i3s.up.pt

am@acreditar.pt

fsilva@i3s.up.pt

bmacedo@i3s.up.pt

hprazer@i3s.up.pt

Abstract: The paediatric oncology field still faces significant challenges, despite the substantial progress in childhood cancer diagnosis and treatment. Not only in terms of incidence and mortality rate reduction but also in terms of patients, their support system (e.g. family, school staff) and the cancer survivors' well-being. The use of innovation has provided new forms to support the paediatric oncology community. As these solutions continue to emerge it is necessary to test and validate them based on the end-users' specific needs. In this context, this article shares the ongoing work in the development of an unprecedented and unique Living Lab project. In this ecosystem, a paediatric oncology patients' physiological monitoring device, an app that combines technology and science with culture and arts to create mental health promotion solutions device, a virtual reality solution to help paediatric oncology patients manage pain via gamified environments and a methodology to diagnose difficulties in problem-solving that arise among parents and caregivers of children with cancer survivors, breakthroughs technologies were supported and leveraged during their participation in this Living Lab program. Considering the symbiotic interdependence between end-users empowered by Living Labs and the Living Labs' success dependency on the end-users involvement and motivation, an original methodology for entrepreneurship fostering and innovation support based on end-user participants' high involvement was proposed and evaluated. This methodology was based on interlinked and tailored sessions which were characteristically re-designed based on the stage of development of the proposed innovation, the technical support required and the end-users' needs and engagement level as well as the feedback obtained from previous activities. As a result of the complexity of the context in which the solutions are implemented and the changing openness and engagement of the end-users, the activities and sessions were constantly being created and customized. Although this is a work-in-progress, the tailored engagement program developed already allowed the value creation for all the participants and an efficient evaluation and validation of new end-user-centred solutions which will harness progress through their path to the market.

Keywords: Living Lab; Paediatric; Oncology patients; Childhood cancer; Caregivers

1. Introduction

Globally, childhood cancer is a significant, but comparatively neglected, cause of morbidity and mortality (Johnston et al. 2021) and which concern should also be extended to the network of intervenients whose needs should not be neglected. Patients' caregivers (parents and the family) which provide the children's primary source of physical and psychosocial support have to cope with psychological stress and fear (Suzuki and Kato 2003, Carrion-Plaza et al. 2020) while additionally being associated with an increased mortality rate and health issues as a result of caring for their loved ones (Morrison et al. 2016).

The Living Labs (LLs) have been applied around the globe, to generate impactful solutions (technologies and/or services) within and suited to real-life problems and contexts (Bronson et al. 2021). These ecosystems provide the conditions for innovations co-designing, evaluation, validation, testing, prototyping and commercial strategy development in cooperation with and adapted to the end-users' needs. So, the LL tool is expected to foster the societal impact of the breakthroughs by enhancing their robustness, inclusiveness and delivered value (Niitamo et al. 2006, Nakagawa et al. 2021).

As solutions for paediatric oncological patients and their caregivers continue to increase and progress, the question, of whether the innovations are designed based on and to fit the patient’s specific needs, arises. There is also a concern if innovations for paediatric oncology survivors and their families and caregivers are being suitably developed. In this context, this article shares the ongoing work in the development of a LL which was tailored to support innovations centred on the well-being of paediatric cancer patients and their support system. This LL initiative was developed by the RESOLVE-Health 2.0 program, based at the Institute of Health Innovation and Research (i3s in Portuguese Instituto de Investigação e Inovação em Saúde). This action had the collaboration of the Associação Acreditar in Porto, an organization that assists families of children with cancer.

There is reduced literature describing and discussing LLs for cancer-based solutions (Hague University of Applied Sciences (THUAS) 2013, Institut National du Cancer 2023) and to the authors' best knowledge, this is the first LL dedicated to supporting innovations with an oncological pediatric focus.

2. Methods

This study was developed in collaboration with the Associação Acreditar ('ACREDITAR Associação de Pais e Amigos de Crianças com Cancro') which provides support for the development of the LLs in terms of physical space, technical support material (e.g. projectors, tables and chairs, coffee machine for coffee breaks etc.) and access to their internal personnel.

The end-users considered were oncological children’s parents and personnel from the Associação Acreditar. The activities were tailored and designed based on an action research methodology. This research approach aims at both taking action and creating knowledge or theory about that action as it unfolds (Coghlan 2023).

3. Results and discussion

An international open call for solutions to improve the health and quality of life of paediatric oncology patients and their families during patients’ journeys was made. The program was not extended to large players and SMEs as innovative solution providers as is often suggested in the literature (Niitamo et al. 2006). The breakthrough technologies that participated in this LL are presented in Figure 1.

Acronym	Description	TRL
IMAGI	Virtual reality solution to help paediatric oncology patients to manage pain via gamified environments	2
NeuroCog	A methodology to diagnose difficulties in problem-solving that arise among parents and caregivers of children with cancer survivors and how it affects their personal, social and professional lives	2
Flanair	An app that combines technology and science with culture and arts to create mental health promotion solutions	2
LuckieTech	Paediatric oncology patients' physiological monitoring device that provides immediate and continuous information for parents and clinicians	4

Figure 1: Information regarding the participant innovations’ acronym, short description and technology readiness levels (TRL)

As it is possible to verify in Figure 1, different solutions to improve the health and quality of life of paediatric cancer patients, the survivors and their network support system, participated in this LL. The actions developed in this LL were organized into three categories, conceptualization, concretion and specialization, as presented in Figure 2.

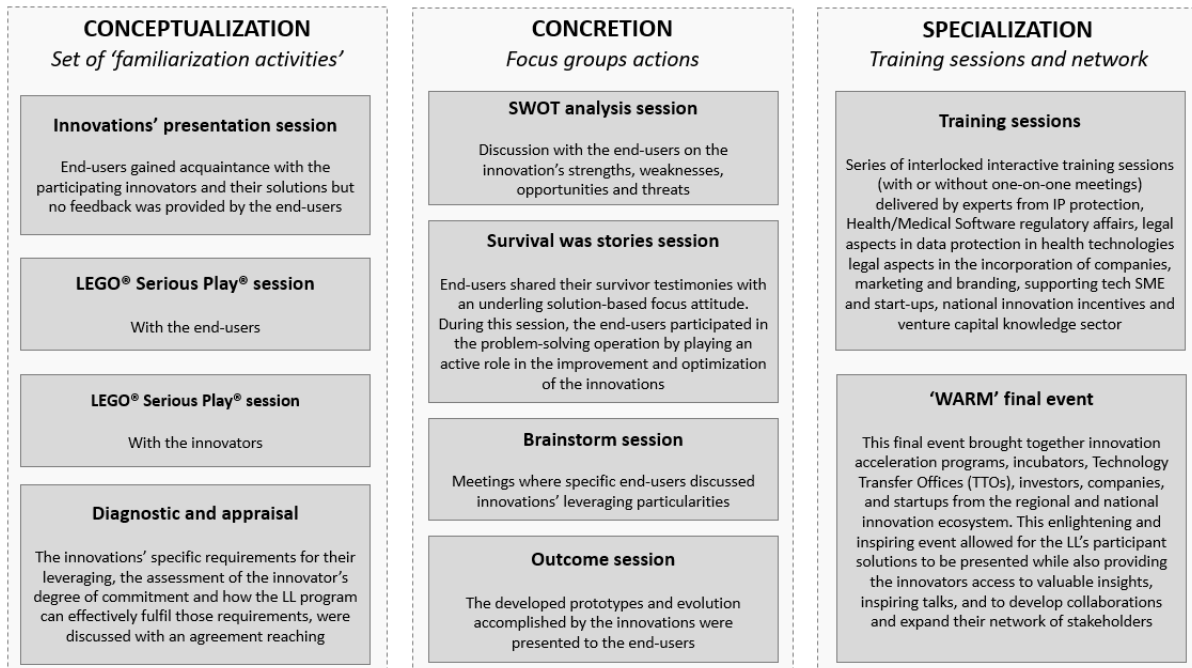


Figure 2: Schematic representation of the actions developed in the LL according to a three-stage framework process constituted by the conceptualization, concretion and specialization stages.

The activities and sessions were designed based on the stage of development of the participant innovations, the technical support required and the end-users needs and engagement level. Due to the complexity of the context in which the innovation will be implemented and the changing openness and engagement of the end-users, the activities and sessions are constantly being created and customized based on the action research method. As it is possible to verify in Figure 2 this created an ecosystem which was able to integrate different stakeholders for the user-driven validation and leveraging of the solutions that aim to improve the health and quality of life of paediatric cancer patients, the survivors and their network support system. This LL also created a comfortable and 'safe space' for caregivers to disclose their concerns and unmet needs so synergetic collaboration could be developed for both the improvement of the participating solutions and the end-users value creation. The activities allow the creation of value for all the LL participants in the form of knowledge acquisition, empowerment, interpersonal bonding, mindset change, and education.

It is important however to highlight that, although the LL achieved excellent engagement from end-users, some of them decided not to share their views. Despite finding the activities involved, they preferred to listen to others and be in the community. This illustrates that despite the desire and effort to involve end-users, their engagement in some cases can remain limited. The outcomes so far obtained from the innovators' participation in this LL program are presented in Figure 3.

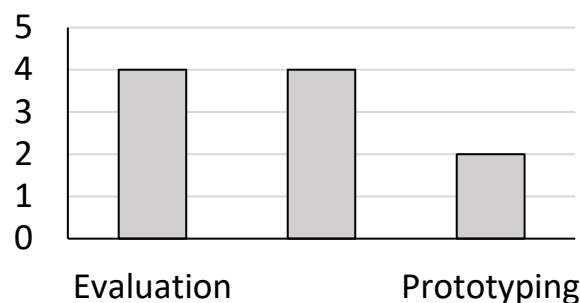


Figure 3: Number of evaluations, validations and prototypes obtained from the innovations participation in the LL

From Figure 3 it is possible to verify that prototypes were developed and solutions were evaluated and validated by the end-users which will increase their acceptance, adoption and deliver value to the market. These outcomes

resulted from the significant engagement registered which was associated with the development of tailored sessions based on active research methodology but also due to end-user empowerment and emphasis given to their opinions and needs. We do believe that an additional upgrade in these innovations improvement and optimization level could in the future be obtained if a wider network of end-user intervenient, namely oncological patients themselves or cancer survivors and other caregivers (e.g. teachers, schoolmates, and peers who provide significant areas for the promotion of patient's psychosocial adjustment intervention (Suzuki and Kato 2003)), could be included in the LL sessions.

4. In conclusion

This LL was able to create value for all the participants through the development of a tailored program to enhance their engagement and guarantee an efficient evaluation and validation of new end-user-centred solutions. Hence through this unique innovation system, disruptive solutions in the field of paediatric oncology evolved in their path to reach the market while also guaranteeing increased acceptability and effectiveness of these technologies to the end-users' needs. In the long term, we would like this study to encourage a more general adoption of LLs for end-user-based paediatric cancer innovations.

Acknowledgements

RESOLVE 2.0 (Respostas Específicas para Superar Obstáculos que Limitam a Valorização Eficaz) is funded by FEDER – Programa Operacional Competitividade e Internacionalização, in the setting of Contrato de Concessão, under the reference POCI-01-0246-FEDER-181287. We thank the support from Associação Acreditar as well as the participation and contribution of the “Barnabés”, caregivers, volunteers and other stakeholders to this Living Lab.

References

- 'ACREDITAR Associação de Pais e Amigos de Crianças com Cancro', [online], available: <https://www.acreditar.org.pt/en/> [Accessed 17th March 2023].
- Bronson, K., Devkota, R. and Nguyen, V. (2021) 'Moving toward generalizability? A scoping review on measuring the impact of living labs', *Sustainability*, 13(2), 502.
- Carrión-Plaza, A., Jaen, J. and Montoya-Castilla, I. (2020) 'HabitApp: New play Technologies in Pediatric Cancer to improve the psychosocial state of patients and caregivers', *Frontiers in psychology*, 11, 157.
- Coghlan, D. (2023) 'Action research' in *The Palgrave Encyclopedia of the Possible*, Springer, 9-16.
- Hague University of Applied Sciences (THUAS) (2013) 'A healthy lifestyle for cancer patients (Medical Delta Living Lab Better In Better Out)', [online], available: <https://www.thuas.com/research/centre-expertise/healthy-lifestyle-cancer-patients-medical-delta-living-lab-better-better> [Accessed July 12th 2023].
- Institut National du Cancer (2023) 'The Living Lab of the Institut National du Cancer', [online], available: <https://living-lab.e-cancer.fr/> [Accessed July 12th 2023].
- Johnston, W., Erdmann, F., Newton, R., Steliarova-Foucher, E., Schüz, J. and Roman, E. (2021) 'Childhood cancer: Estimating regional and global incidence', *Cancer epidemiology*, 71, 101662.
- Morrison, C. F., Szulczewski, L., Strahlendorf, L. F., Lane, J. B., Mullins, L. L. and Pai, A. L. (2016) 'Designing technology to address parent uncertainty in childhood cancer', *Advances in Nursing Science*, 39(1), 15-25.
- Nakagawa, A., Freeman, S., Koopmans, A., Ross, C. and McAloney, R. (2021) 'Best Practices for Living Labs When Studying Older Adults Living in Rural Communities', *Innovation in Aging*, 5(Supplement_1), 1026-1026.
- Niitamo, V.-P., Kulkki, S., Eriksson, M. and Hribernik, K. A. (2006) State-of-the-art and good practice in the field of living labs, translated by IEEE, 1-8.
- Suzuki, L. K. and Kato, P. M. (2003) 'Psychosocial support for patients in pediatric oncology: the influences of parents, schools, peers, and technology', *Journal of Pediatric Oncology Nursing*, 20(4), 159-174.