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Luxembourg launches a large national survey for cancer patients to improve cancer care in the country

The Luxembourg Institute of Health, in collaboration with the Ministry of Health as part of the National Cancer Plan, introduces Colive Cancer, a nationwide initiative in which current and former cancer patients can share their experiences to improve cancer care in the country.

The Luxembourg Institute of Health (LIH) announces the launch of Colive Cancer, a study aimed at improving the quality and efficiency of the current national cancer healthcare system by interacting directly with patients via an online feedback system. Colive Cancer is led by Dr Guy Fagherazzi of the LIH Department of Precision Health Phenotyping research unit in collaboration with the Ministry of Health as part of the Plan National Cancer 2 (PNC2), running from 2020 to 2024.

According to the National Cancer Registry and the European Cancer Information System, every year roughly 3000 new cases of cancer are discovered in Luxembourg and approximately 1100 people die from the disease, about a quarter of all annual deaths nationwide. Cancer is the leading cause of death for men and the second leading for women. Currently there are estimated to be approximately 18000 people living with cancer in Luxembourg, almost 3% of the population, making the disease a priority for the Ministry of Health and the Luxembourgish biomedical research community.

The PNC2 is a continuation of the successful Plan National Cancer, originally initiated by the Ministry of Health in 2014. This second phase of the plan, initiated in 2020, is focused on translational oncology, digitalization of data, and working with patients rather than just for or about them, and aims to directly implement their feedback in order to improve cancer diagnosis and treatment in Luxembourg.

Colive Cancer is an online survey that can be accessed via smartphone or laptop where participants can share their experiences and express their opinions about the current healthcare system in relation to cancer and their overall quality of life. It is split into several short modules and is available in four languages: English, French, German and Portuguese. Participation is limited to adult patients, including patients currently or formerly treated for cancer in Luxembourg within the last five years.

Participants will be asked to give details about their diagnoses and treatments, the care and support they received, and their overall experiences in all aspects. Former patients will also be asked to provide feedback about their follow-up care and their post-cancer lives in general. Colive Cancer will also give participants useful information about cancer and exercise, diet, psychological support, and more throughout the study.



All data will be treated as strictly confidential. Personal data will be pseudonymised, a confidential reference code will be used, and all data will be stored at the LIH in secure servers.

"This project is a unique opportunity to improve the cancer care system in Luxembourg, thanks to direct inputs from the patients themselves! This patient-centred approach will allow us, for the first time in Luxembourg, to identify what works well, and also perhaps more importantly, what to improve on in the National Cancer Plan" according to Dr Guy Fagherazzi, leader of the project.

Colive Cancer is currently recruiting participants on the official website.

Funding and collaborations

Colive Cancer is a research programme led by the Luxembourg Institute of Health (LIH) under the auspices of the Luxembourg Government via the Plan National Cancer 2.

About the Luxembourg Institute of Health (LIH)

The Luxembourg Institute of Health (LIH) is a public biomedical research organisation focused on precision health and invested in becoming a leading reference in Europe for the translation of scientific excellence into meaningful benefits for patients.

The LIH places the patient at the heart of all its activities, driven by a collective obligation towards society to use knowledge and technology arising from research on patient derived data to have a direct impact on people's health. Its dedicated teams of multidisciplinary researchers strive for excellence, generating relevant knowledge linked to immune related diseases and cancer.

The institute embraces collaborations, disruptive technology and process innovation as unique opportunities to improve the application of diagnostics and therapeutics with the long-term goal of preventing disease.

About Research Luxembourg

Research Luxembourg is a unified, agile team of thought leaders working to learn, explore and make an impact to shape a better future. By connecting all players in Luxembourg and abroad, Research Luxembourg aims to become a leader in research and innovation focusing on four research priority areas: (1) Industrial and Service Transformation; (2) Personalised Healthcare; (3) Sustainable and Responsible Development; (4) 21st Century Education.

Research Luxembourg is a joint initiative of the main actors in Luxembourg public research with the support of the Luxembourg Minister of Higher Education and Research, including Luxembourg Institute of Health (LIH); Luxembourg Institute of Socio and Economic Research



(LISER); Luxembourg Institute of Science and Technology (LIST); the Luxembourg National Research Fund (FNR); Luxinnovation and the University of Luxembourg (uni.lu).

About PNC2

The Minister of Health, Paulette Lenert, launched the second National Cancer Plan 2020-2024 at an online conference on 11 December 2020. During this conference, the actors of the National Cancer Plan 2020-2024 (NCP2 2020-2024) presented the different phases and actions inherent to the NCP for the next 4 years. With the transversal theme of supporting the patient in the quality of care, this new plan is resolutely placed under the sign of digitalisation with the priority of improving the flow of information and data between specialists and the various institutions. The National Cancer Plan, whose acronym is PNC2 2020-2024, is a continuation of the first National Cancer Plan (PNC) and consolidates its progress.

<u>www.qouvernement.lu</u> <u>www.sante.lu</u>

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