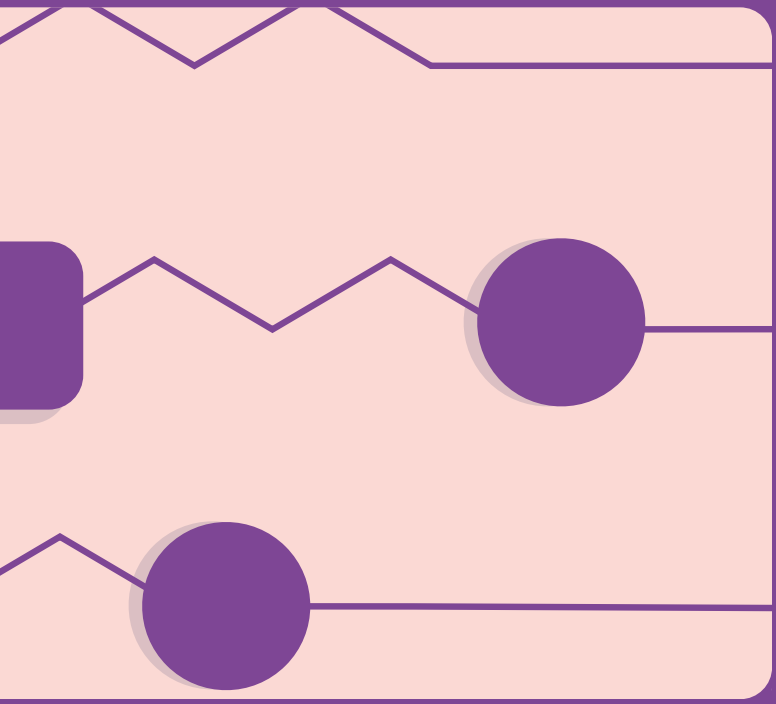
LivACT

Living and Ageing with Chronic Conditions and Technological Devices: Meanings, Practices and Recompositions of Autonomy through Time



Aspirations for Autonomy

Chronic Living

Care Infrastructures

Experiences

Norms

Technologies

This project is supported by the Priority Research Program (PPR) Autonomy

LivACT in Brief

To what extent can technologies be considered as a response to the demand for autonomy among people living and ageing with chronic conditions? The project seeks to understand how body-technology-environment assemblages and innovative solutions align with their aspirations for autonomy.

Project Leader: Lucie Dalibert, Researcher in Philosophy.

+30 Researchers

2 PhD students

4 postdoctoral researchers

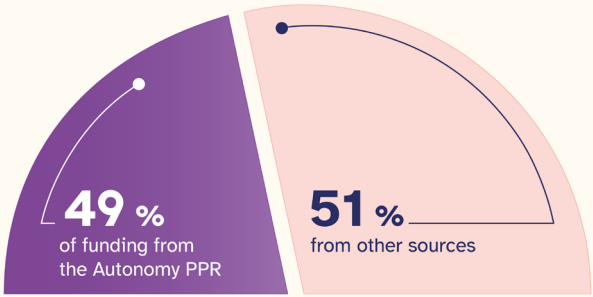
+10 Master's trainees

1 international summer school

2 monthly seminars

+ research residency abroad

5 years of funding



Disciplines Involved

Anthropology | Biomechanics | Law | Philosophy | Robotics | Information and Communication Sciences | Health Sciences

LivACT in Detail

Context

Chronic illnesses can generate disabilities that evolve over time. In response, **technological devices** are increasingly integrated into daily lives of chronically ill people. However, these devices do not always fulfil their promise of enhancing user autonomy.

The LivACT project originates from several key observations. First, **a third of the French population lives with at least one chronic illness**, a prevalence expected to increase with ageing. Second, chronic illnesses can cause **significant impairments and disabilities**, which may worsen or shift over time due to disease progression, the emergence of multi-morbidities, and ageing.

Third, **technologies can appear as a solution** not only to mitigate, slow down, or even prevent the loss of capacities associated with chronic conditions, but also to enable individuals to manage their lives independently at home. To achieve this, both bodies and living spaces -particularly homes -are equipped with technological devices. However, these devices **do not always fulfil their promise** of autonomy and empowerment: they can be quite restrictive, incompatible with certain environments, or even create new vulnerabilities. Moreover, they depend on a broader care infrastructure to function effectively.

Project's Objectives

1 Question the concept of autonomy in light of the experiences of people living with chronic conditions and using technological devices.

2 Support the design of technologies that better align with to the needs, practices, and aspirations of their users.

The LivACT research team seeks to understand to what extent **technologies designed to promote** functional autonomy – allowing people to manage daily activities independently – align with or contradict their conceptions and aspirations regarding autonomy.

People living with chronic illnesses, their loved ones, technological device designers and prescribers, as well as (health)care institutions and infrastructures, **may have different understandings of autonomy.** It is therefore essential to explore these perspectives to identify the types of practices, environments and devices that best support the aspirations of those living and ageing with a chronic condition. By doing so, LivACT's findings can inform technological design, providing developers **with insights into users' expectations and priorities** regarding autonomy and technology.

Work Program

- Explore the **experiences of autonomy among people living and ageing with chronic conditions who use technological devices** *implanted* in, *attached to*, or *connected both to* their bodies and environments.

- Study **chronic care infrastructures** to assess the expectations and constraints imposed on individuals with chronic conditions and understand **how these ecosystems either support or hinder their aspirations for autonomy.**

- Analyze how autonomy is conceptualized by actors in engineering and healthcare when designing, prescribing and adapting technological devices.

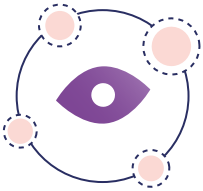
- Identify innovative solutions and configurations of bodies, technologies, and environments that best support the autonomy aspirations of people living and ageing with chronic conditions.

Methodology

The LivACT team employs a **qualitative methodology**: researchers realise **multi-site**, **longitudinal ethnographic fieldwork**. Researchers conduct **interviews and observations** in the homes of people living and ageing with chronic conditions, more particularly with Parkinson's disease, type 1 or type 2 diabetes, and post-stroke conditions. They also engage with associations, (health)care institutions, robotics and engineering research laboratories, and manufacturers of technological devices.

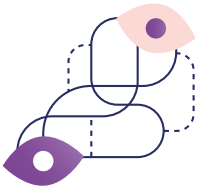
Additionally, the LivACT's research team carries out a **socio-legal analysis** to understand how technological innovations for autonomy are regulated.

Finally, researchers organize **focus groups and workshops** with stakeholders to identify avenues for technological innovation and determine the most effective formats for communicating the LivACT's findings.



Ethnographic fieldwork

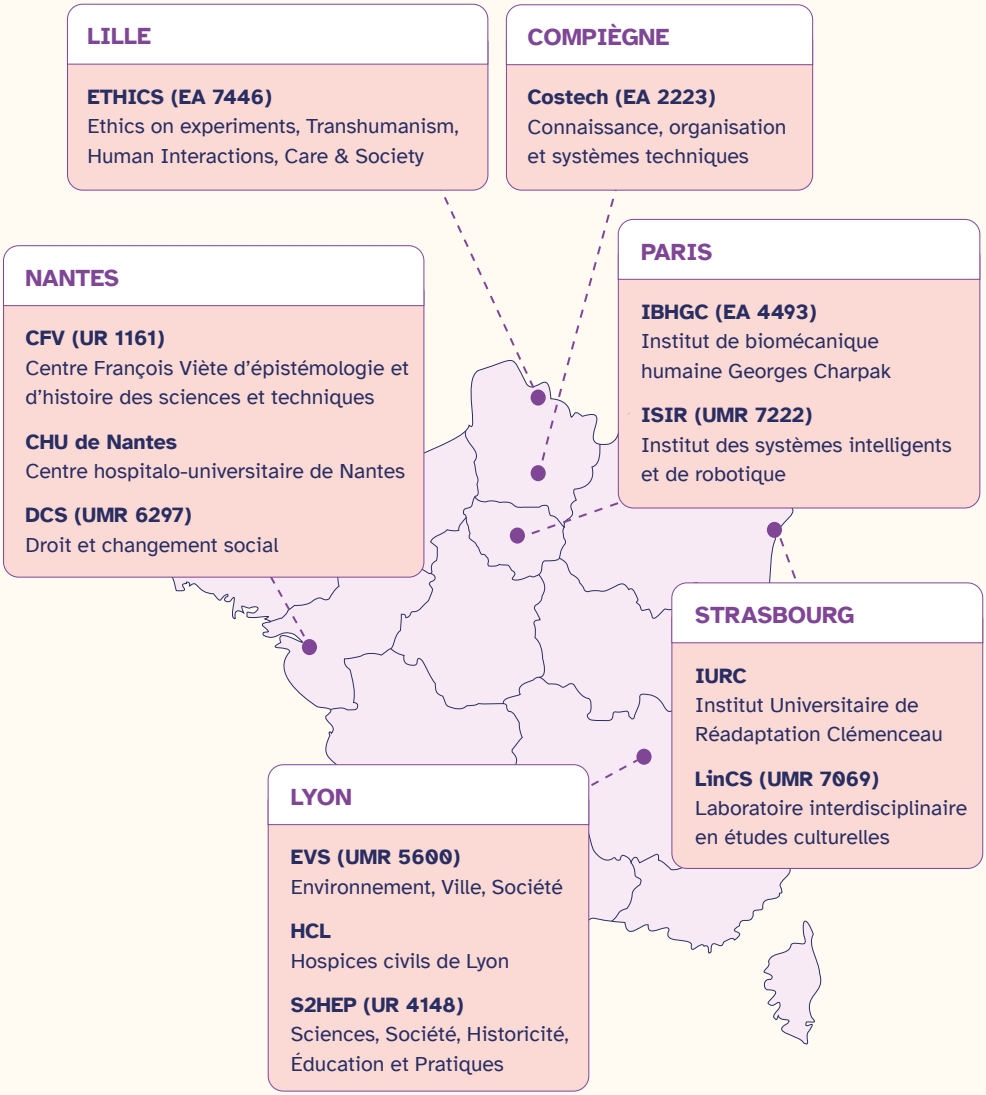
Longitudinal approach



Interdisciplinarity

Partnerships

Academic Partners in France: Laboratories Involved



International Academic Partners

Department of Thematic Studies (TEMA)
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School of Social and Political Science
Université d'Edimbourg
United Kingdom

Department of Anthropology
Université de Copenhague
Denmark

School of Humanities
Université de Tasmanie
Australia

Other Partners

Building With and For People Living With Chronic Illnesses and Technologies.

LivACT is a research project conducted with and for people living with chronic conditions and with technological devices. Five associations - *Advance NeuroRehabilitation Therapies and Sports (ANTS), France Parkinson, Association de Défense et d'Entraide des Personnes Amputées (ADEPA), Association pour l'Utilisation du Rein Artificiel dans la région Lyonnaise (AURAL)* and *Métropole aidante* - are partners in the project. These associations contribute their expertise enabling the production of socially relevant knowledge.

Find Out More

If you are interested in the issues and challenges involved in the LivACT project and would like to find out more, the project's teams have put together a reading list of the latest scientific literature.

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- Dalibert, L., Gourinat, V., & Groud, P. F. (2023). Les processus d'appropriation des prothèses de membres. Dynamiques et diversité des usages et des non-usages.
- Diasio, N. (2019). Chronic illness and the ideology of the individual: towards a critique of the concept of agency, *Salute e società,* 3, 35-48, 37 p.
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- Haddow, G. (2021). *Embodiment and everyday cyborgs: Technologies that alter subjectivity.* Manchester : Manchester University Press.
- Käll, L., & Zeiler, K. (2014). Bodily relational autonomy. *Journal of consciousness studies, 21*(9-10), 100-120.

- Lancelot, M., & Guchet, X. (2023). Introduction - Qu'est-ce qu'un soin technologique ? *Cahiers François Viète, III*(15), 5-21.
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Partners


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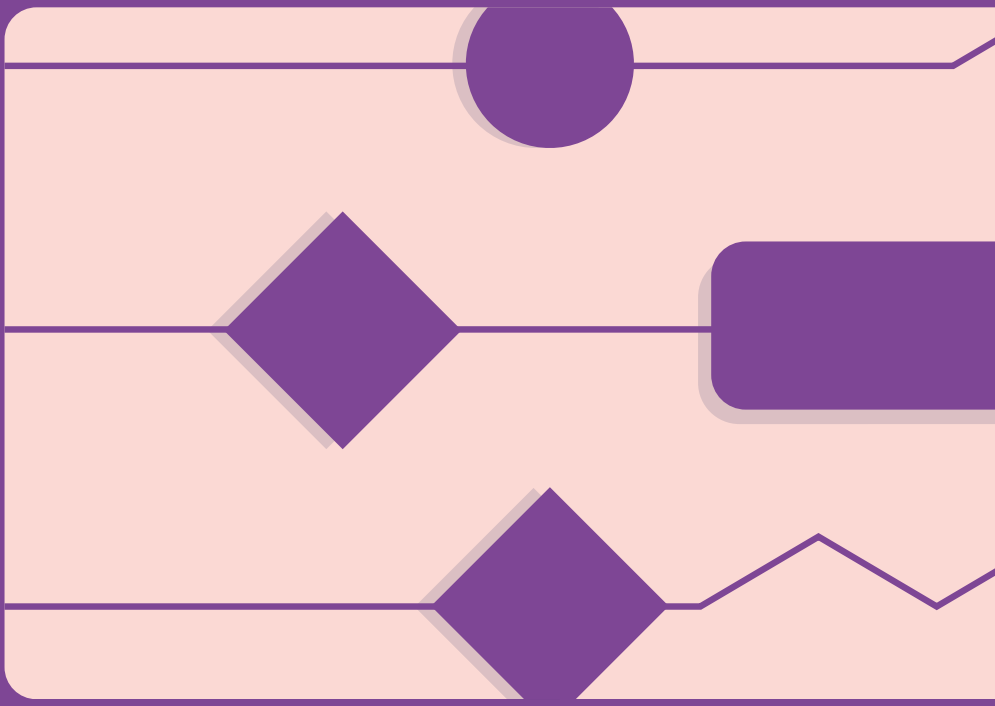
COPENHAGEN

Want to learn more about the project ? Get in touch with us:

ppr-autonomie@cnrs.fr



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