**PROJECT SHEET – COLLECTIVE INFORMATION FOR DATA SUBJECTS**

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| **Official title** | **ADHESURV: Adherence to hormone therapy after non-metastatic breast cancer: determinants and impact on prognosis** |
| **Condition** | Breast cancer |
| **Contact** | University of Zurich: elise.dumas@uzh.ch<br>French National Cancer Institute: lesdonnees@institutcancer.fr |

## Project description

**Background:** Breast cancer is the most common cancer among women, with 2.3 million new cases worldwide in 2022. Advances in screening and treatment have significantly improved survival rates, leading to an increase in the number of BC survivors. However, women with a history of early-stage BC remain at a significant risk of recurrence throughout their lives and face specific challenges regarding medical follow-up, late effects of treatment, and quality of life. After initial treatment—typically involving surgery, chemotherapy, and/or radiation therapy—patients with hormone receptor-positive (HR+) breast cancer receive adjuvant endocrine therapy for at least five years to reduce the risk of recurrence. Many patients have difficulty adhering to endocrine therapy, particularly due to its common side effects.

**Objectives:** In this project, we will analyze data from the SNDS using modern causal inference methods to understand the factors associated with adherence to endocrine therapy and to estimate the effect on prognosis of partial adherence to hormone therapy following initial treatment for early-stage breast cancer. In particular, the project aims to assess the impact of partial adherence to hormone therapy and its determinants (e.g., combination with other anticancer drugs, side effects, and their treatments) on survival and the risk of recurrence. Specific analyses will be conducted on patients at the extremes of the age spectrum, on certain side effects and their management, and on the adoption of new therapeutic strategies in real-world practice, including gonadotropin-releasing hormone agonists (LH-RH agonists), CDK4/6 inhibitors, and PARP inhibitors.

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**Methodology:** ADHESURV is an observational study using SNDS ("*Systeme National des Données de Santé*") data from the French National Cancer Institute data warehouse (EDS-RNC data).

**Study population:** Adult women diagnosed with incident non-metastatic breast cancer between 01/01/2011 and 31/12/2027 and treated at least with breast surgery.

**Data used:** EDS-RNC data: including patient characteristics (age, area of residence, deprivation index, CMU-C registration), diagnosis dates, treatments (surgery, chemotherapy, radiotherapy, target therapy, endocrine therapy), tumor characteristics (inferred from received treatment and diagnostic codes), comorbidities, deaths, causes of death (when available), recurrences, surveillance examinations and consultations

No other data will be used. No linkage with external data.

## Project agenda

**Study conduct period:** October 2025 - March 2030.

**Results availability:** Ongoing study.

**Data retention:** 5 years in the project space; 20 years in the EDS-RNC.

## Administrative and legal information

**Project lead:** University of Zurich (EBPI). Contact: elise.dumas@uzh.ch

**Participating teams:** Team 1. University of Zurich (responsibility: project conduct);

Team 2. French National Cancer Institute (responsibility: data provider).

**Regulatory framework:** CNIL authorization (tacit authorisation).

**Legal basis:** Legitimate interest (GDPR Art. 6(1)(f)) and scientific research (GDPR Art. 9(2)(j)).

**Exercise of rights:** The individuals concerned may exercise their rights of access, objection, rectification, restriction, and erasure in accordance with the procedures set out at https://lesdonnees.e-cancer.fr/, as well as lodge a complaint with the CNIL.

**Data protection contact :** privacy@rud.uzh.ch ; dpo@institutcancer.fr