

Survey 'Living with and beyond cancer'

Submission date 08/05/2024	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input checked="" type="checkbox"/> Protocol
Registration date 10/05/2024	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 10/01/2025	Condition category Cancer	<input type="checkbox"/> Individual participant data <input type="checkbox"/> Record updated in last year

Plain English summary of protocol

Background and study aims

A cancer diagnosis and its ensuing treatments can cause long-term effects and may impact daily living even years after any treatment has stopped. Persons diagnosed with cancer and living beyond cancer treatments are called cancer survivors. Our study explores cancer survivors' symptoms and problems up to ten years after their diagnosis. Our aim is to describe self-reported symptoms and problems experienced by cancer survivors between five and ten years post-diagnosis. Further, we will explore cancer-related factors that might help to predict long-term problems. To achieve our aims, we will use a survey to gather relevant data.

Who can participate?

Cancer survivors who have been treated in canton Fribourg at one of the hospital sites linked to Fribourg cantonal hospital (HFR). Participants must have a diagnose of breast, colorectal, lung or prostate cancer, or a lymphoma or myeloma. The date of their diagnosis must lie between one and ten years before the recruitment date. Study participants need to understand written French or German to complete the questionnaires. In this study we will apply no intervention to participants. Eligible study participants will receive study information and questionnaires by postal mail. If they agree to participate, they will complete the questionnaires online or on paper once; no follow-up assessment will be carried out.

What does the study involve?

Our survey will use the National Comprehensive Cancer Network patient assessment questionnaire to assess long-term problems and the Self-Administered Comorbidity questionnaire. Overall, participants will answer 52 questions, which will take about 20 minutes. Questions are related to physical symptoms (e.g. breathing, skin alterations, pain, fatigue), emotional symptoms (e.g. stress, depressive mood), financial challenges, return to work, and healthy behaviour. Comorbidities are for example cardiovascular diseases, high blood pressure, diabetes, arthritis, or other common chronic conditions. Study collaborators will collect 18 items in order to explore details related to cancer diagnosis, complications during initial treatment, and further participant characteristics from medical records. The study results will show how frequent cancer-related long-term symptoms are, and how severe they are respectively one to five and five to ten years after diagnosis. Further, we will perform calculations with treatment- and diagnosis-related information which are linked to later problems and symptoms. Cancer

survivors are expected to live with long-term effects caused by their cancer. This survey study results will have the potential to inform future early interventions and support for cancer survivors.

What are the possible benefits and risks of participating?

Study participants will receive no personal benefit by participating in the study and no study-specific risks are expected. Eligible participants are free to decide to answer the questions or not. Study participants will provide insights on their cancer survivorship experience in a Swiss canton. This information may help to improve cancer survivorship care in this region, a fact that might be of benefit later for the participants.

Where is the study run from?

HFR Fribourg – cantonal Hospital (Switzerland)

When is the study starting and how long is it expected to run for?

March 2023 to December 2024

Who is funding the study?

HFR Fribourg and the Fondation fribourgeoise pour la recherche et la formation sur le cancer (Switzerland)

Who is the main contact?

Prof. Marika Bana, RN PhD, marika.bana@hefr.ch

Contact information

Type(s)

Scientific, Principal investigator

Contact name

Prof Marika Bana

ORCID ID

<https://orcid.org/0000-0002-9988-6299>

Contact details

Haute école de santé Fribourg

Route des Arsenaux 16a

Fribourg

Switzerland

1700

+41 26 429 60 67

marika.bana@hefr.ch

Type(s)

Public

Contact name

Dr Marc Küng

Contact details

HFR Fribourg - Hôpital cantonal
Case postale
Fribourg
Switzerland
1708
+41 26 306 00 00
marc.kueng@h-fr.ch

Additional identifiers

Clinical Trials Information System (CTIS)

Nil known

Protocol serial number

Nil known

Study information

Scientific Title

Cancer Survivorship Survey - Fribourg

Acronym

CSS-Fri

Study objectives

Our primary objective is to describe the prevalence of self-reported cancer-related symptoms / problems reported by residents treated or still followed for cancer, assessed by study questionnaire and HFR (hôpital fribourgeois) medical record documentation one to five years, and five to ten years post-diagnosis. Our secondary objective is to define predictive factors for supportive care needs and duration of return to work / family duties caused by cancer and/or treatment long-term or delayed effects, to inform a future survivorship programme and to identify relevant patient-reported outcomes to evaluate its impact.

Ethics approval required

Ethics approval required

Ethics approval(s)

approved 03/01/2024, Commission cantonale d'éthique de la recherche sur l'être humain CER-VD (Av. de Achilly 23, Lausanne, 1012, Switzerland; +41 21 316 18 36; CER@vd.ch), ref: 2022-00837_2205

Study design

Retrospective cross-sectional survey

Primary study design

Observational

Study type(s)

Other, Quality of life

Health condition(s) or problem(s) studied

Cancer survivors diagnosed with breast, colorectal, lung, prostate, lymphoma or myeloma

Interventions

We evaluate cancer survivors long-term problems and symptoms by applying the NCCN survivorship patient assessment complemented with additional questions on co-morbidities and medical characteristics related to diagnosis and cancer treatment. Participants can choose to complete the questionnaire online or in paper format. Medical information will be assessed from medical records.

Intervention Type

Other

Primary outcome(s)

Summarize the most frequent cancer related symptoms and problems perceived by study participants, measured by questionnaire

Key secondary outcome(s)

Explore predictive factors related to long-term and late symptoms and/or problems measured using questionnaire and patient records

Completion date

31/12/2024

Eligibility

Key inclusion criteria

1. Adult residents (18 years and older) treated at a site linked to the Fribourg cantonal hospital
2. Diagnosis of breast, colorectal, lung or prostate cancer
3. Diagnosis of myeloma or lymphoma
4. Cancer diagnosis one to five years ago
5. Cancer diagnosis five to ten years ago
6. Returned completed questionnaire

Participant type(s)

Patient, Resident

Healthy volunteers allowed

No

Age group

Adult

Lower age limit

18 years

Upper age limit

99 years

Sex

All

Total final enrolment

333

Key exclusion criteria

1. Does not understand/speak French or German
2. Not treated at the HFR
3. Currently hospitalised for a cancer treatment
4. Currently under intravenous anticancer treatment

Date of first enrolment

28/02/2024

Date of final enrolment

31/05/2024

Locations

Countries of recruitment

Switzerland

Study participating centre

HFR Fribourg - Hôpital cantonal

Case postale

Fribourg

Switzerland

1708

Sponsor information

Organisation

HFR Freiburg Kantonsspital

ROR

<https://ror.org/00fz8k419>

Funder(s)

Funder type

Charity

Funder Name

Fondation fribourgeoise pour la recherche et la formation sur le cancer

Funder Name

HFR Freiburg Kantonsspital

Funder Name

HES-SO University of Applied Sciences and Arts Western Switzerland - Fribourg, School of Health Sciences

Results and Publications

Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study are/will be available upon request from Marika Bana (marika.bana@hefr.ch)

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	in French version 2.4	15/11/2023	10/05/2024	No	Yes
Participant information sheet	in German version 2.4	15/11/2023	10/05/2024	No	Yes
Protocol file	version 3.0	22/11/2023	10/05/2024	No	No