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Survey 'Living with and beyond cancer'

Submission date
08/05/2024

Recruitment status
No longer recruiting

Registration date
10/05/2024

Overall study status
Completed

Last Edited
10/01/2025

Condition category
Cancer

[_] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[_] 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

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Public

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Additional identifiers

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 lêtre 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