



SWISS
CANCER PATIENT
EXPERIENCES

QUESTIONNAIRE ON PATIENTS' EXPERIENCES WITH CANCER CARE



Scan the QR-Code to complete the
online questionnaire.

We **thank you** for your contribution and for the time you will spend answering the questionnaire. **Your participation is valuable and important.**

Please read each question and all possible answers carefully. Tick the answer that best fits your point of view.

Correct:

Please mark only one answer per question, unless it is specified that multiple answers are possible; please also answer all questions, unless the instructions indicate to skip a question.

It is your opinion that matters; there is no right or wrong answer. It is important to answer honestly to reflect the real situation. Please feel free to write your own comments at the end of the questionnaire.

Completing the questionnaire takes between 20 and 30 minutes.

The questions must be answered by the person named in the invitation letter. If this person needs help completing the questionnaire, a relative or friend may help, but the answers must be given from the perspective of the person invited - not from the relative or friend.

Declaration of consent

By returning the completed questionnaire, I declare:

- ✓ Having been informed in writing of the objectives and conduct of the SCAPE-CH survey
- ✓ Taking part in this survey voluntarily and accepting the content of the information sheet that was given to me about the SCAPE-CH survey
- ✓ Having had enough time to make my decision
- ✓ Having received satisfactory answers to the questions I asked in connection with my participation in the SCAPE-CH survey
- ✓ Accepting that the specialists of the competent Ethics Commission may consult my uncoded data to carry out controls, while strictly ensuring the confidentiality of the data
- ✓ Being aware that the data provided in this questionnaire will be analyzed and stored without the possibility of identifying me by Unisanté; no information permitting to identify me will be transmitted to third parties
- ✓ Being aware that I can revoke my consent to participate in the survey up to the end of the survey (30.06.2024) and without having to justify it, without any repercussions on my care. The questionnaire data collected so far will nevertheless be analyzed in such a way that it is not possible to identify me

**CONSULTATIONS WITH A FAMILY DOCTOR /
GENERAL PRACTITIONER (GP)
*before the cancer diagnosis***

*For people who have had more than one cancer,
please answer with the last diagnosed cancer in
mind.*

1. How many times did you see a family doctor / GP for the symptoms caused by cancer before seeing a specialist?
 - None - I went directly to a specialist
 - None - I had no symptoms and the cancer was detected during a routine or follow-up examination or through a screening program
 - I saw a doctor once or twice
 - I saw a doctor 3 or 4 times
 - I saw a doctor 5 or more times
 - I don't know / I can't remember
2. How do you feel about the length of time you had to wait before your first appointment with a specialist?
 - I was seen as soon as I thought it was necessary
 - I should have been seen a bit sooner
 - I should have been seen a lot sooner
 - I didn't have to wait because I didn't make an appointment (for example emergency consultation)
 - I don't know / I can't remember

DIAGNOSTIC TESTS

3. During the last 12 months, have you had a diagnostic test for cancer, such as endoscopy, biopsy, mammography, or scan at the hospital named in the invitation letter?
 - Yes → **Go to question 4**
 - No → **Go to question 7**

Thinking about the last time you had a diagnostic test for cancer at the hospital named in the invitation letter...

4. Before the test, did you have all the information you needed about this test?
 - Yes, completely
 - Yes, to some extent
 - No
5. Overall, how did you feel about the length of time you had to wait between the prescription of the test and its completion?
 - It was about right
 - It was a little too long
 - It was much too long
6. Were the results of the tests explained in a way you could understand?
 - Yes, completely
 - Yes, to some extent
 - No, I didn't understand the explanation
 - I didn't have an explanation but would have liked one
 - I didn't need an explanation

FINDING OUT ABOUT YOUR CANCER

For people who have had more than one cancer, please answer with the last diagnosed cancer in mind.

7. How long ago were you told you had the cancer for which you were treated or followed up in 2023?
- Less than 1 year ago
 - Between 1 and 5 years ago
 - More than 5 years ago
 - I don't know / I can't remember
8. Who was the first person to tell you that you had cancer? (*Several answers possible*)
- A family doctor / GP
 - A specialist doctor (for example, oncologist, gynecologist, urologist, surgeon)
 - A nurse
 - Someone else
 - I don't know / I can't remember
9. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?
- Yes
 - No
 - I was told I had cancer by phone or letter
 - I don't know / I can't remember
10. How do you feel about the way you were told you had cancer?
- It was done sensitively
 - It should have been done a bit more sensitively
 - It should have been done a lot more sensitively
 - I don't know / I can't remember

11. Did you understand the explanations of what was happening to you?
- Yes, I completely understood
 - Yes, I understood to some extent
 - No, I didn't understand
 - I don't know / I can't remember
12. When you were told you had cancer, were you given written information about the type of cancer you had?
- Yes, and it was easy to understand
 - Yes, but it was difficult to understand
 - No, but I would have liked to receive some
 - I didn't need written information
 - I don't know / I can't remember
13. Have you been offered to see a health professional to address your concerns and fears following the cancer diagnosis?
- Yes → a nurse
 - a psychologist
 - a doctor
 - a social worker
 - another professional
 - No, but I would have liked to
 - That wasn't necessary
 - I don't know / I can't remember

DECIDING THE BEST TREATMENT FOR YOU

14. Before your cancer treatment started, were your treatment options explained to you?
- Yes, completely
 - Yes, to some extent
 - No
 - There was only one type of treatment that was suitable for me
 - I don't know / I can't remember

15. Were the possible side effects of treatment(s) explained in a way you could understand?

- Yes, definitely
- Yes, to some extent
- No, I didn't understand the explanation
- I didn't have an explanation but would have liked one
- I didn't need an explanation
- I don't know / I can't remember

16. Were you also told about any side effects that could occur later rather than straight away?

- Yes, definitely
- Yes, to some extent
- No, but I would have liked to be told
- I didn't need to be told
- I don't know / I can't remember

17. Were you involved as much as you wanted to be in decisions about your care and treatment?

- Yes, definitely
- Yes, to some extent
- No, I would have liked to be more involved
- I don't know / I can't remember

18. Were your family and/or friends able to be involved as much as you wanted them to be in decisions about your care and treatment?

- Yes, definitely
- Yes, to some extent
- No, I would have liked them to be more (or less) involved
- Not applicable
- I don't know / I can't remember

19. Were your lifestyle, family situation, and/or work situation considered in decisions about your care and treatment?

- Yes, definitely
- Yes, to some extent
- No, but I would have liked it
- It wasn't necessary
- I don't know / I can't remember

20. Did anyone discuss with you or give you information about the impact of cancer on your daily activities (for example, work, hobbies)?

- Yes
- No, but I would have liked to have a discussion or information
- It wasn't necessary
- I don't know / I can't remember

HOSPITAL CARE AS AN INPATIENT (stay lasting more than 24 hours)

21. During the last 12 months, have you stayed overnight for cancer care or treatment at the hospital named in the invitation letter?

- Yes → **Go to question 22**
- No → **Go to question 35**

Thinking about the last time you stayed overnight for cancer care or treatment at the hospital named in the invitation letter...

22. Did doctors and nurses talk in front of you as if you were not there?

- Yes, often
- Yes, sometimes
- No

- 23.** Did you have confidence and trust in the doctors looking after you?
- Yes, in all of them
 - Yes, in some of them
 - No, in none of them
- 24.** If a member of your family or friend wanted to talk to a doctor, were they able to?
- Yes, definitely
 - Yes, to some extent
 - No
 - My family or friends didn't want to talk to a doctor / not applicable
- 25.** Did you have confidence and trust in the nurses looking after you?
- Yes, in all of them
 - Yes, in some of them
 - No, in none of them
- 26.** Were you given enough privacy when discussing your condition or treatment?
- Yes, always
 - Yes, sometimes
 - No
- 27.** Was a member of staff available when you needed them?
- Yes, always
 - Yes, sometimes
 - No
 - I didn't need any help
- 28.** During your hospital stay, did you find someone on the hospital staff to talk to about your worries and fears?
- Yes, always
 - Yes, sometimes
 - No
 - I didn't have any worries or fears
- 29.** Do you think the hospital staff did everything they could to help control your pain?
- Yes, definitely
 - Yes, to some extent
 - No
 - I didn't have any pain
- 30.** Overall, did you feel you were treated with respect and dignity during your stay in the hospital?
- Yes, always
 - Yes, sometimes
 - No
- 31.** Were you given written information about what you should or should not do after leaving the hospital?
- Yes, and it was easy to understand
 - Yes, but it was difficult to understand
 - No, but I would have liked to receive some
 - I didn't need written information
 - I don't know / I can't remember
- 32.** Did someone from the hospital explain to you the warning signs related to your condition or operation that you should watch for when you got home?
- Yes, definitely
 - Yes, to some extent
 - No
 - I don't know / I can't remember

33. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left the hospital?

- Yes
- No, but I would have liked to
- It wasn't necessary
- I don't know / I can't remember

34. Did the organization of your hospital discharge go well?

- Yes, definitely
- Yes, to some extent
- No

**HOSPITAL CARE AS A DAY PATIENT /
OUTPATIENT
(stay lasting less than 24 hours)**

35. During the last 12 months, have you been followed up or treated as an outpatient or day case for cancer care at the hospital named in the invitation letter?

- Yes → **Go to question 36**
- No → **Go to question 39**

36. While you were being treated as an outpatient or day patient, did you find someone on the hospital staff to talk to about your worries or fears?

- Yes, always
- Yes, sometimes
- No
- I didn't have any worries or fears

37. Overall, how do you feel about the time you spent in the waiting room when you had an appointment for an outpatient cancer consultation or treatment?

- It was about right
- It was a little too long
- It was much too long

38. When you asked the doctor important questions during outpatient consultations or treatment, did you get answers you could understand?

- Yes, always
- Yes, sometimes
- No
- I didn't ask any question

NURSING CONSULTATION

Some oncology centers offer nursing consultations with a clinical nurse specialist to support patients and their families/friends in coping with cancer.

39. Did you have a nursing consultation at the hospital named in the invitation letter to support you in coping with cancer?

- Yes → **Go to question 40**
- No, but I would have liked it
- No, it wasn't necessary
- I don't know / I can't remember

**Go to
question 42**

40. How easy or difficult was it to contact a nurse from the nursing consultation?

- Very easy
- Rather easy
- Rather difficult
- I didn't try to contact a nurse from the nursing consultation

41. When you asked the nurse important questions during the nursing consultation, did you get answers you could understand?

- Yes, always
- Yes, sometimes
- No
- I didn't ask any question

TREATMENTS

42. During the last 12 months, what type(s) of cancer treatment have you received? (*Tick all that apply*)

- Surgery
 Chemotherapy
 Radiotherapy
 Hormone therapy
 Immunotherapy
 Targeted therapy
 Other _____
 I received my treatment(s) more than 12 months ago
 I haven't received any treatment yet
 I don't know

} **Go to
question 46**

For the following three questions, please answer for each treatment received in the last 12 months.

43. Before your treatment started, did you have all the information you needed about the treatment?

	Surgery	Chemotherapy	Radiotherapy	Hormone therapy	Immunotherapy	Targeted therapy
Yes, completely	<input type="checkbox"/>					
Yes, to some extent	<input type="checkbox"/>					
No	<input type="checkbox"/>					

44. Were you offered practical advice and/or support in dealing with the side effects of your treatment?

	Surgery	Chemotherapy	Radiotherapy	Hormone therapy	Immunotherapy	Targeted therapy
Yes, completely	<input type="checkbox"/>					
Yes, to some extent	<input type="checkbox"/>					
No, but I would have liked to be offered some	<input type="checkbox"/>					
It wasn't necessary	<input type="checkbox"/>					

45. Once your treatment started, were you given information about its results in a way you could understand?

	Surgery	Chemotherapy	Radiotherapy	Hormone therapy	Immunotherapy	Targeted therapy
Yes, completely	<input type="checkbox"/>					
Yes, to some extent	<input type="checkbox"/>					
No, I didn't understand the information	<input type="checkbox"/>					
No, I didn't get the information, but I would have liked it	<input type="checkbox"/>					
I didn't need information	<input type="checkbox"/>					
It is too early to know if the treatment is working	<input type="checkbox"/>					

HOME CARE AND SUPPORT

46. Did a staff member at the hospital named in the invitation letter ensure that you had the necessary help (for example, home care) and equipment (for example, wheelchair) at home to help you carry out your daily activities?

- Yes, definitely
- Yes, to some extent
- No
- It wasn't necessary

47. Were your family or friends given all the information they needed to help care for you at home?

- Yes, definitely
- Yes, to some extent
- No
- It wasn't necessary
- Not applicable

48. Were you offered enough practical advice and/or support in dealing with your symptoms (such as pain, nausea, fatigue, anxiety)?

- Yes, definitely
- Yes, to some extent
- No
- It wasn't necessary

49. Were you given enough care and support from health or social services (for example, home nurse, social worker)?

- Yes, definitely
- Yes, to some extent
- No
- It wasn't necessary

LIVING WITH AND BEYOND CANCER

This section refers to the follow-up period, after the end of the treatments started after the cancer/recurrence diagnosis. If you are still undergoing chemotherapy or radiotherapy, go to question 54.

50. Were you offered enough practical advice and/or support in dealing with the long-term effects of cancer or treatment (such as fatigue, pain, anxiety)?

- Yes, definitely
- Yes, to some extent
- No
- It wasn't necessary

51. At the end of the treatments, did you have all the information you needed about follow-up care?

- Yes, definitely
- Yes, to some extent
- No
- I don't know / I can't remember

52. Are you in regular contact with a reference person (such as a doctor, nurse, social worker) for follow-up care?

- Yes → An oncologist / specialist
 - A family doctor / GP
 - A nurse
 - A social worker
 - Another professional

- No, but I would like to
- No, it's not necessary
- I don't know

} Go to question 54

53. Did this reference person provide you with a follow-up plan that outlines your needs and solutions and sets up regular appointments to reassess them?

- Yes
- No
- It wasn't necessary

CARE FROM YOUR FAMILY DOCTOR / GP OFFICE

54. Do you think that your family doctor / GP and their team did everything they could to support you during your cancer treatment?

- Yes, definitely
- Yes, to some extent
- No, they could have done more
- My family doctor / GP wasn't involved
- I don't have a family doctor / GP

55. Did your family doctor / GP discuss your cancer treatment with you?

- Yes
- No
- I didn't want my family doctor / GP to be involved
- I don't have a family doctor / GP

SUPPORT FOR CANCER PATIENTS

56. Were you given information about support or self-help groups for people with cancer?

- Yes
- No, but I would have liked information
- It wasn't necessary
- I don't know / I can't remember

57. Were you given information about help and support to help you deal with your emotions (for example, stress, anxiety, sadness)?

- Yes
- No, but I would have liked information
- It wasn't necessary
- I don't know / I can't remember

58. Were you given information about how to get financial help or any benefits you might be entitled to?

- Yes
- No, but I would have liked information
- It wasn't necessary
- I don't know / I can't remember

YOUR OVERALL CARE

59. Did the different people treating and caring for you (such as your family doctor / GP, oncologist, hospital doctors and nurses, home care) work well together to give you the best possible care?

- Yes, always
- Yes, sometimes
- No
- I don't know / I can't remember

60. Were you given a care plan? (A care plan is a written document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional(s) to help meet those goals.)

- Yes
- No
- I don't know / understand what a care plan is
- I don't know / I can't remember

61. During your care, have test results or medical records ever been unavailable at the time of your care appointment?

- Yes, often
- Yes, sometimes
- No
- I don't know / I can't remember

62. During your care pathway, have you ever been given confusing or conflicting information about your health condition or treatment?

- Yes, often
- Yes, sometimes
- No
- I don't know / I can't remember

63. During your care, was there a time when you felt that tests or other assessments were repeated unnecessarily?

- Yes, often
- Yes, sometimes
- No
- I don't know / I can't remember

64. Overall, how would you rate your care?

Very											Very
poor											good
<input type="checkbox"/>											
0	1	2	3	4	5	6	7	8	9	10	

YOUR CONDITION

65. What is the main type of cancer for which you have been treated or monitored in the last 12 months? (Please check only one answer)

- Bladder
- Brain
- Breast
- Colon / rectum / colorectal
- Esophagus
- Kidney
- Liver
- Leukemia
- Lung / bronchus / trachea
- Lymphoma
- Melanoma of the skin
- Mouth / Throat
- Myeloma
- Ovary
- Pancreas
- Prostate
- Stomach
- Testis
- Thyroid
- Uterus
- Other: _____
- I don't know

66. The cancer reported above is:

- A 1st cancer
- A recurrence of a cancer treated in the past (cancer diagnosed, treated, and previously cured but now back again)
- A 2nd or 3rd cancer (completely different from a previously diagnosed cancer)

67. Had your cancer spread to other organs or parts of your body (metastatic cancer) at the time you were first told you had cancer?

- Yes
- No, but the cancer spread after
- No, and the cancer didn't spread
- I don't know / don't remember

68. Have you received one or more complementary medicine therapies for cancer treatment or symptom management? (*Multiple responses possible*)

- None
- Aromatherapy, Bach flowers, phytotherapy (including CBD products)
- Ayurveda, traditional Chinese medicine (including acupuncture)
- Homeopathy, anthroposophic medicine (including mistletoe), naturopathy
- Hypnosis, meditation, sophrology
- Kinesiology, reiki, bioresonance
- Osteopathy, therapeutic massages, reflexology, shiatsu
- Other: _____

69. Have you received any medical treatment in the last 12 months or are you currently being treated for a chronic health problem other than cancer?

- Yes, I have at least one other chronic disease (e.g., depression, diabetes, hypertension, cardiovascular disease, lung disease)
- No, I don't have any other chronic disease
- I don't know

70. In general, would you say your health is:

Excellent Very good Good Fair Poor

-

71. FACT-G7 (Version 4)

Below is a list of statements that other people with your illness have said are important. Please indicate your response as it applies to the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	<input type="checkbox"/>				
I have pain	<input type="checkbox"/>				
I have nausea	<input type="checkbox"/>				
I worry that my condition will get worse	<input type="checkbox"/>				
I am sleeping well	<input type="checkbox"/>				
I am able to enjoy life	<input type="checkbox"/>				
I am content with the quality of my life right now	<input type="checkbox"/>				

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72. Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious, or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

73. During the past month, ...

	Yes	No
...have you often been bothered by feeling down, depressed, or hopeless?	<input type="checkbox"/>	<input type="checkbox"/>
...have you often been bothered by little interest or pleasure in doing things?	<input type="checkbox"/>	<input type="checkbox"/>

74. To what extent are you currently concerned about...

	Not at all	A little bit	Somewhat	Quite a bit	Very much	I don't know / not concerned
The cancer progression	<input type="checkbox"/>					
Your professional situation	<input type="checkbox"/>					
Your financial situation	<input type="checkbox"/>					
Your future	<input type="checkbox"/>					

75. When you get written information about a medical treatment or your health condition, do you have any problems understanding it?

- Always
- Often
- Sometimes
- Occasionally
- Never

76. In general, how do you prefer to make medical decisions about cancer?

- I prefer to make the decisions myself
- I prefer my doctor and I make decisions together
- I prefer my doctor to make the decisions

PERSONAL INFORMATION

77. You are:

- Female
- Male
- Non-binary
- Other: _____

78. How old are you? _____

79. What is your main language, that is the language you think in and know the best?

- French
- German (or Swiss German)
- Italian
- Other

80. What is your nationality? (*Multiple answers possible*)

- Swiss
- European
- Extra-European

81. What is your civil status?

- Single
- Married / registered partnership
- Divorced / dissolved partnership
- Widowed

82. What best describes your current living situation?

- I live alone
- I live alone with child(ren) at home
- I live as a couple without children at home
- I live as a couple with child(ren) at home
- I live with other person(s) (for example, relative(s), roommate(s))
- Other (for example, in an institution)

83. What is the highest level of education you have completed?

- No schooling / compulsory education
- General education school / high school-leaving certificate or vocational baccalaureate / teacher training school
- Apprenticeship (federal diploma/certificate of vocational education and training) / full-time vocational school / basic vocational education and training
- Advanced technical and professional training / higher technical or commercial college
- University, university of applied sciences or teacher education, polytechnic (ETH/EPFL)
- Other: _____

84. What best describes your current work situation?

- Full-time professional activity (80%-100%)
- Part-time professional activity (<80%)
- In training (student, apprentice)
- Seeking a job (registered for unemployment or not)
- Looking after home or family
- On disability (for example, disability insurance (DI) pensioner) or on extended sick leave
- Retired (OASI, other pension) or other annuitant excluding disability pensions
- Other: _____

85. During the last 12 months, have you had trouble paying household bills (taxes, insurance, telephone, electricity, credit card, etc.)?

- Yes
- No

86. During the last 12 months, have you forgone care because of the cost?

- Yes
- No

FINANCIAL IMPACT OF CANCER

87. Have you or your family had to make financial sacrifices because of cancer, cancer treatment(s), or related long-term effects? *(Multiple answers possible)*

- Cutting back on spending on vacations or leisure activities
- Forgoing major purchases (for example, car)
- Cutting back on basic expenses (for example, food or clothing)
- Using savings set aside for other purposes (for example, retirement, education)
- Other: _____
- No financial sacrifice

88. Have you ever been afraid of losing your job and income, or having your income limited in the future because of cancer?

- Yes
- No
- No paid professional activity at the time of cancer diagnosis

89. Has a family member or friend ever taken unpaid leave or reduced work hours to support you?

- Yes
- No
- Family member or friend without professional activity / not concerned

Is there anything you appreciate or have particularly appreciated during your cancer care?

Is there anything that could be improved?

Other comments

You completed this questionnaire: By yourself With someone's help

Note: This questionnaire isn't transmitted to healthcare professionals. If you have any medical questions or symptoms, we advise you to speak to a healthcare professional.

The main results of this survey will be published on the website www.scape-enquete.ch.

Thank you for taking the time to answer our questions. We appreciate your feedback.

Please return the questionnaire using the prepaid envelope to the following address:
Unisanté – SCAPE, Route de la Corniche 10, 1010 Lausanne