

Contribute now to the improvement of the care provided to Cancer of Unknown Primary patients

World CUP Alliance advocate for the interests of people impacted by Cancer of Unknown Primary (CUP). We would like to know about your experiences with the (suspected/probable) diagnosis of Cancer of Unknown Primary (CUP). Your opinion on Cancer of Unknown Primary helps us to know what is going well and what could be done to improve care and pathways. It also allows us to make the case for sustainable healthcare improvements.

Participation is anonymous (no one knows who you are or which answers you have given). Or in case you are a loved one of someone with or who passed away from CUP, then if you wish, you may fill in this questionnaire on behalf of your loved one with CUP. *For example, if the questionnaire says 'What is your gender?' – then do not fill in your own gender, but that of your loved one with CUP. This applies to all the questions.*

Completing the questionnaire takes about **15 minutes**.

Download the PDF, fill in the answers and save! Once completed, please send it via email at info@worldcupalliance.org

Background

World CUP Alliance (WCA) is the international advocacy organisation for patients and the loved ones and relatives of patients with metastatic cancer with an unknown primary tumour, also known as CUP. WCA was co-founded by the Irish *Sarah Jennifer Knott Foundation* and the Dutch *Missie Tumor Onbekend Foundation*, with support from the British CUP Foundation, *Jo's Friends*. These organisations have been active in their respective countries for many years improving care and access to treatments and diagnostics for this patient group. Two years ago, we joined forces to drive and deliver healthcare improvements for CUP on an international level.

Thank you!

For taking the time to complete this questionnaire, we aim to use this information to drive changes and improvements for people living with CUP.

SELECTION QUESTION

01 | Do you have cancer (*Cancer of Unknown Primary, CUP*)?

- Yes, and there is a suspicion of CUP in my case
- Yes, and I have been diagnosed with CUP
- No, but I am a loved one/relative of someone with CUP
- No, and I do not have any loved ones with CUP.
(questionnaire not applicable)

02 | If a loved one: Which of the following applies to your loved one with CUP?

- He/she is alive
- He/she is deceased

GENERAL QUESTIONS

If you are completing this questionnaire on behalf of your loved one, then please answer all the questions how they would have answered themselves.

03 | What is your gender?

- Male
- Female
- Other
- I don't want to say

04 | What is your age?

- 18-25 years
- 26-40 years
- 41-60 years
- 61-75 years
- 75-85 years
- 86+ years

05 | What is the highest level of education you completed?

- Primary school (elementary education)
- Lower vocational education
- Secondary general education
- Secondary vocational education
- General higher education
- Higher vocational education
- Academic education (university-level)
- I don't want to say
- Other, namely

06 | In which country do you live, and to which country does this questionnaire pertain?

Enter the name of the country here

ABOUT THE DIAGNOSIS

07 | In which year was 'Cancer of Unknown Primary' (CUP) first diagnosed or suspected?

Enter the year here

08 | Are you currently undergoing treatment for CUP?

- No – I am still having tests (*investigations*)
- No – my treatment has not started
- Yes – I am receiving chemotherapy for CUP
- Yes – I am receiving a targeted treatment for CUP
- No – my treatment for CUP has finished
- No – my treatment for CUP was stopped as it was not working and I am receiving only pain relief
- Other, namely

THE FIRST SYMPTOMS

09 | What were the symptoms that first took you to the GP?

The following symptom(s) – describe briefly:

Not applicable – I ended up directly in the hospital due to my symptoms. *(If this is your answer, please continue to question 12)*

10 | What did the GP do? *Multiple answers possible*

- Physical examination
- Took blood tests
- Prescribed medication
- Directly referred me to the hospital for further investigations and/or treatment
- Nothing; if the symptoms persisted, I was told to come back to the GP
- Other, namely

11 | How long did it take (approximately) before you were referred to the hospital due to the symptoms?

- Within one week
- Within one month
- Within several months
- Within six months
- Within one year
- More than one year
- I don't remember

12 | Are you receiving support from your GP in terms of guidance related to the (possible) diagnosis of CUP (Cancer of Unknown Primary)?

- No
- Some support
- A lot of support
- Not applicable

13 | Are you receiving support from your GP in terms of guidance during or after the treatment(s) you undergo for CUP?

- No
- Some support
- A lot of support
- Not applicable

14 | Space for further explanation about the CUP-related care provided by the GP

15 | After you were referred to the hospital or ended up there, how long did it take for CUP, or probable CUP, to be diagnosed?

- Within one week
- Within one month
- Within several months
- Within six months
- Within one year
- More than one year
- I don't remember

16 | With regard to CUP (or probable CUP), have you been to any other hospital(s) for a diagnosis?

- Yes, 1 other hospital
- Yes, 2 other hospitals
- Yes, more than 2 other hospitals
- No

17 | If yes, what are the reasons you have been to several hospitals? *Multiple answers possible*

- My GP recommended this
- The people around me recommended this
- My doctor at the first hospital referred me
- I asked for a referral myself, as I was left without a diagnosis
- I had a bad experience with the first hospital I went to
- The first hospital could not make a diagnosis
- The first hospital did not offer certain diagnostics
- The first hospital did not offer certain treatments
- I went for a second opinion and then stayed there
- The last hospital I visited (the new hospital) had a lot of experience with CUP
- The last hospital I visited (the new hospital) was easier or less expensive to reach
- The last hospital I visited (the new hospital) had shorter waiting times
- I went to another hospital in order to access clinical trials/scientific research
- Other, namely

18 | Sometimes one or more diagnostic tests are repeated at a new hospital. For example, a CT scan or MRI that was also performed at the previous hospital. Were diagnostic tests repeated at the last hospital you visited (*new hospital*)?

- No
- I don't know
- Yes, the following tests were repeated (describe briefly):

19 | Have the diagnostics (the tests or examinations) already been completed, or are the doctors in the hospital continuing to try to find the primary tumour? Are doctors still doing tests to find a primary cancer, or have all tests been completed?

- All investigations have been completed: I am diagnosed with Cancer of Unknown Primary
- I am still having investigations to find for the primary cancer
- I don't know

20 | Some hospitals offer 'Whole Genome Sequencing' 'Whole Exome Sequencing' or other forms of 'Next Generation Sequencing' (WGS & NGS). These are types of comprehensive molecular diagnostics. These tests can detect genetic flaws that may have contributed to the cancer and could possibly guide treatment options, in some cases, it can also provide clues to the location of the primary tumour. This can be a blood test or additional tests on a tissue sample taken for biopsy or both. Are you aware of the existence of and the possibility for using these comprehensive DNA diagnostics for CUP?

- Yes, I have had these tests
- Yes, I have heard/read about this, but, to my knowledge, these tests were not used in my case
- Yes, I am aware of this, but during the diagnostic phase, this type of testing was not yet available in the country where I live
- No
- It is unclear to me what is meant by 'Whole Genome Sequencing' or 'Next Generation Sequencing' in this question

21 | Is there a specific primary tumour or type of cancer suspected at this time, on the basis of comprehensive molecular diagnostics?

- No
- I don't know
- Yes, namely (name tumour or type of cancer)

22 | What went through your mind or how did you feel when you heard the diagnosis 'Cancer of Unknown primary' (CUP) or probable CUP?

23 | Had you or anyone close to you ever heard about (possible) CUP before?

- No
- Other, namely

24 | What do you find most troublesome about the (possible) diagnosis of CUP?**25 | Have you searched for information about the (possible) diagnosis of CUP?**

No
 Yes, online
 Yes, through a healthcare professional
 Yes, I have contacted a patient organisation specialising in CUP. Enter the name of the organization here:

Other, namely

I don't remember

26 | There are hospitals that specialise in (possible) 'Cancer of Unknown Primary' (CUP). Did you know these existed?

No
 Yes
 I don't remember

27 | Have you or has your doctor been in contact with one of these specialised centres of expertise regarding (probable) CUP?

I don't know
 No
 Not applicable; I am already at a centre of expertise or CUP outpatient clinic
 Yes, namely (e.g. how)

28 | Which of these do you prefer?

I prefer to visit the specialist hospital
 I prefer to stay in my own hospital, where I know my attending doctor will get advice from a centre of expertise
 I have no preference
 I don't know
 Other, namely

29 | Can you explain your answer in greater detail? Why do you have a particular preference (or no preference)?**30 | To what extent do you agree with the following statements about (probable) 'Cancer of Unknown Primary'?**

A | I get enough information about (probable) CUP from my attending doctor

Yes I don't know
 No NA

B | I get enough information about (probable) CUP from other care providers in the hospital (e.g. the nurse specialist)

Yes I don't know
 No NA

C | I was offered support while in the hospital (e.g. in dealing with emotions or physical symptoms)

Yes I don't know
 No NA

D | My loved ones (e.g. my partner/family) were offered support due to my illness

Yes I don't know
 No NA

E | I felt that I could decide together with my doctor about the use of diagnostics and/or treatments throughout my disease process (shared decision-making)

Yes I don't know
 No NA

F | I was given the opportunity to participate in scientific research studies* because of the CUP diagnosis

Yes I don't know
 No NA

** Explanation of scientific research studies: Doctors and scientists are always looking for new/better treatments and care for cancer. They want to improve the chances of survival, survival time or quality of life. Scientific research is the basis for this. Trials are discussed in different ways in the hospital. Other terms are: medical-scientific research, clinical study, clinical trial or experimental treatment. All these terms mean: a possible new/better treatment or care offer of which doctors investigate the effect and results in patients. Sometimes, as a CUP patient, you may be eligible to participate in such a scientific study or trial.*

31 | Do you have a healthcare provider who oversees your illness and treatment process and is a regular point of contact for you? For example, a nurse specialist or your attending physician - someone you can contact with questions.

Yes
 No
 I am not sure

32 | If yes, who is your permanent point of contact?

Multiple answers possible

My attending physician
 A nurse specialist
 My GP
 Other, namely

TARGETED THERAPY

Targeted therapy is a treatment that could be given to patients when a DNA flaw has been discovered with comprehensive molecular diagnostics. Then a targeted treatment can be directed specifically to that flaw in the DNA. Sometimes these types of therapy are given as part of a scientific research study and sometimes they are available as part of standard clinical care.

33 | Have you received any information about targeted therapy?

- Yes, and I have also been offered targeted therapy
- Yes, but I have not (yet) made use of targeted therapy
- No
- I don't know (remember)

34 | Is this targeted therapy being given as part of a scientific research study?

- Yes
- No
- I don't know (remember)

35 | Space for further explanation:

SUPPORTIVE CARE

Supportive care is care given to patients when a cure for cancer is no longer possible and one can receive life-extending support. Supportive care includes all care and support aimed at giving the person with the life-threatening illness (and their loved ones) the highest possible quality of life.

With supportive care, the focus not only lies on the physical symptoms the sick person may face during the continuation of the illness. Attention is also paid to the psychological, social and/or spiritual problems that (may) arise in the patient and/or in his or her loved ones. The supportive care phase can last for years, months or weeks, depending on the needs of the individual patient.

36 | Have you received any information about supportive care?

- Yes, and I have also made use of supportive care
- Yes, but I have not (yet) made use of supportive care
- No
- I don't know (remember)

37 | If yes, from whom did you receive this information?

Multiple answers possible

- From my oncologist
- From a nurse or nurse specialist
- From the supportive care team at the relevant hospital
- From my GP
- I don't know (remember)
- Other, namely

IN CONCLUSION

Space to explain in greater detail how you experienced hospital care and additional comments or suggestions you may have:

World CUP Alliance is here for you. If you would like us to contact you to provide more information or to exchange ideas, then please leave your e-mail address below. (This is certainly not obligatory.)

In response to the results of this questionnaire, worldcupalliance.org would like to conduct some additional interviews. We would like to use this information to map in greater detail the experiences of people with a (possible) CUP diagnosis. We are curious about exploring the entire 'route' of your illness, from the onset of the first symptoms until now. The route varies greatly from patient to patient, and we are interested in finding out examples or suggestions for a best possible route.

A route like this, in the context of healthcare, is also sometimes known as a 'patient journey'. Mapping out the patient journey can lead to a care pathway in which healthcare professionals agree with one another on the timelines, duration and quality of all the care provided to patients with a specific cancer diagnosis. Your input can be used to improve this care. Especially now, because in several countries a national care pathway or a new guideline on CUP is in place or being developed.

World CUP Alliance (WCA) is a partner in creating these kinds of pathways and would like to bring the experiences of a variety of CUP patients to the table. For example, when it comes to a length of time allocated to certain examinations or tests, we want to hear first from patients whether it is realistic or not. *The interviews will take about 1 hour and will be conducted by an experienced interviewer. The interviews will take place via (video) calls.*

Are you interested in being interviewed about your experiences by a staff member of World CUP Alliance?

- No
- Yes, and my e-mail address or phone number is: