

# **BENCH-CAN MANUAL**

## **ANNEX 3**

### **MEASURING PATIENT EXPERIENCE AND SATISFACTION**

### **EUROPEAN CANCER CONSUMER QUALITY INDEX (ECCQI)**

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# 1. INTRODUCTION

To see if care is responsive and personalized, patients are asked for their experiences with the use of a European Cancer Consumer Quality Index (ECCQI). The ECCQI is an internationally accepted patient experience survey based on the CAPHS (Consumer Assessment of Healthcare Providers and Systems) that was developed in the US. This has been translated and validated in different countries, amongst other in the Netherlands for general cancer patients, breast cancer patients, and radiotherapy.

## 2. TECHNICAL INFORMATION

### 2.1. Translation of the questionnaire

Please see if a version of the ECCQI is available in your language. The available languages are: English, Dutch, Portuguese, Italian, Hungarian, Lithuanian, and Romanian. Should your language be unavailable, the ECCQI is free to be translated. It is however important to make sure this is done by an official translation company that uses back translation, i.e. after translation the questionnaire needs to be translated back into English again in order to ensure no information is lost in translation. The English version is attached. For further instructions about the proper translations of the ECCQI please see Box 1.

### 2.2. Sampling

In order to get a representative sample, a minimum of 100 patients needs to fill in the ECCQI. Since patients do not always fill the questionnaire in the correct way some questionnaires might need to be excluded from the analysis. It is therefore recommended to recruit at least 150 patients to start with and preferably as diverse as possible, e.g. all ages above 18, male/female, and different types of cancer. Questionnaires can be distributed on paper or you can decide to use an online tool such as SurveyMonkey. It is advised to assign a contact person who ensures efficient distribution and collection of the questionnaires. Patient organization can also assist in the distribution. It is important that patients feel free to express their opinion; therefore it is crucial that questionnaires are collected anonymously. It is preferred that patients fill in the questionnaire themselves in a private environment, should patients need assistance, please, keep this to a minimum.

## **Box.1 Cross-translation**

### **1. Forward translation**

One translator, preferably a health professional, familiar with terminology of the area covered by the instrument and with interview skills should be given this task. The translator should be knowledgeable of the English-speaking culture but his/her mother tongue should be the primary language of the target culture.

The following general guidelines should be considered in this process:

- Translators should always aim at the conceptual equivalent of a word or phrase, not a word-for-word translation, i.e. not a literal translation. They should consider the definition of the original term and attempt to translate it in the most relevant way.
- Translators should strive to be simple, clear, and concise in formulating a question. Fewer words are better. Long sentences with many clauses should be avoided.
- The target language should aim for the most common audience. Translators should avoid addressing professional audiences such as those in medicine or any other professional group.
- Translators should consider the typical respondent for the instrument being translated and what the respondent will understand when s/he sees the question.
- Translators should avoid the use of any jargons. For example, they should not use: technical terms that cannot be understood clearly; and colloquialism, idioms or vernacular terms that cannot be understood by common people in everyday life.
- Translators should consider issues of gender and age applicability and avoid any terms that might be considered offensive to the target population.

### **2. Back-translation**

Using the same approach as that outlined in the first step, the instrument will then be translated back to English by an independent translator, whose mother tongue is English, and who has no knowledge of the questionnaire. As in the initial translation, emphasis in the back-translation should be on conceptual and cultural equivalence and not linguistic equivalence. Discrepancies should be discussed with the editor-in-chief and further work (forward translations, discussion by the bilingual expert panel, etc.) should be iterated as many times as needed until a satisfactory version is reached.

### 3. THE ECCQI QUESTIONNAIRE

#### Introduction

The purpose of this questionnaire is to measure the quality of the care experienced in hospital by cancer patients and to adapt care better to patients' wishes. The questionnaire takes about 20 minutes to complete.

All the information it contains will be treated in the strictest confidentiality. This means that no-one will ever know who gave which answers. Participation in this study is voluntary. We would greatly appreciate it if you could complete the questionnaire.

If you do not wish to complete the questionnaire, mark this box  with a cross and return this page to us. Whether or not you participate in this study, it will have no influence on your further treatment.

#### Instructions for completing this questionnaire

- ◆ It is important that the questions are answered by the person whose name is stated on the cover letter, so the questionnaire should not be completed by anyone else. If this person is too ill to complete it, we hope that someone will help them do so. The same applies to people whose command of <English> is not very good. In all cases, the answers should describe the experience of the person the questionnaire was sent to.
- ◆ Because a computer will be used to register your answers, please use a soft pencil to put a cross in the box to the left of your answer.
- ◆ If you accidentally put a cross in the wrong box, please erase it completely and put a cross in the right box.
- ◆ Some questions seem similar. Please answer them all anyway.
- ◆ Some questions may not apply to you, or may not apply to an aspect of care that you have not experienced. Please answer such questions with "not applicable", "I don't know", or the extra options that accompany the specific question.
- ◆ Sometimes you will be asked to skip a particular question or group of questions. You will then see an arrow that indicates which question you should answer next, as in this example:

<input type="checkbox"/> Yes <input type="checkbox"/> <b>now go to question 7</b>
<input type="checkbox"/> No

1. **In the last 2 years, have you been examined, treated or had aftercare for cancer at NAME OF HOSPITAL?**

- No  *If you answered no, this questionnaire does not apply to you.*
- Yes

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This questionnaire concerns the care you have had at NAME OF HOSPITAL in the past 2 years. Please do not include any experiences you have had at other hospitals. We wish to know about your experiences in the last 2 years, and not about experiences with any examinations, treatments and aftercare you may have had more than 2 years ago.

2. **Which form of cancer do you have or have you had?**

*(more than one answer is possible)*

- Of the digestive organs:** oesophagus/oesophagus, stomach, small bowel, large bowel, rectum, anus, liver, gall bladder, bile ducts, pancreas.
- Lung cancer**
- Breast cancer**
- Of the male reproductive organs:** penis, prostate, testicle
- Skin cancer**
- Of the blood, bone marrow, and/or lymph nodes**
- Of the urinary tract:** kidney, pelvis of the kidney, ureter, bladder
- Of the female reproductive organs:** labia, vagina, cervix, body of the uterus, ovary, placenta
- Of the head and neck area:** lip, mouth, salivary gland, throat, nose, middle ear, nasal sinus, larynx
- Of the central nervous system:** meninges, brain
- Of the bone or soft tissue:** bone, Kaposi's sarcoma, soft tissue
- Of the endocrine glands:** thyroid, adrenal gland
- Of the eye or eye socket**
- Other, please state (*in block capitals*):**

3. This was diagnosed in:

--	--	--	--	--	--

month

--	--	--	--	--	--

year

4. For which examinations or treatment have you been to this hospital in the last 2 years?  
(more than one answer is possible)

- Examinations, e.g. physical examination, X-ray examination, ultrasound, blood tests, CT scan, MRI scan, PET scan
- Surgery
- Radiotherapy
- Chemotherapy
- Hormone therapy
- Immunotherapy
- Aftercare
- Other treatment, please state (*in block capitals*):

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- The last examinations, treatment and/or aftercare I received were longer than 2 years ago  
 **If the last examinations, treatment and/or aftercare you received were longer than 2 years ago, this questionnaire no longer applies to you.**

5. Which of the following applies most to your current situation? (mark only one answer)

- I am having investigations to make a diagnosis
- I have been diagnosed and will be treated soon
- I am having treatment that is intended to cure
- I have been diagnosed and can no longer be treated for my disease
- The treatment I am receiving is not intended to cure the tumour, but to control the symptoms associated with the disease and/or to slow down the growth of the tumour.
- I have finished having treatment and attend this hospital for check-ups and/or for treatment of the symptoms associated with the disease
- I have finished having treatment and check-ups

I no longer remember

**6. When was the last time you went to this hospital for examinations, treatment or checks for cancer?**

Less than 1 month ago

1-2 months ago

2-4 months ago

4-8 months ago

8-12 months ago

Over 12 months ago

***ACCESSIBILITY***

**7. Was it difficult to get to NAME OF HOSPITAL (either by your own transport, by public transport or by taxi)?**

Very difficult

Not very difficult

Not at all difficult

I don't know/I no longer remember

**8. Was it difficult to park at NAME OF HOSPITAL?**

Very difficult

Not very difficult

Not at all difficult

Not applicable: I didn't use my own transport

**9. Was it difficult to reach NAME OF HOSPITAL by phone?**

Very difficult

Not very difficult

Not at all difficult

Not applicable: I didn't try to phone them

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**ORGANIZATION AT NAME OF HOSPITAL**

The following questions concern your experience of waiting times and the speed of the care process.

**10. Was your diagnosis of cancer made at this hospital within the last 2 years?**

- No  *now go to question 14*
- Yes

**11. How long did it last between your referral to the hospital and your first visit there?**

- Less than 6 weekdays
- 6-10 weekdays
- 11-15 weekdays
- More than 15 weekdays
- I don't know/I no longer remember
- Not applicable

**12. How long did it last between your first visit/examination and your diagnosis?**

- Less than 6 weekdays
- 6-10 weekdays
- 11-15 weekdays
- More than 15 weekdays
- I don't know/I no longer remember
- Not applicable

**13. Did you hear the diagnosis sooner or later than you had expected?**

- Much sooner
- Sooner
- When I'd expected it
- Later
- Much later
- I don't know/I no longer remember

**14. Once the diagnosis was known, was it possible to start treatment as quickly as you wanted?**

- No
- Yes
- I don't know/I no longer remember
- Not applicable

**15. If you desired this, was it possible at this hospital to plan several appointments for examination and/or treatment (e.g. surgery, radiotherapy, etc.) on the same day?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**YOUR STAY IN HOSPITAL**

**16. During your treatment, did you spend one or more nights in hospital?**

- No **now go to question 22**
- Yes
- I don't know/no longer remember

**17. Were the toilet, shower and bathroom in or near the room?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**18. Was your privacy sufficiently respected at this hospital (when changing clothes, washing/showering, during visiting hours, no information given in the presence of other patients)?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**19. Were you able to receive visitors at the times you wanted?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember

Not applicable

**20. Were you able to be undisturbed whenever you wished?**

Never

Sometimes

Usually

Always

I don't know/I no longer remember

Not applicable

**21. Was it possible to eat at the times you wished?**

Never

Sometimes

Usually

Always

I don't know/I no longer remember

Not applicable

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***SAFETY IN THIS HOSPITAL***

**22. When you were being given medicine, did anyone check that it was really intended for you – by asking your name, for example, or checking your hospital wristband?**

Never

Sometimes

Usually

Always

I don't know/I no longer remember

Not applicable: I did not take any medicine

**23. Before treatment, examination or an operation began, did anyone check that you were the right person – by asking your name and date of birth, for example?**

- Never
  - Sometimes
  - Usually
  - Always
  - I don't know/I no longer remember
  - Not applicable
- 

***ATTITUDE OF HEALTHCARE PROFESSIONALS***

The following questions concern your experiences with all the healthcare professionals at NAME OF HOSPITAL who were involved in your treatment – for example, nurses, radiotherapists, oncologist, and/or surgeons.

**24. Did the healthcare professionals listen to you attentively?**

- No, none of them did
- Some of them did, please specify
  - Only nurses
  - Only doctors
  - Other, .....
- Most of them did
- Yes, all of them did
- I don't know/I no longer remember
- Not applicable

**25. Did the healthcare professionals have enough time for you?**

- No, none of them did
- Some of them did, please specify
  - Only nurses
  - Only doctors
  - Other, .....
- Most of them did
- Yes, all of them did
- I don't know/I no longer remember
- Not applicable

**26. Did the healthcare professionals take you seriously?**

- No, none of them did
- Some of them did, please specify
  - Only nurses
  - Only doctors
  - Other, .....
- Most of them did
- Yes, all of them did
- I don't know/I no longer remember
- Not applicable

**27. Were there opportunities to talk with your healthcare professionals about how you felt?**

- Never
- Sometimes, please specify
  - Only with nurses
  - Only with doctors
  - Other, .....
- Usually
- Always
  - I don't know/I no longer remember
  - Not applicable

**28. Did your healthcare professionals pay attention to your loved one(s)?**

- No, none of them did
- Some of them did, please specify
  - Only with nurses
  - Only with doctors
  - Other, .....
- Most of them did
- Yes, all of them did
- I don't know/I no longer remember
- Not applicable

**29. Did your healthcare professionals show due respect to faith or philosophy of life?**

- No, none of them did
- Some of them did, please specify
  - Only with nurses
  - Only with doctors
  - Other, .....
- Most of them did
- Yes, all of them did
- Not applicable to contact

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**COMMUNICATION AND THE PROVISION OF INFORMATION**

The following questions concern communication and the information you were given. By “communication”, we mean the contact between you and the healthcare professionals (doctors and nursing staff).

**30. Did healthcare professionals explain things to you in ways that were clear and understandable?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**31. Did the healthcare professionals give you information about any side-effects of the treatment?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**32. During your treatment, were you informed about its effect (for example whether you were responding to it)?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**33. Was the written information about the examinations or treatment clear?**

- Never
  - Sometimes
  - Usually
  - Always
  - I don't know/I no longer remember
  - Not applicable
-

### ***YOUR OWN INPUTS***

The following questions concern the extent to which you were involved in discussions about your care and treatment and could take part in decisions about it.

**34. If you wanted, could you take part in decisions about the care and treatment you received?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable: I didn't want to be

**35. Was it possible for loved ones to be involved in discussions on your care and treatment?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

### ***COORDINATION DURING YOUR CARE***

The following questions concern the various healthcare professionals involved in your care – such as the radiologist, surgeon, internist, nurses and general practitioner/family doctor, and how they collaborated and were coordinated. This only involves healthcare professionals from this hospital

**36. Were the treatment and examinations you had from different healthcare professionals (within this hospital) well-coordinated?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**37. Were your healthcare professionals(within this hospital) aware of the appointments you had with other healthcare professionals?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**38. Did you always deal with the same person in this hospital – such as a doctor or nurse – when anything needed to be arranged?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**39. Were you seen by the same care providers during your investigations and treatments?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

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***SUPERVISION AND SUPPORT***

The following questions concern the supervision and support you received during the treatment process.

**40. During the diagnostic phase, was attention paid to your pain?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**41. During the treatment phase, was attention paid to your pain?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**42. During aftercare, was attention paid to your pain?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**43. During the diagnostic phase, was attention paid to your complaints about fatigue?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**44. During the treatment phase, was attention paid to your complaints about fatigue?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**45. During the aftercare, was attention paid to your complaints about fatigue?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**46. Did this hospital provide you with information about help with coping with emotions and other forms of counselling on this?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**47. Did this hospital provide you with information about help with dealing with practical problems caused by cancer and other forms of counselling on this?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**48. Did healthcare professionals (within this hospital) inform you about patient organisations?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**49. Was it possible to talk to a spiritual or moral counsellor, such as a hospital chaplain or humanistic counsellor?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

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***ROUNDING OFF THE TREATMENT***

The following questions concern how your course of treatment at NAME OF HOSPITAL was concluded.

**50. Was your treatment concluded at the hospital?**

- No  ***now go to question 56***
- Yes

**51. When your treatment in this hospital was concluded, were you informed about possible symptoms or health problems you should be aware of/watch out for?**

- No, not at all
- Not really
- More or less
- Yes, fully
- I don't know/I no longer remember
- Not applicable

**52. Did you know who you could approach in this hospital with questions or problems after treatment had been concluded?**

- No, not at all
- Not really
- More or less
- Yes, fully
- I don't know/I no longer remember
- Not applicable

**53. Were important people and organizations, such as your general practitioner/family doctor, homecare provider, rehabilitation centre) informed that your hospital treatment had been concluded?**

- No, not at all
- Not really
- More or less
- Yes, fully
- I don't know/I no longer remember
- Not applicable

**54. Were the care and support you needed at home arranged for you?**

- No, not at all
- Not really
- More or less
- Yes, fully
- I don't know/I no longer remember
- Not applicable

**55. Were you offered help with your questions about resuming your day-to-day activities (family, school, work) at the check-up?**

- Never
- Sometimes
- Usually
- Always
- I don't know/I no longer remember
- Not applicable

**OVERALL OPINION OF NAME OF HOSPITAL**

The following questions concern your overall opinion of NAME OF HOSPITAL. Please do not base this opinion on the experiences you may have had at any other hospitals.

**56. Which score would you award this hospital? 0 means very bad indeed, 10 means excellent.**

0 Very bad hospital

1

2

3

4

5

6

7

8

9

10 Excellent hospital

**57. How likely is it that you would recommend the hospital to other patients with cancer? 0 = very unlikely; 10 very likely.**

0 Very unlikely

1

2

3

4

5

6

7

8

9

10 Very likely

58. Name one thing that should have been different about the care you received in the hospital  
(Please write in block capitals)

**ABOUT YOURSELF**

The following questions concern yourself. Your answers will give us insight into different groups of people.

59. What is your age?

18–24

25–34

35–44

45–54

55–64

65–74

75 or more

60. Are you a male or female?

Male

Female

61. Please indicate highest degree of your education (including primary education but excluding short courses)

Number of years:

62. How would you describe your overall physical health?

Excellent

Very good

Good

Moderate

Poor

63. Did anyone help you complete this questionnaire?

No

Yes

64. How did this person help you?

*(more than one answer is possible)*

By reading out the questions

By writing down my answers

By answering the questions for me

By translating the questions into my language

By helping me as follows:

**THANK YOU VERY MUCH FOR COMPLETING THE QUESTIONNAIRE**

## 4. HANDLING THE DATA

### 3.1. Recoding

Data received through the ECCQI needs to be recoded first, in order to analyse the data in a proper way. Almost all the categories in the ECCQI consist of questions with four response options which can be recoded in: never = 1, sometimes = 2, usually = 3, and always = 4, except for the categories: **'accessibility'**, and **'organisation'**.

The questions of **'accessibility'** have only three response options and therefore, response codes need to be recoded into: very difficult = 1, not very difficult = 3, and not at all difficult = 4.

The category **'organisation'** consists of questions with different response categories. The response codes to question 11 and 12 needed to be reversed and thereby were recoded into: more than 15 weekdays = 1, 11-15 weekdays = 2, 6-10 weekdays = 3 and less than 6 weekdays = 4. Question 13 has five response options and also needed to be revised; response codes were recoded into four codes: much later = 1, later = 2, when I'd expected it = 3, sooner = 4, much sooner = 4. Question 14 has only two response options and therefore, response codes were recoded into: no = 1 and yes = 4.

In addition, the response codes of the questions about demographic characteristics were recoded. The age categories were recoded into three categories: 18 – 34, 35 – 64 and 65 or older. The number of years of education were categorised into: low, moderate and high level of education, where 1 – 8 years is categorised as low, 9 – 13 as moderate and 14 or more as high level of education.

### 3.2. Missing data

The answers 'I don't know/I no longer remember' and 'Not applicable' are considered as missing data. In addition, questions that are answered while they needed to be skipped (invalid answers) are also considered as missing data. These answers do not count in the calculations.

## 5. STATISTICAL ANALYSIS

After the recoding, data needs to be analysed. It is advised to record the data in an excel sheet or SPSS file. Analysis can also be done in Excel or SPSS<sup>1</sup>. A description of the sample characteristics can assist in determining whether the tested group in your institute is comparable to the sample or to other institutes.

- Percentage of respondents per age categories
- Percentage of respondents per female/male
- Percentage of respondents per level of education

After this, the mean of each category of the questionnaire can be calculated. This makes it easier to get an overall picture and to calculate whether differences between categories or between centres (applicable if multiple centres participate) are significant. Significance can be calculated by means of a t-test or other statistical measurement. In addition, the overall patient satisfaction can be analysed by means of calculating the mean of all categories. A mean close to 4 indicates a good overall score, while a mean close to 1 indicates a bad score, i.e. room for improvement. To look for specific improvement individual questions can be analysed.

**Please note that the *full version of this questionnaire* is available also as a separate downloadable WORD file.**

For further information about ECCQI please, contact Anke Wind researcher at [ankewind@gmail.com](mailto:ankewind@gmail.com) .

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<sup>1</sup> Statistical software