

NEUROENDOCRINE TUMOUR ENETS CENTRES OF EXCELLENCE - PATIENT EXPERIENCE SURVEY

This questionnaire is about your care and treatment for a neuroendocrine tumour at an ENETS Centre of Excellence which is a **specialist Neuroendocrine Tumour (NET) centre**. You will also see them referred to as **'Specialist NET Units', or 'Specialist NET Centres'**. You will have been signposted to this questionnaire from attending one of these centres. **They contain clinicians who are specialists in NETs and provide optimal management for patients with neuroendocrine tumours, taking into account how the tumour affects each individual. If you are unsure if you are being treated in an ENETS Centre of Excellence, please click here to look at a map of all centres.**

The purpose of the survey is to provide information which can help the European Neuroendocrine Tumor Society (ENETS) monitor and improve the future quality of health services and social care for people with neuroendocrine tumours who present at specialist NET Centres. Neuroendocrine tumours (also known as NETs) present numerous, complex clinical problems. Due to their relatively rare occurrence, research and patient care guidelines have been lacking since the 1990s. As a result, the European Neuroendocrine Tumor Society (ENETS) was founded in 2004 and currently has more than 1,800 members, who bring with them a variety of expertise from the fields of oncology, pathology, radiology, nuclear medicine, endocrinology, surgery, and gastroenterology.

Taking part in this survey is voluntary. Published reports will not contain any personal details.

Who should complete the questionnaire?

The questions should be answered by you, as the person being treated for a neuroendocrine tumour. If you need help to complete the questionnaire, the answers should be given from your point of view – not the point of view of the person helping. **Your answers should all relate to the care and treatment you receive at an ENETS Centre of Excellence**, not for example at a local hospital where you may receive follow up care. **If you are responding to this during the Covid-19 pandemic, and are receiving care and treatment remotely, please give your answers as if you were attending an ENETS Centre of Excellence and being treated in person as normal.**

Completing the questionnaire

For each question please click on the box next to the answer option that is closest to your views. You can go back and change your mind by using the back button at the bottom of the page. Once you have finished please press the **submit** button at the end of the questionnaire.

IMPORTANT INFORMATION

Your responses are completely confidential and anonymous. The information is being collected for ENETS by Quality Health, an experienced survey provider. Quality Health are subject to strict obligations regarding the security and confidentiality of your information and will not use your details for any other purpose unless you give us explicit permission to do so.

Information from your responses will not be released unless required by law or where there is a clear overriding public interest. Your responses will be grouped with other respondents so that we can produce an overall set of data which will highlight the key issues. This will help ENETS improve the services it offers. Further information on who we are, how we use your data and your rights under the relevant legislation can be found in the Privacy Policy, which you can access at: <https://www.quality-health.co.uk/data-protection>

By completing this questionnaire, you are giving your consent for the information you provide to be used for the above purpose.

Quality Health is registered with the Information Commissioner's Office (ico.org.uk) and this survey is being undertaken in line with all relevant requirements of the General Data Protection Regulation 2018 (GDPR). Thank you for taking part in this survey. Your insights will help improve services for NET patients, and their families today and in the future.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number on **0800 783 1775** or by email info@quality-health.co.uk

INTRODUCTION

1. How long is it since you were first **treated** for a neuroendocrine tumour? (*This might include surgery, chemotherapy, radiotherapy, or other treatment for your NET. Being diagnosed and put on 'watch and wait' is classed as treatment.*)

- 1 Less than 1 year
- 2 1 to 5 years
- 3 More than 5 years
- 4 More than 10 years
- 5 Don't know / can't remember

2. Have you been diagnosed with a neuroendocrine tumour within the last twelve months?

- 1 Yes  GO TO Q3
- 2 No  GO TO Q11
- 3 Don't know  GO TO Q11

3. At the ENETS Centre of Excellence, how did you feel about the length of time you had to wait for your scans or other diagnostic tests to be done at your original diagnosis?

- 1 It was about right
- 2 It was a little too long
- 3 It was much too long
- 4 N/A
- 5 Don't know / can't remember

4. At the ENETS Centre of Excellence, did you understand the explanation of what was wrong with you?

- 1 Yes, I completely understood it
- 2 Yes, I understood some of it
- 3 Nothing was explained to me
- 4 No, I did not understand it
- 5 Don't know / can't remember

5. At the ENETS Centre of Excellence, when you were told you had a neuroendocrine tumour, were you offered written information about it?

- 1 Yes, and it was easy to understand
- 2 Yes, but it was difficult to understand
- 3 No, I was not offered written information about the type of tumour I had
- 4 I did not need written information
- 5 Don't know / can't remember

6. At the ENETS Centre of Excellence, how do you feel about the way you were told you had a neuroendocrine tumour?

- 1 It was done sensitively
- 2 It should have been done a bit more sensitively
- 3 It should have been done a lot more sensitively
- 4 I was not diagnosed at a specialist NET centre
- 5 Don't know / can't remember

DIAGNOSIS

7. How do you feel about the length of time you had to wait before your first appointment with a specialist?

- 1 I was seen quicker than expected
- 2 I was seen as soon as I thought was necessary
- 3 I should have been seen a bit sooner
- 4 I should have been seen a lot sooner

8. How long did you have to wait between being referred to and being seen at an ENETS Centre of Excellence?

- 1 Less than 2 weeks
- 2 2-4 weeks
- 3 5-8 weeks
- 4 9+ weeks
- 5 Don't know / can't remember
- 6 N/A

9. At the ENETS Centre of Excellence, before any tests, did a member of staff explain the purpose of the scans and other diagnostic tests?

- 1 Yes, all scans and other diagnostic tests were explained
- 2 Only some of the scans and other diagnostic tests were explained
- 3 None of the scans and other diagnostic tests were explained
- 4 I did not need explanations
- 5 Don't know / can't remember

10. If you had scans or other diagnostic tests in the last 6 months at an ENETS Centre of Excellence, were you given written information about your scan(s) or other diagnostic tests? *(This is additional information explaining the scans – not just an appointment letter).*

- 1 Yes, for all scans or other diagnostic tests that were done
- 2 Only for some of the scans or other diagnostic tests
- 3 No, not for any of the scans or other diagnostic tests
- 4 I did not need written information
- 5 Don't know / can't remember

11. If you had tests in the last 6 months at an ENETS Centre of Excellence, how long did you have to wait for the results of your scans or other diagnostic tests?

- 1 Less than 2 weeks
- 2 2-4 weeks
- 3 5-8 weeks
- 4 9+ weeks
- 5 Don't know / can't remember

12. After the scans or other diagnostic tests at the ENETS Centre of Excellence, were the results explained in a way you could understand?

- 1 Yes, for all scans or other diagnostic tests that were done
- 2 Only for some of the scans or other diagnostic tests
- 3 No, not for any of the scans or other diagnostic tests
- 4 I did not need explanations of results
- 5 Don't know / can't remember

TREATMENT

13. Before your treatment for a neuroendocrine tumour started, were all the treatment options explained to you? (*please note that 'watch and wait' counts as treatment*).

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No
- 4 It was explained to me that there was only one type of treatment that was suitable for me
- 5 Don't know / can't remember

14. As far as you were aware, was your treatment plan discussed at a Multi-Disciplinary Team (MDT) / tumour board?

MDTs are made up of a variety of expert health care professionals who have specialised knowledge and training in specific tumours. The teams meet regularly to discuss individual cases and to plan the best course of treatment for the patient.

- 1 Yes, in a NET specific MDT/Tumour board  GO TO Q15
- 2 Yes, in another MDT/Tumour Board related to the site of the Tumour (e.g. Colorectal /Pancreatic)  GO TO Q15
- 3 No  GO TO Q16
- 4 I wasn't informed  GO TO Q16
- 5 Don't know / can't remember  GO TO Q16

15. Were you informed of the outcome of this meeting?

- 1 Yes
- 2 No, but I would have liked to have been
- 3 I did not want to know the outcome
- 4 Don't know / can't remember

SURGERY & INPATIENT STAYS

16. During the last 12 months, have you had surgery at an ENETS Centre of Excellence as part of your treatment for a neuroendocrine tumour?

- 1 Yes  GO TO Q17
- 2 No  GO TO Q19

17. Before any decisions, did you have all the information you needed about your operation?

- 1 Yes
- 2 No, I would have liked more information
- 3 Don't know / can't remember

18. After the operation, did a member of staff explain how it had gone in a way you could understand?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I was not given an explanation
- 4 I did not need an explanation
- 5 Don't know / can't remember

19. Were you given the option of participating in a clinical trial? ***Clinical trials are research studies that involve people. Through clinical trials, doctors find new ways to improve treatments and the quality of life for people with cancer.***

- 1 Yes, and I took part in the trial
- 2 Yes, I was asked but I didn't want to participate
- 3 No, I wasn't asked
- 4 There were no clinical trials
- 5 Don't know / can't remember

20. At the ENETS Centre of Excellence, were you offered practical advice and support in dealing with the side effects of your treatment(s) for a neuroendocrine tumour?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I did not need any support
- 5 Don't know / can't remember

21. Were you involved as much as you wanted to be in decisions about your care and treatment for your neuroendocrine tumour?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked to be involved
- 4 Don't know / can't remember

22. Was the care and support after you were discharged from the ENETS Centre of Excellence what you expected and available when you needed it?

This refers to your discharge after a hospital stay, not your complete discharge from the service.

- 1 Yes, care was available, and it was as I expected
- 2 Yes, care was available, but it was not as I expected / or it did not fulfil my expectations
- 3 No, care was not available, but I would have liked this
- 4 No, I was not interested in support/care options after discharge
- 5 Don't know / not sure

23. Was your discharge home delayed for any reason?

This refers to your discharge after a hospital stay, not your complete discharge from the service.

- 1 Yes, under a week
- 2 Yes, 1-2 weeks
- 3 Yes, 2-4 weeks
- 4 Yes, over a month
- 5 No, my discharge was not delayed
- 6 Don't know / can't remember

SPECIALIST NURSES

24. Did you have access to a Specialist Nurse (CNS), who is a specialist in neuroendocrine tumours? ***This is a nurse with a specialist understanding of NET. It could be an oncology CNS).***

- 1 Yes  GO TO Q25
- 2 No  GO TO Q27
- 3 Don't know  GO TO Q27

25. When you had important questions to ask your Specialist Nurse, how often did you receive answers you could understand?

- 1 All or most of the time
- 2 Some of the time
- 3 Rarely or never
- 4 I have not asked any questions

26. Did the Specialist Nurse have a good awareness of your specific tumour?

- 1 Yes
- 2 No
- 3 Don't know / can't remember

INFORMATION AND SUPPORT

27. Did hospital staff at the ENETS Centre of Excellence give you information about support or self-help groups for people with neuroendocrine tumours?

- 1 Yes
- 2 No, but I would have liked information
- 3 It was not necessary
- 4 Don't know / can't remember

28. At the ENETS Centre of Excellence, were you able to have a discussion about the way in which your neuroendocrine tumour would impact on your day-to-day life?

- 1 Yes
- 2 No, but I would have liked a discussion or information
- 3 It was not necessary / relevant to me
- 4 Don't know / can't remember

29. Do you have access to advice from a dietary expert such as a dietitian at the ENETS Centre of Excellence?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 I did not need any dietary advice
- 5 Don't know / can't remember

30. Do you feel you got enough emotional support from hospital staff at the ENETS Centre of Excellence?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 I did not need any emotional support
- 5 Don't know / can't remember

OVERALL RATING OF CARE

31. At the ENETS Centre of Excellence, were you given enough privacy when discussing your condition or treatment?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 Don't know / can't remember

32. At the ENETS Centre of Excellence, were you given enough privacy when being examined or treated?

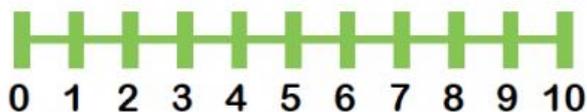
- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 Don't know / can't remember

33. Overall, did you feel you were treated with respect and dignity by those treating you at the ENETS Centre of Excellence?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 Don't know / can't remember

34. At the ENETS Centre of Excellence, how would you rate Doctors in terms of...		Poor	Fair	Good	Very good	Excellent	N/A
a	The attention they gave to your physical symptoms?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
b	The thoroughness in treating your physical symptoms?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
c	The interest they showed in you as a person?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
d	The time devoted to you.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
35. At the ENETS Centre of Excellence, how would you rate Nurses in terms of...		Poor	Fair	Good	Very good	Excellent	N/A
a	The attention they gave to your physical comfort?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
b	The information they gave you about your care and treatment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
c	The advice they gave you on managing your physical symptoms?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
d	The interest they showed in you as a person?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
e	The time devoted to you.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
36. At the ENETS Centre of Excellence, how would you rate...		Poor	Fair	Good	Very good	Excellent	N/A
a	Clerical / administrative / secretarial staff you may have come into contact with?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
b	The way doctors, nurses and other caregivers involved in your care seem to work together as a team?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
c	The exchange of information with other care services in the community (general practitioner, home care, nursing home, social services, etc.)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆
d	The kindness and helpfulness of the technical, reception, laboratory personnel?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆

37. Overall, how would you rate your care at the ENETS Centre of Excellence? (**Please circle a number where 0 is very poor and 10 is excellent**)



38. We would like you to think about your recent experience at an ENETS Centre of Excellence.

How likely would you be to recommend this service to friends and family if they needed similar care or treatment?

- 1 Extremely likely
- 2 Likely
- 3 Neither likely nor unlikely
- 4 Unlikely
- 5 Extremely unlikely
- 6 Don't know

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's not your own.

39. Please indicate your age group

- 1 20 and under
- 2 21-30
- 3 31-40
- 4 41-50
- 5 51-60
- 6 61-70
- 7 71 or over

40. Please tell us your gender.

- 1 Male
- 2 Female
- 3 Prefer not to say
- 4 Prefer to self-describe (please specify below)

FINAL QUESTIONS BEFORE YOU GO

These questions help us form a profile of the types of patients responding to the questionnaire.

41. Please indicate the hospital service or clinic you **have most recently accessed as part of your treatment for a neuroendocrine tumour** (Tick all that apply)

- 1 ENETS Centre of Excellence
- 2 NET clinic (not an ENETS CoE)
- 3 Outpatient radiotherapy
- 4 Outpatient chemotherapy
- 5 Outpatient oncology
- 6 In patient for non-surgery procedure
- 7 In patient for surgery
- 8 Other (Please specify below)

42. Which site was your primary tumour?

- 1 Stomach
- 2 Small bowel (Jejunum duodenum, ileum)
 - 3 Pancreas
 - 4 Appendix
 - 5 Large bowel (colon)
 - 6 Lung
 - 7 Thyroid
 - 8 Adrenal
 - 9 Other (please specify)

43. Do you have any tumours present on scans now?

- 1 Yes
- 2 No
- 3 Don't know

44. How long does it take for you to get to your ENETS Centre of Excellence (the site where you have most of your treatment)?

- Under 1 hour
- 1-2 hours
- Over 3 hours
- Don't know