

Questionnaire CEAPIR

Thank you for taking the time to fill out this questionnaire. Your input is very valuable!

1. When you had dialysis for the very first time, was it with:
 Haemodialysis (HD) Peritoneal Dialysis (PD) Not applicable

2. How is your kidney disease currently being treated?

Haemodialysis
 Satellite / Hospital / Home

Peritoneal Dialysis
 CAPD APD (machine)

Not on dialysis:
 Transplanted / Diagnosed as requiring dialysis soon

3. How long (in years and months) have you been treated by your current modality for kidney disease?

 Pre-dialysis: Years _____ Months _____

 Haemodialysis: Years _____ Months _____

 Peritoneal Dialysis: Years _____ Months _____

 Transplanted: Years _____ Months _____

If your answer to question 3 is “Transplanted” please go directly to question 6.

4. During this treatment time, has anyone every spoken to you about alternative dialysis options and the possibility of changing treatments?
 Yes / No / I don't know / Not applicable

5. Are you on the transplant waiting pool?
 Yes / No / I don't know

6. Who referred you to a nephrologist or kidney specialist?
 General Practitioner / Another specialist /
 Other (please specify):

7. How useful was the information you received about kidney diseases or dialysis options from your nephrologist or kidney specialist?
 Very helpful / Somewhat helpful / Somewhat unhelpful / Not at all helpful /
 I did not receive any information / I don't know

8. Was it ever suggested to you that a certain treatment option would not be suitable for you because of your social circumstances (e.g. living conditions, life style, work)?
 Yes/ No/ I don't know

9. Do you believe that the treatment for your kidney condition has ever been effected by discrimination on the basis of your age, sex, race, culture or religious beliefs?

- Yes (Specify how) _____
 No / I don't know

10. Have you ever felt discriminated because you have kidney disease?

- Yes / No / I don't know

If yes, please specify how _____

11. Please indicate how satisfied you are with the level of access to the following specialists if you ever need their support:

- | | |
|---------------|---|
| Social worker | <input type="checkbox"/> Very satisfied / <input type="checkbox"/> Somewhat satisfied / <input type="checkbox"/> Somewhat unsatisfied / <input type="checkbox"/> Very unsatisfied / Not available to me |
| Dietician | <input type="checkbox"/> Very satisfied / <input type="checkbox"/> Somewhat satisfied / <input type="checkbox"/> Somewhat unsatisfied / <input type="checkbox"/> Very unsatisfied / Not available to me |
| Counsellor | <input type="checkbox"/> Very satisfied / <input type="checkbox"/> Somewhat satisfied / <input type="checkbox"/> Somewhat unsatisfied / <input type="checkbox"/> Very unsatisfied / Not available to me |

12. How satisfied are you with the overall level of care you have received for your kidney disease?

- Very satisfied / Somewhat satisfied / Somewhat unsatisfied / Very unsatisfied

13. If you are ever dissatisfied with your treatment, would you know who to direct your complaint to?

- Yes / No

14. Thinking about the cost of your kidney disease treatment, do you personally have to pay for any of the following?

- | | |
|-----------------------|--|
| Medical consultations | <input type="checkbox"/> Yes / <input type="checkbox"/> No / <input type="checkbox"/> I don't know |
| Medication | <input type="checkbox"/> Yes / <input type="checkbox"/> No / <input type="checkbox"/> I don't know |
| Dialysis | <input type="checkbox"/> Yes / <input type="checkbox"/> No / <input type="checkbox"/> I don't know |
| Dietician: | <input type="checkbox"/> Yes / <input type="checkbox"/> No / <input type="checkbox"/> I don't know |
| Counselling: | <input type="checkbox"/> Yes / <input type="checkbox"/> No / <input type="checkbox"/> I don't know |
| Other: | Please specify: _____ |

15. Is cost a barrier to optimal treatment for you?

- Yes / No / I don't know

16. If you travelled while being on dialysis, did you have to pay extra?

- Yes / No / I don't know / Not applicable

17. Have you received education and / or rehabilitation to help you to manage in your day-to-day life?

- Yes / No / I don't know

18. If you changed your employment status because of kidney disease, which of the following are true?

- I stopped working
- I reduced my working hours
- I felt I had no choice but to change my job
- I chose to change my job
- I didn't have to change my job
- I was retired
- I was unemployed
- Not applicable
- I don't know

19. If you changed your job due to your kidney disease, did you receive training or education to help you find a new job?

- Yes / No / I don't know / I have not changed my job / Not applicable

20. How long was the time interval from your first knowledge of having kidney disease and the start of your treatment?

- More than 1 year
- 6-12 months
- 3-6 months
- 1-3 months
- Less than a month

21. In the year prior to starting dialysis, did you receive information from the hospital staff (nurse or kidney specialist) regarding any of the following:

Reduced Kidney function: Yes / No / I don't know

Diet: Yes / No / I don't know

Patient organizations or ways to meet other kidney disease patients: Yes / No / I don't know

Not applicable

22. How helpful have each of the following been as a source of information on kidney disease?

- Doctors Very helpful / Somewhat helpful / Somewhat unhelpful / Very unhelpful
- Nurses Very helpful / Somewhat helpful / Somewhat unhelpful / Very unhelpful
- Patient organisations Very helpful / Somewhat helpful / Somewhat unhelpful / Very unhelpful
- Websites Very helpful / Somewhat helpful / Somewhat unhelpful / Very unhelpful
- Online social media Very helpful / Somewhat helpful / Somewhat unhelpful / Very unhelpful

23. How satisfied were you with the information you had about each of the following treatment options before a decision was made?

Transplantation

Very satisfied / Somewhat satisfied / Somewhat unsatisfied / Very unsatisfied

In-centre HD treatment

Very satisfied / Somewhat satisfied / Somewhat unsatisfied / Very unsatisfied

Satellite HD Treatment

Very satisfied / Somewhat satisfied / Somewhat unsatisfied / Very unsatisfied

Peritoneal dialysis

Very satisfied / Somewhat satisfied / Somewhat unsatisfied / Very unsatisfied

Home haemodialysis

Very satisfied / Somewhat satisfied / Somewhat unsatisfied / Very unsatisfied

Not applicable

24. How involved were you in the decision making process to determine which type of treatment you would receive?

Very involved / Somewhat involved / Somewhat uninvolved / Not at all involved

25. Could you choose your preferred dialysis centre?

Yes / No / I don't know / Not applicable

26. Could you choose your preferred treatment method?

Yes / No / I don't know

If not, could you elaborate on why? _____

27. How old are you?

18-29 / 30-39 / 40-49 / 50-59 / 60-69 70 or more

28. What is your gender?

Male / Female

29. What is your current work-status?

- Student
- Employed (including self-employed)
- On sick leave
- Unemployed
- Retired
- Housewife / househusband
- Other

30. Do you have any other points you would like to make?

31. If you would you like to receive a copy of the results of the survey, please give your e-mail or postal address below:

32. What is your nationality?

33. What is your current country of residence?

34. Where did you find this questionnaire?

I received it by email / I found it on a website / I found it on facebook /

Other (please specify) _____