

Multi-Country Survey of Patient Choice of RRT in Europe

EKHA is embarking on a Multi-Country Survey to build a Snapshot of Renal Patient Choice in Europe. The overarching goal is to explore and address the patient choice of treatment (or lack thereof) in select Member States and address how it relates in the context of sustainability of kidney care, economic impact on health systems, and outcomes impact on the patient and his or her quality of life.

The results of this survey will be presented at the European Kidney Forum in April 2017, along with a call to action asking Policy Makers to address any inequalities of access to choice of treatment for patients in the EU.

Questionnaire for Patients:

1. What European country do you live in?
 - ...
2. Gender
 - Male
 - Female
 - Prefer not to answer
3. What is your age in years?
 - Less than 18
 - 18-29
 - 30-45
 - 45-59
 - 60-79
 - More than 80
4. What is your current work status?
 - Student
 - Employed (including self-employment)
 - House wife/house man
 - Retired
 - On sick leave from employment
 - Unemployed
 - Other
5. How long have you been on renal replacement therapy (dialysis / transplantation)?
 - 1-3 months
 - 3-12 months
 - 12-24 months
 - More than 24 months
 - I am not on renal replacement therapy (not on dialysis and not transplanted)
6. Do you have or have you had one or more of the following conditions (choose all that apply)?
 - High blood pressure

- Diabetes
 - Heart condition /cardiovascular disease
 - Amputation
 - Stroke
 - Cancer
 - Hereditary/genetic kidney disease
 - Other
7. In the time before the start of renal replacement therapy (dialysis/transplantation/etc), did you receive information on:
- Blood pressure control
 - Reducing salt intake
 - Other dietary measures for preserving kidney function
 - Physical exercise
 - Quitting smoking
8. What treatment method are you on currently?
- In-centre haemodialysis
 - Satellite haemodialysis (self-care)
 - Home haemodialysis
 - Peritoneal dialysis
 - Continuous Ambulatory Peritoneal Dialysis (manual exchanges)
 - Automated Peritoneal Dialysis (machine exchanges)
 - Living with functioning kidney transplant
 - From living kidney donation
 - From deceased kidney donation
 - Conservative care (supportive treatment without dialysis or transplantation)
9. Is this treatment, in your opinion, the best option for you?
- Yes
 - No
10. If no, why?
- Too much time lost because of treatment and travel
 - Too much dependency
 - Too much medication
 - Hinders your professional activities
 - Only possibility to keep working
 - Too high out-of-pocket costs
 - Too much stress
 - Too much pressure on your family
 - You are dissatisfied with your quality of life
 - Esthetical/appearance concerns
 - Other
11. In the period before the start of renal replacement therapy, were you told that there are different treatment options (haemodialysis, peritoneal dialysis, transplantation, conservative care)?

- Yes
 - No
12. If yes, how long before the start of renal replacement were you told about choices?
- Less than 1 month
 - 1-3 months
 - 4-12 months
 - More than 12 months
13. How were you given this information?
- By consultation with a health care professional
 - Through a brochure
 - Through a website
 - By a consultation with a patient organisation
14. In the period before the start of renal replacement, do you think that you received enough information about in-centre haemodialysis?
- Yes
 - No
15. In the period before the start of renal replacement, do you think that you received enough information about peritoneal dialysis?
- Yes
 - No
16. In the period before the start of renal replacement, do you think that you received enough information about home haemodialysis?
- Yes
 - No
17. In the period before the start of renal replacement, do you think that you received enough information about haemodialysis overnight?
- Yes
 - No
18. Are you on a waiting list to receive a kidney transplantation ?
- Yes
 - No
19. If no, have you ever been on a kidney transplant waiting list?
- Yes
 - No
20. Do you think you received enough information about kidney transplantation?
- Yes
 - No
21. If kidney transplantation was discussed, were both options (living donation and donation from a deceased donor) presented to you?
- Only deceased donation was discussed
 - Only living donation was discussed
 - Both were discussed
22. If kidney transplantation was discussed, did you receive information about the range of possible waiting time before a kidney from a deceased donor might become available?

- Yes
 - No
23. If transplantation was not discussed as an option, do you know why it didn't happen?
- Previous cancer
 - Severe heart disease
 - Stroke
 - Overweight
 - Other major health problems
 - Age
 - I don't know
 - Other
24. In the period before the start of renal replacement therapy, was the option of conservative care (supportive treatment without transplantation or dialysis) discussed with you?
- Yes
 - No
25. If different treatment methods were discussed with you, were you given a choice of which one you preferred to proceed with?
- Yes
 - No
26. Was your family (spouse, partner, children, parents, other important person in your life) included in the discussion?
- Yes
 - No
27. Which person or source offered you the most useful information about renal replacement choices?
- Nephrologist
 - Other specialist physician (e.g. cardiologist, endocrinologist, diabetologist, etc)
 - General practitioner (house doctor)
 - Nurse
 - Other patient(s)
 - Educational programme (organised individual or group information and teaching)
 - Educational materials
 - Internet
 - Other
28. During your time on renal replacement therapy, have you wanted to change to a different treatment method ?
- Yes
 - No
29. If yes, was your wish to change treatment addressed by your health care professional?
- Yes
 - No
30. In terms of reimbursement by the national health insurance / health plan coverage of your treatment, is there a difference financially which treatment you are on? In other words, does one treatment require you own financial contribution while another treatment not?

a. Yes

b. No

31. If yes, which treatment requires your own financial contribution?

- In-centre haemodialysis
- Satellite haemodialysis (self-care)
- Home haemodialysis
- Peritoneal dialysis
- Living with functioning transplant kidney