

TRANSNephro EURO Survey

Online survey to assess the current transition situation of adolescents and young adults after kidney transplantation at European pediatric nephrology sites.

The survey has been approved by Hannover Medical School ethics committee. Data is transmitted via SSL encryption. Your institution's name is only used to prevent duplicates. After the form is submitted data will be pseudonomized.

* Erforderlich



The survey consists of up to 12 sections (on up to 20 pages) depending on your answers and will take 10-15 minutes to complete (mandatory part). At the end we will ask for some retrospective data to back this research (optional). We kindly ask you to provide anonymous data on course of creatinine (last 5 values preceeding transfer), immunosuppression trough levels (last 5 values preceeding transfer), and transfer age of up to 5 patients who you recently transferred to adult care.

If any question should arise, please do not hesitate to contact team@TRANSNephro.de

1. Please enter your institution's name
and city : *

General Questions

2. **How many patients following kidney transplantation are under your center's care? ***

Markieren Sie nur ein Oval.

- ☐ <10
☐ 10-20
☐ 20-50
☐ 50-100
☐ >100

3. **At what facility are the patients seen? ***

Markieren Sie nur ein Oval.

- ☐ University hospital
☐ Community hospital
☐ Doctor's practice
☐ Other

4. **How often do you hold transplantation clinics? ***

Markieren Sie nur ein Oval.

- ☐ Daily (workday)
☐ 2 to 4 times a week
☐ Weekly
☐ 1 to 3 times a month
☐ Less than once a month

5. **At which time of day do you hold transplantation clinics? [multiple selections possible] ***

Wählen Sie alle zutreffenden Antworten aus.

- ☐ Morning
☐ Afternoon
☐ Evening

6. **How many kidney transplanted patients are (on average) transferred out to an adult clinic per year? (If less than one, please try to estimate and enter as decimal place. E.g. for one patient in two years enter 0.5) ***

Initiating the transition process

'Transition' is a process that involves purposeful, planned efforts to prepare the pediatric patient to move from caregiver-directed care to disease self-management in the adult unit.

7.

At which age do you usually introduce the concept of transition to the patient? *

Markieren Sie nur ein Oval.

- ☐ <12 years *Weiter mit Frage 8*
- ☐ 12-14 years *Weiter mit Frage 8*
- ☐ 14-16 years *Weiter mit Frage 8*
- ☐ 16-18 years *Weiter mit Frage 8*
- ☐ >18 years *Weiter mit Frage 8*
- ☐ Never, because patients after kidney transplantation remain under pediatric care at all ages. (Choosing this answer will terminate the survey!) *Weiter mit Frage 66*
- ☐ Never, because the patient is transferred to an adult clinic without special preparation. *Weiter mit Frage 29*

Transition procedure

'Transition' is a process that involves purposeful, planned efforts to prepare the pediatric patient to move from caregiver-directed care to disease self-management in the adult unit.

8.

Do you have an at least unwritten transition agreement / plan / procedure at your center? *

Markieren Sie nur ein Oval.

- ☐ Yes *Weiter mit Frage 9*
- ☐ No *Weiter mit Frage 22*
- ☐ No, not at the center, but I myself use some kind of transition procedure with my patients. *Weiter mit Frage 9*

Details of your transition procedure

9.

Which of the following components do you use for transition? [multiple selections possible] *

Wählen Sie alle zutreffenden Antworten aus.

- ☐ The concept of transition and goals in self-management to acquire are explained to the patient (and family) in early adolescence.
- ☐ An unwritten plan for transition is made and communicated with the patient.
- ☐ A written transition plan is made and communicated with the patient.
- ☐ From a certain age the patient consults the nephrologist without a parent first - if applicable, the parent joins the consultation later on.
- ☐ Individual in-house training courses of transition relevant skills.
- ☐ Group training courses of transition relevant competencies at your center.
- ☐ External training of transition relevant skills (including inpatient rehab programs).
- ☐ Written information material about transition/transfer (e.g. handout, magazine, flyer, book...).
- ☐ Transition medical passport.
- ☐ Computer-based training/education (e.g. software, online/internet/intranet, app etc.).
- ☐ Progress of self-management skills is monitored by nephrologist/social worker WITHOUT special tools.
- ☐ Progress of self-management skills is monitored by a score-based system.
- ☐ Progress of self-management skills is monitored by questionnaire.
- ☐ Readiness of transfer is determined by using an appropriate tool (e.g. transition scale, questionnaire, self rating)
- ☐ Other

10.

If you ticked "Other" in the previous question, please specify:

Transition policy

11.

At our clinic information about transition is given to the patient in a gradual manner appropriate to developmental state. *

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

12.

We have at least one transition/tranfer coordinator (nephrologist, social worker, nurse...) at our clinic, who is responsible for management of all transition relevant issues. *

Markieren Sie nur ein Oval.

☐ Yes

☐ No

13.

The transition plan is individualized for each patient. *

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

14.

Who do you actively include in the transition process (in addition to the patient...)? *

Wählen Sie alle zutreffenden Antworten aus.

☐ Parents/Guardian

☐ Siblings

☐ Boyfriend/Girlfriend

☐ Peers/Friends

☐ Classmates

☐ Teacher

15.

Progress of self-management skills is monitored on a regular basis. *

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

16.

Is the patient offered the opportunity of an informal visit to the nominated adult service before transfer occurs? *

Markieren Sie nur ein Oval.

☐ Yes

☐ No

☐ Not applicable

17.

At our center transition/transfer clinics are held for the patients (e.g. alternating consultations with adult and pediatric nephrologist, shared consultations, transfer to a "young adult" clinic, etc.). *

Markieren Sie nur ein Oval.

- ☐ Yes *Weiter mit Frage 18*
- ☐ No *Weiter mit Frage 22*

Transition clinics

18.

How often do you hold transition clinics? *

Markieren Sie nur ein Oval.

- ☐ Daily
- ☐ 2 to 4 times a week
- ☐ Weekly
- ☐ 1 to 3 times a month
- ☐ Less than once a month

19.

The transition clinics are held... *

Markieren Sie nur ein Oval.

- ☐ ... specifically only for patients with kidney disease (nephrology).
- ☐ ... for patients with diverse chronic diseases (e.g. diabetes, asthma, etc.).

20.

Which transition clinics model do you use? [multiple selections possible] *

Wählen Sie alle zutreffenden Antworten aus.

- ☐ Adult and pediatric nephrologist share one consultation (side by side).
- ☐ Alternating consultations with adult and pediatric nephrologist.
- ☐ "Young adult clinic": Patients are seen by adult nephrologist, who is specialized on adolescents and young adults.
- ☐ A physician, who is specialized on transition medicine holds transition clinics in addition to transplant clinics.
- ☐ Other.

21.

If you ticked "Other" in the previous question, please specify:

Transfer policy

Please rate the following statements in regard to the transfer procedure/principles applied at your center.

Rate from 1 = never to 5 = always.

22.

Transfer at our center is individualised for each patient after s/he has completed a transition plan; this will depend upon completion of physical growth and, where possible, educational, social and psychological attainment. *

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

23.

Transfer at our center is agreed upon jointly by the patient and his/her family/carers in conjunction with the paediatric and adult renal care teams. *

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

24.

Transfer at our center DOES NOT take place during a period of crises, especially if there is unstable social support. *

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

25.

Transfer at our center takes place after completing school education. *

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

26.

We take into account treatment plans by other subspecialties (e.g. urological supervision).

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never	☐	☐	☐	☐	☐	Always

Transfer

27.

Which health care professionals are actively involved within the transfer? *

Wählen Sie alle zutreffenden Antworten aus.

- ☐ Pediatric nephrologist
- ☐ Adult nephrologist
- ☐ Family doctor / general practitioner
- ☐ Pediatrician
- ☐ Psychologist (pediatric)
- ☐ Psychologist (adult)
- ☐ Social worker (pediatric)
- ☐ Social worker (adult)
- ☐ Nutritionist (pediatric)
- ☐ Nutritionist (adult)
- ☐ Nursing staff (pediatric)
- ☐ Nursing staff (adult)
- ☐ Other

28.

If you ticked "Other" in the previous question, please specify:

Transfer age

29.

At what age are patients most commonly transferred from your center out to adult care? *

Markieren Sie nur ein Oval.

- ☐ <14 years
- ☐ 14-16 years
- ☐ 16-18 years
- ☐ 18-19 years
- ☐ 19-21 years
- ☐ 21-24 years
- ☐ >24 years

30.

Which is the most appropriate age for transfer in your opinion? *

Markieren Sie nur ein Oval.

- ☐ <14 years
- ☐ 14-16 years
- ☐ 16-18 years
- ☐ 18-19 years
- ☐ 19-21 years
- ☐ 21-24 years
- ☐ >24 years
- ☐ Can't really say...

31.

Is age at transfer subject to regulation at your clinic? *

Markieren Sie nur ein Oval.

- ☐ Yes *Weiter mit Frage 32*
- ☐ No *Weiter mit Frage 37*

Regulation of transition age

You stated previously, that age at transfer is subject to regulation at your center:

32.

Who placed the condition? [multiple selections possible] *

Wählen Sie alle zutreffenden Antworten aus.

- ☐ Physicians' association (e.g. national/regional association/s of statutory health insurance physicians)
- ☐ Health insurance company (including NHS in GB)
- ☐ Care provider (e.g. hospital)
- ☐ Pediatric nephrology unit
- ☐ Other

33.

If you ticked "Other" in the previous question, please specify:

34.

At which age is the conditon placed? *

Markieren Sie nur ein Oval.

- ☐ 15 years
- ☐ 16 years
- ☐ 17 years
- ☐ 18 years
- ☐ 19 years
- ☐ 20 years
- ☐ 21 years
- ☐ Other

35.

Is it possible to postpone transfer beyond the set age / do you grant individual exemptions to extend pediatric care ? *

Markieren Sie nur ein Oval.

- ☐ Yes
- ☐ No

36.

If you ticked "Yes" in the previous question: In how many cases (%) do you try to achieve extended pediatric care?

Markieren Sie nur ein Oval.

	1	2	3	4	5	
Never (0%)	☐	☐	☐	☐	☐	Always (100%)

Health care provider after transfer

37.

To what kind of health care provider do you transfer your patients? [multiple selections possible] *

Wählen Sie alle zutreffenden Antworten aus.

- ☐ University hospital
- ☐ Community hospital
- ☐ Nephrologist's practice
- ☐ General practitioner's office / ambulatory health care centers
- ☐ Other
- ☐ Unknown

38.

If you ticked "Other" in the previous question, please specify:

Supplementary data (optional)

Please help us to back the results of this survey with retrospective data. This will take not much time, but really helps to enhance the knowledge regarding transition.

We would ask you to provide anonymous data on course of creatinine (last 5 values preceeding transfer), immunosuppression trough levels (last 5 values preceeding transfer), and transfer age of up to 5 patients who you recently transferred to adult care.

39.

Would you provide supplementary retrospective data (please!)? *

Markieren Sie nur ein Oval.

- ☐ Yes *Weiter mit Frage 41*
- ☐ Yes, but at a later date
- ☐ No *Weiter mit Frage 66*

Supplementary retrospective data

To enter retrospective data at a later date please copy and save the following address:

https://docs.google.com/forms/d/e/1FAIpQLSc_AGH9c_MLBA1sOwxBqr5ov7hsng_cXP8IWSLMQIKmXosSkiw/viewform?c=0&w=1&usp=mail_form_link

40.

Do you want to submit the survey? *

Markieren Sie nur ein Oval.

- ☐ No, I want to provide the retrospective data now.
- ☐ Yes. *Weiter mit Frage 66*

Retrospective data: Patient 1

Please enter the data for creatinine and immunosuppression trough levels separated with semicolons (e.g.: 1.02;1.11;0.96;1.08;1.22).

Immunosuppressive agents: Tacrolimus, Ciclosporine A, Sirolimus and Everolimus only!

41.

**Age at transfer (years & months e.g. 19
6/12)**

42.

**Last 5 serum creatinine values
preceeding transfer (please separate
using semicolons)**

43.

Unit

Markieren Sie nur ein Oval.

☐ mg/dl

☐ $\mu\text{mol/l}$

44.

**Last 5 immunosuppression trough levels
(please separate using semicolons)
preceeding transfer**

45.

Immunosuppressive agent

Markieren Sie nur ein Oval.

☐ Tacrolimus

☐ Ciclosporine A

☐ Sirolimus

☐ Everolimus

Retrospective data: Patient 2

Please enter the data for creatinine and immunosuppression trough levels separated with semicolons (e.g.: 1.02;1.11;0.96;1.08;1.22).

Immunosuppressive agents: Tacrolimus, Ciclosporine A, Sirolimus and Everolimus only!

46.

**Age at transfer (years & months e.g. 19
6/12)**

47.

**Last 5 serum creatinine values
preceeding transfer**

48.

Unit

Markieren Sie nur ein Oval.

☐ mg/dl

☐ $\mu\text{mol/l}$

49.

**Last 5 immunosuppression trough levels
preceeding transfer**

50.

Immunosuppressive agent

Markieren Sie nur ein Oval.

- ☐ Tacrolimus
- ☐ Ciclosporine A
- ☐ Sirolimus
- ☐ Everolimus

Retrospective data: Patient 3

Please enter the data for creatinine and immunosuppression trough levels separated with semicolons (e.g.: 1.02;1.11;0.96;1.08;1.22).

Immunosuppressive agents: Tacrolimus, Ciclosporine A, Sirolimus and Everolimus only!

51.

**Age at transfer (years & months e.g. 19
6/12)**

52.

**Last 5 serum creatinine values
preceeding transfer**

53.

Unit

Markieren Sie nur ein Oval.

- ☐ mg/dl
- ☐ µmol/l

54.

**Last 5 immunosuppression trough levels
preceeding transfer**

55.

Immunosuppressive agent

Markieren Sie nur ein Oval.

- ☐ Tacrolimus
- ☐ Ciclosporine A
- ☐ Sirolimus
- ☐ Everolimus

Retrospective data: Patient 4

Please enter the data for creatinine and immunosuppression trough levels separated with semicolons (e.g.: 1.02;1.11;0.96;1.08;1.22).

Immunosuppressive agents: Tacrolimus, Ciclosporine A, Sirolimus and Everolimus only!

56. **Age at transfer (years & months e.g. 19
6/12)**

57. **Last 5 serum creatinine values
preceeding transfer**

58. **Unit**
Markieren Sie nur ein Oval.

☐ mg/dl

☐ $\mu\text{mol/l}$

59. **Last 5 immunosuppression trough levels
preceeding transfer**

60. **Immunosuppressive agent**
Markieren Sie nur ein Oval.

☐ Tacrolimus

☐ Ciclosporine A

☐ Sirolimus

☐ Everolimus

Retrospective data: Patient 5

Please enter the data for creatinine and immunosuppression trough levels separated with semicolons (e.g.: 1.02;1.11;0.96;1.08;1.22).

Immunosuppressive agents: Tacrolimus, Ciclosporine A, Sirolimus and Everolimus only!

61. **Age at transfer (years & months e.g. 19
6/12)**

62. **Last 5 serum creatinine values
preceeding transfer**

63.

Unit

Markieren Sie nur ein Oval.

☐ mg/dl

☐ µmol/l

64.

**Last 5 immunosuppression trough levels
preceeding transfer**

65.

Immunosuppressive agent

Markieren Sie nur ein Oval.

☐ Tacrolimus

☐ Ciclosporine A

☐ Sirolimus

☐ Everolimus

Thank you

You have successfully completed our survey. We appreciate and value your insights and experience in regard of transition and thank you for your kind support.
Please feel free to leave a comment, if you wish.

Best wishes!

Lars Pape & Martin Kreuzer

66.

Leave a comment (optional):

Bereitgestellt von

