

# Survey on management of transition and transfer from pediatric to adult-based care in pediatric kidney transplant recipients in Europe

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# Health Care Transition

“....a process involving purposeful, planned efforts to prepare the pediatric patient to move from caregiver-directed care to disease self-management in the adult unit”

“... successful if it promotes the patients’ health competence, supports their psychosocial rehabilitation, and improves their self-determination efficacy, including their ability to make decisions and communicate about their care”

Adolescence and coming out of age can be equally challenging for the caregivers – as for the patient...

# ISN / IPNA Consensus 2011

policy forum

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<http://www.kidney-international.org>

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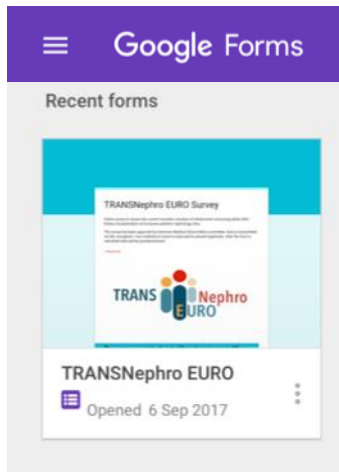
## Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA)

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<sup>1</sup>Co-Chair, IPNA, UK; <sup>2</sup>Co-Chair, ISN, UK; <sup>3</sup>IPNA, USA; <sup>4</sup>ISN, Australia and <sup>5</sup>ISN, Egypt

# ESPN Survey

- 39 centres
- 24 countries
- covering 2500 KTx children



# Transition procedure

No transfer at all: 3 centres

Transfer without any preparation: 2 centres

34 centres left

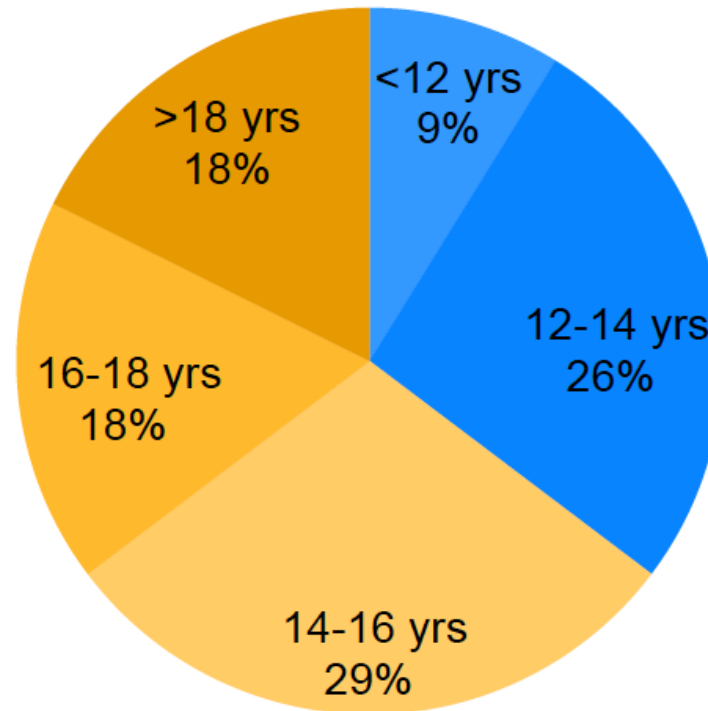
no defined transition procedure: 3 centres

31 centres left

some procedure centre-wide: 28 centres

physician's personal procedure: 3 centres

# Introduction at what age?



**Age at initiation of transition process**

# Who participates *besides* the patient

<b>Group</b>	<b>Number of centres</b>
Parents	31
Siblings	5
Girl-/Boyfriend	8
Peers	4
Teachers	2



# Transition components *not often* used:

- A written transition plan is made and communicated with the patient: 7/31
- Readiness of transfer is determined by using an appropriate tool (e.g. transition scale, questionnaire, self-rating): 6/31
- Transition medical passport: 4/31
- Computer-based training/education (e.g. software, online/internet/intranet, app, social media): **0**/31

# Transition Clinics

15/31 centres held transition clinics

- 14/15 specifically for kidney disease
- weekly: 3 centres
- 1-3 times/month: 5 centres
- < 1/month: 7 centres

Modality (multiple answers possible):

- shared consultation: 12
- alternating consultations: 5 centres
- young adult clinic: 2 centres

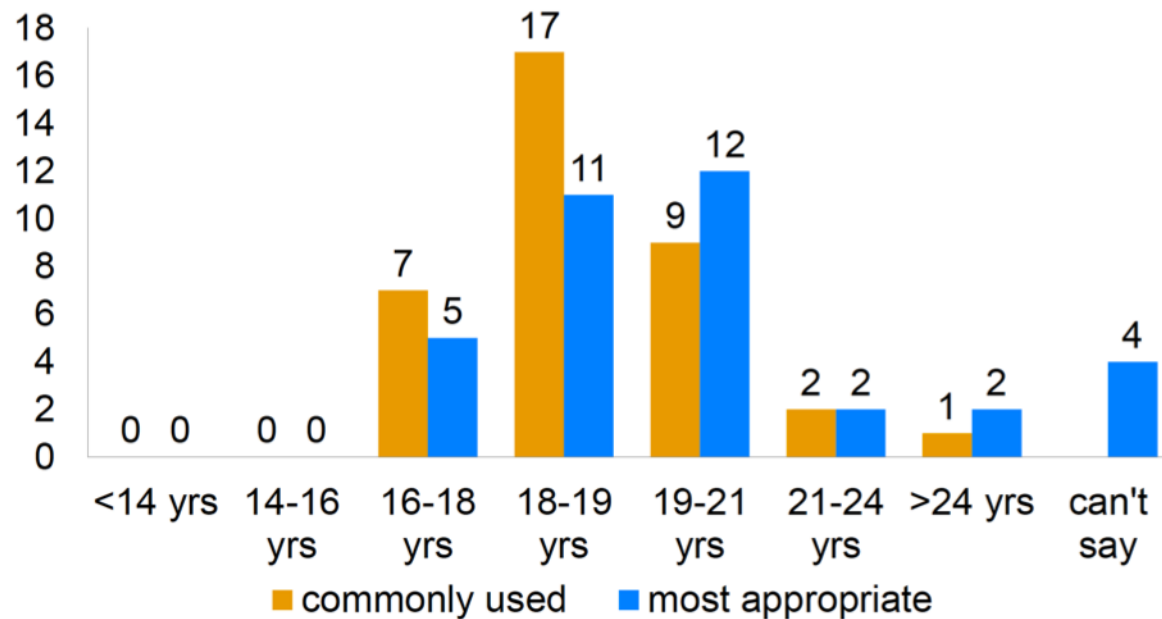
# Specialists *actively* involved in transfer

<b>Profession</b>	<b>involved by</b>
<b>Pediatric nephrologist</b>	33/34
<b>Adult nephrologist</b>	31/34
<b>Family doctor / general practitioner</b>	3/34
<b>Pediatrician</b>	4/34
<b>Psychologist (pediatric)</b>	22/34
<b>Psychologist (adult)</b>	7/34
<b>Social worker (pediatric)</b>	19/34
<b>Youth worker</b>	2/34
<b>Social worker (adult)</b>	6/34
<b>Nutritionist (pediatric)</b>	14/34
<b>Nutritionist (adult)</b>	3/34
<b>Nursing staff (pediatric)</b>	25/34
<b>Nursing staff (adult)</b>	12/34

# Transfer policy (5-point Likert-scale)

Statement	Score
Transfer at our center is <b>individualized</b> for each patient after s/he has <b>completed a transition plan</b> ; this will depend upon completion of physical growth and, where possible, educational, social and psychological attainment.	4 (1-5)
Transfer at our center is <b>agreed upon jointly</b> by the patient and his/her family/careers in conjunction with the pediatric and adult renal care teams.	4 (2-5)
Transfer at our center <b>DOES NOT take place during a period of crises</b> , especially if there is unstable social support.	5 (2-5)
Transfer at our center takes place <b>after completing school</b> education.	3 (1-5)
We take into account <b>treatment plans by other subspecialties</b> (e.g. urological supervision).	4 (2-5)

# Transfer age



**Transfer Age commonly used at participating centers  
and opinion on most appropriate transfer age**

# Gross national income and adherence to ISN/IPNA transition guidelines

