

Lost in Transition

How to improve transition care from childhood/teenagehood to adulthood

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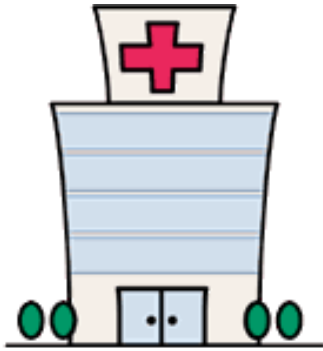


What is transition?

‘the purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health-care systems’

not just ‘transfer’

Why is transition so challenging?



Paediatric health care model

Adult health care model

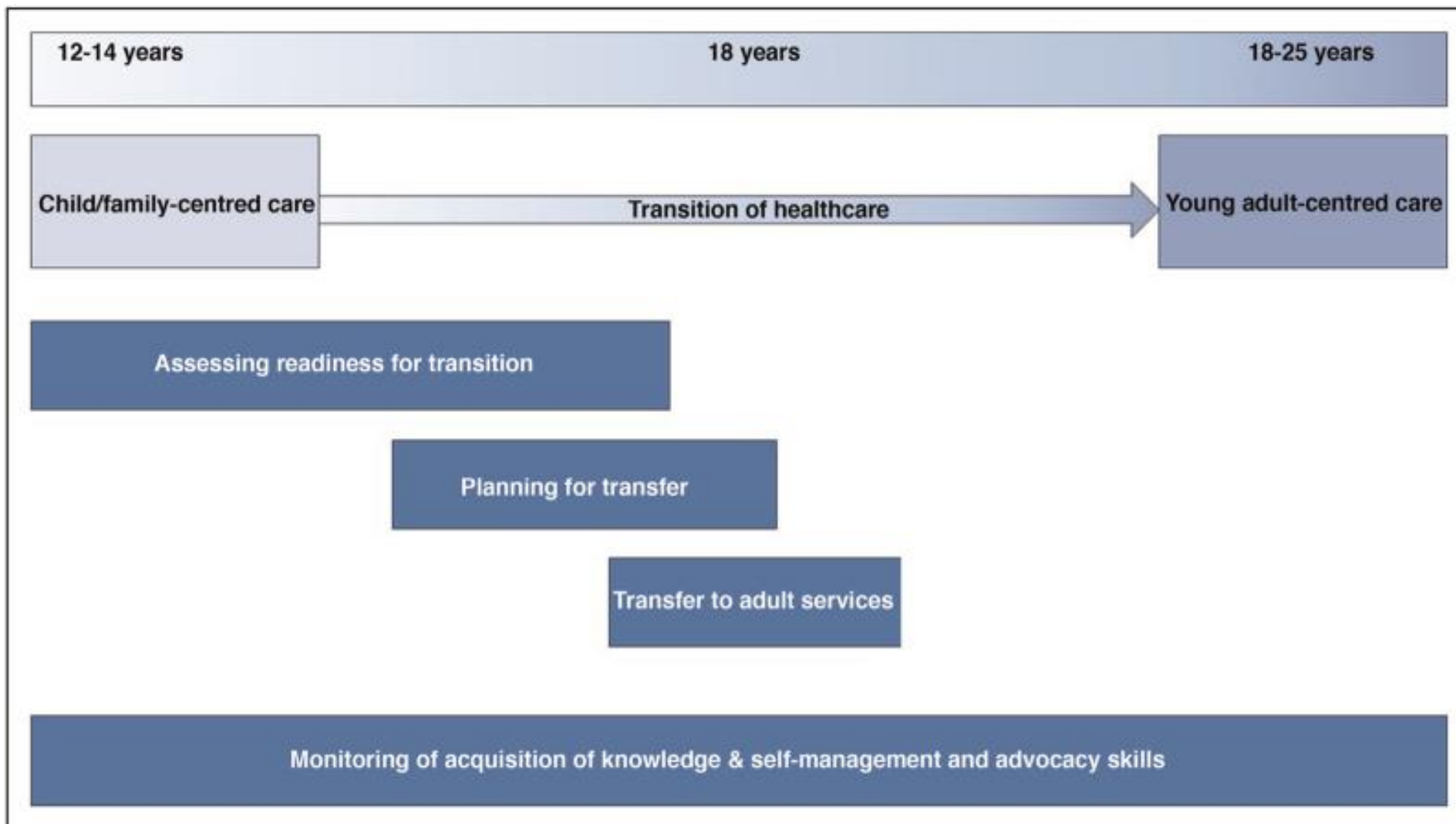
Why is transition so challenging?



Dependent

Independent

Key steps for successful transition



How are we doing?

Journal of Clinical Immunology (2023) 43:206–216
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ORIGINAL ARTICLE



European
Reference
Network

for rare or low prevalence
complex diseases

 Network

Immunodeficiency, Autoinflammatory,
Autoimmune Diseases & Paediatric
Rheumatology (ERN-RITA)

Current Transition Practice for Primary Immunodeficiencies and Autoinflammatory Diseases in Europe: a RITA-ERN Survey

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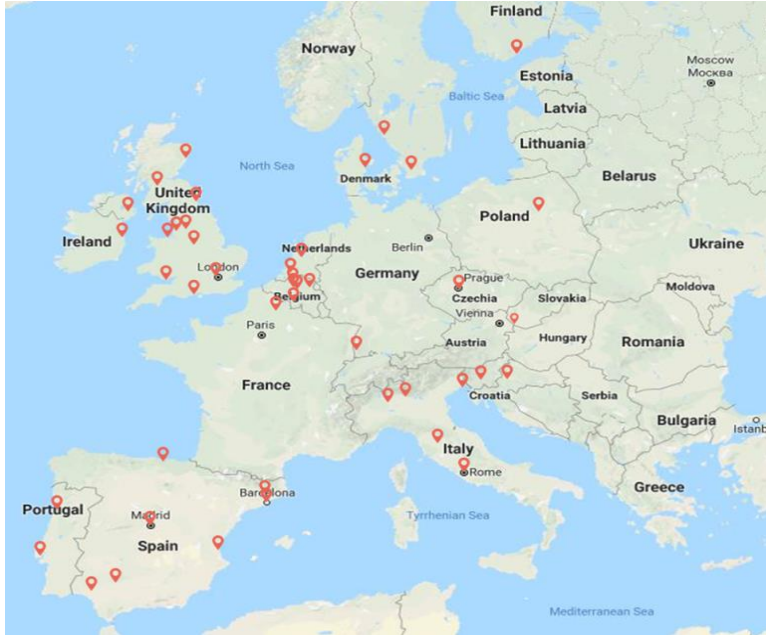
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European Society
for Immunodeficiencies

How are we doing?

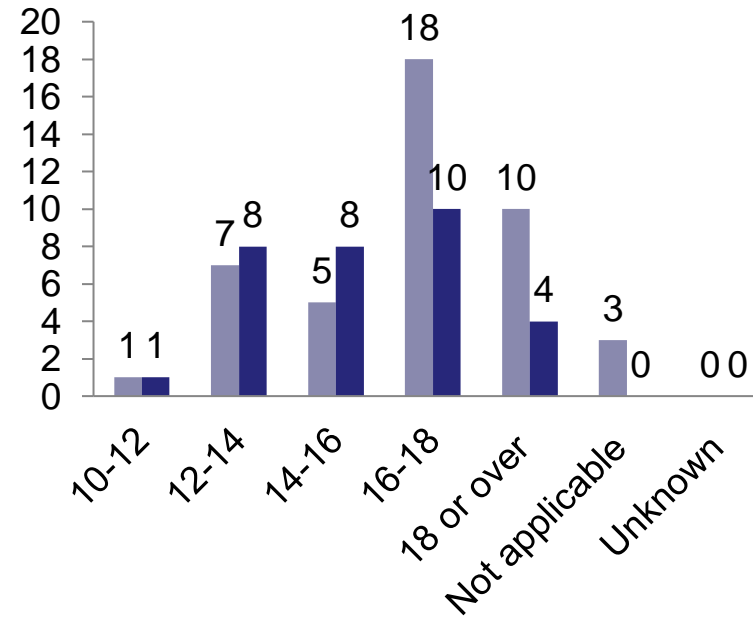


44 PID responses
39 cities in 15 countries

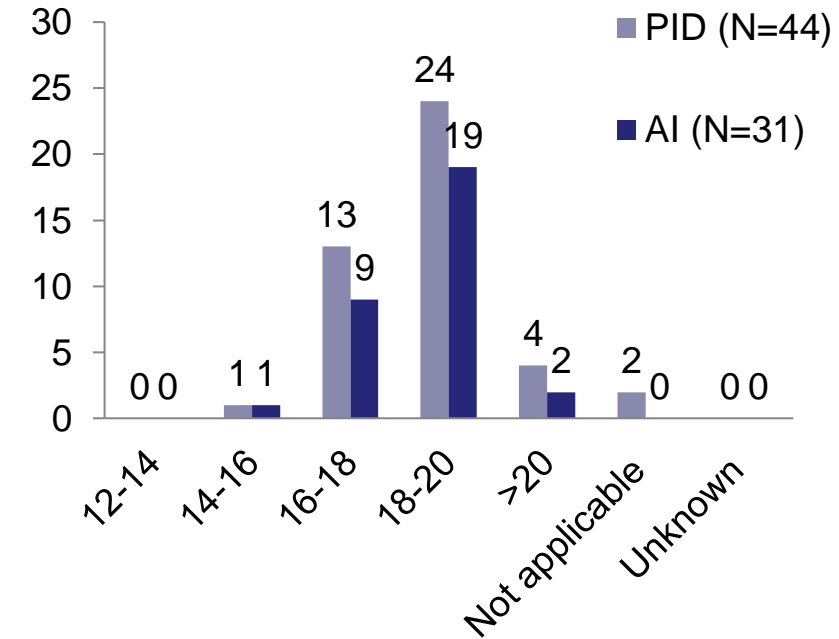
32 AI responses
29 cities in 13 countries

Approx 50% response rate

Age at start of the transition process

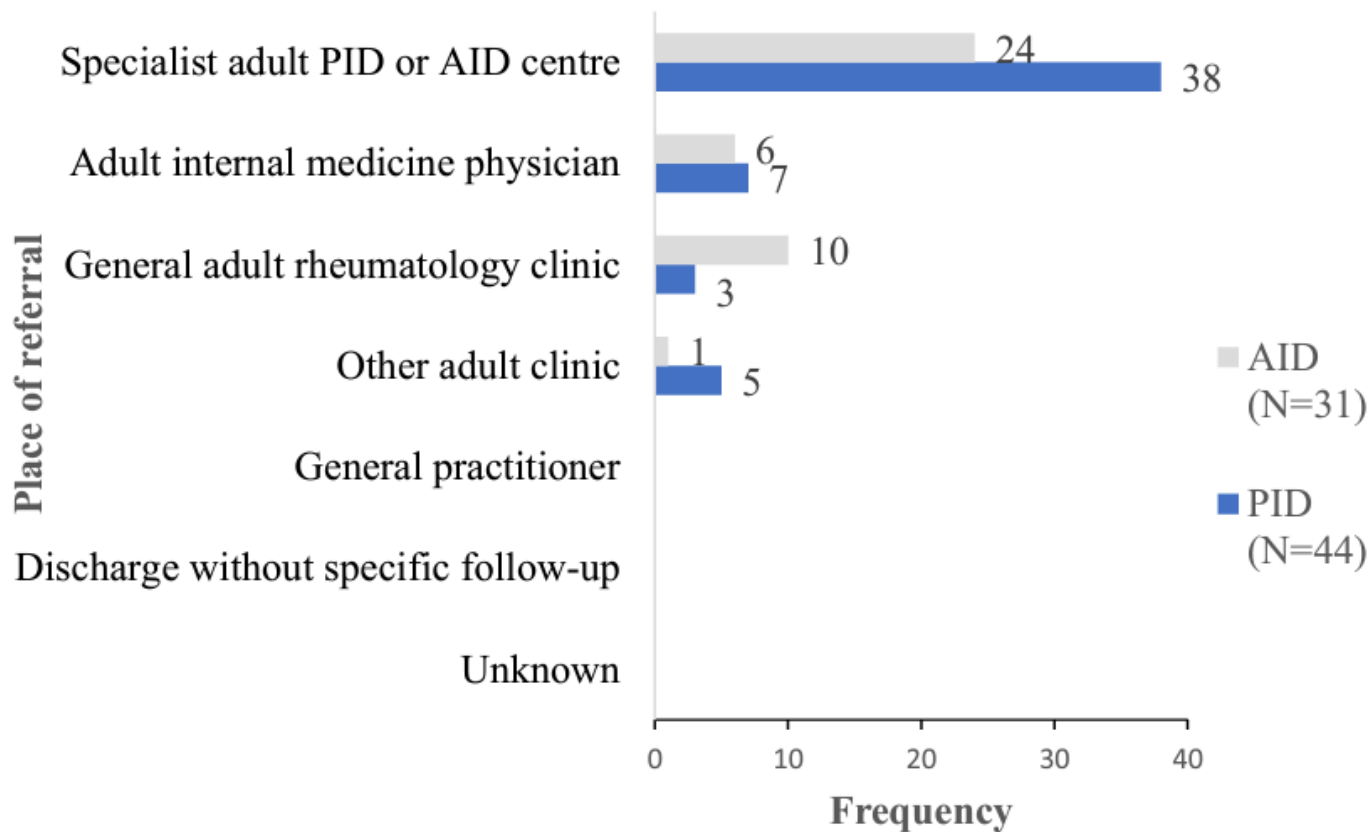


Age at transfer to an adult service



<10% of AI services &
< 25% of PID services
transition more than 10 patients per year

How are we doing?



Most centres have joint paed/adult appointments

(75% PID and 68% AID)

A minority transition to a service with a designated young adult clinic

(11% PID and 29% AID)

What problems are reported by centres?

- No adult specialist centre to refer to (9% PID/27% AID)
- Fragmentation of adult services
- Transfer to services for all the various comorbidities
- Lack of holistic care in both and adult pediatric services
- Lack of provision for patients with learning disability or mental health difficulties in adult services
- Lack of time to prepare documents
- Funding and resource in adult services
- Patients not wanting to engage



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Transition practice for primary immunodeficiency diseases in Southeast Asia: a regional survey

Results: Regionally, **3 out of 7 countries reported having no practice of transition care.** Among cited challenges were **reluctant adaptation by patients and caregivers to unfamiliarized adult healthcare systems, inadequate ratio of adult immunologists to patients and lack of facilities for transfer**

Common problems with transition: the patient perspective

- Perceived differences in quality of care, knowledge and experience of adult healthcare providers
- Anxiety about leaving trusted relationships established with the paediatric team
- Change in environment and structure of adult healthcare services
- Insufficient information prior to transfer

Additional sources of stress:

- Uncoordinated transitions, with poor handover of information
- Unexpected changes when moved to adult services.
- Collision of transfer timing with developmental stage of as teens move into adulthood and assume increasing independence

What can we do to improve transition?



ALL CHANGE

Dependent

Independent

What can we do to improve transition?

- Be purposeful about the transition process
- Start early and work with young people and their families to build gradual independence
- Build a team for transition and transfer – across paediatric and adult services
- Ensure multidisciplinary approach – including nursing and psychology – this is essential and needs to be across both paedics and adult services
- Find adult specialists who will work with you for specific co-morbidities and develop those relationships
- Ensure timely transfer for all co-morbidities as far as possible
- Be collegiate and supportive

What can we do to improve transition?

- Make sure the young person and family have information about transition and transfer (including contact details for paediatric and adult services)
- Have joint appointment(s) prior to transfer & plan timing of the first appointment in adult services
- Do not underestimate the importance of the last paediatric appointment for young people and their families
- Be clear about who is responsible for what during the transition process (especially admissions)
- Ensure clear and thorough documentation to the adult team (including important diagnostic info eg genetic results)
- Fight for resource in your institution to do transition and transfer well

What can we do to improve transition?

- We need to understand the experience of our young people and their families better
- We need to know what our they really want and value in transition, transfer and during adult care
- We need more research in patient reported outcomes
- We need to support young people and their families through what can be a challenging time for everyone

Some specific challenges for PID transition

Specific challenge	Examples of affected PID	Specific requirements
Learning disabilities	22q deletion syndrome, adenosine deaminase (ADA) SCID	Learning disabilities assessment and support
Increased risk of adult-onset psychiatric disease	22q deletion syndrome	Neuropsychiatric vigilance, assessment and follow-up
Disease evolution: new disease features over time or	Various IEIs e.g. CGD, combined immune deficiency acquiring complications	Consideration of HSCT and regular review of indications for HSCT in adolescence/early adulthood
New genetic diagnosis	Various IEIs	Consideration of targeted or curative therapy
Treated as part of a clinical trial eg gene therapy	SCID, CGD	Long-term trial follow up. May require set up of trial at adult centre

New guidelines for transition of patients with PID and AID

- Transition Process
- Administration of Transition
- Transition Appointments
- Content of Transition Programs
- Managing other Systems
- Contraindications to Transfer



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ESID Grand Round Jan 2024

<https://esid.org/Working-Parties/Clinical-Working-Party/Grand-Rounds-2021-2023>



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 Rheumatology (ERN-RITA)

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