IPOPI 4TH REGIONAL ASIAN PID MEETING

19-20 NOVEMBER 2022

KUALA LUMPUR, **MALAYSIA**

an **IPOPI** event

CARE FOR RARE

GLOBAL ALLIANCE EDUCATIONAL SEMINAR

Care-for-Rare Foundation

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Transition Care in PID

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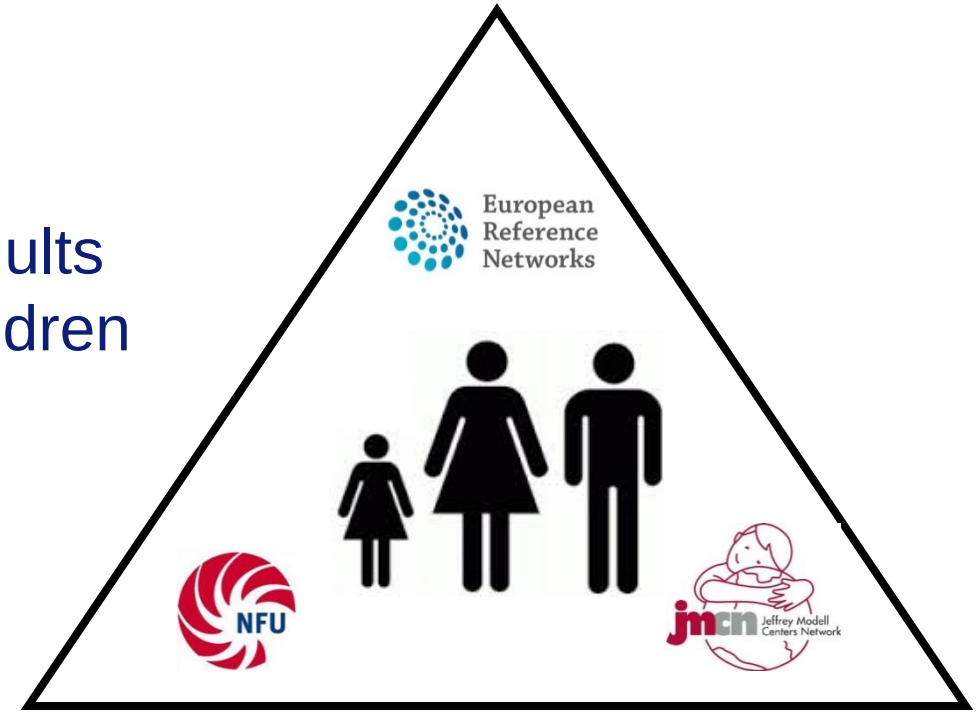
Immunology

~ 650 adults
~ 150 children



Pediatric Immunology and Infectious Disease

Internal Medicine
Allergy & Clinical Immunology

Primary immunodeficiencies: not just paediatric diseases

Andrew R. Gennery[1] and Steven M. Holland[2]

Gennery AR & Holland SM. Eur Resp Journal 2015

Challenges in transition care

When to start

How to do it

Which health care professionals need to be involved

Specific issues?

Do we pay enough attention?

069 Comparing Perspectives on Transition of Care for Primary Immunodeficiency Patients

Shipra Rai[1], Zoya Treyster, MD[2], Artemio Jongco, MD PhD MPH FAAAAI[3]; [1]Cohen Children's Medical Center, [2]Montefiore Medical Center, [3]Donald and Barbara Zucker School of Medi.

RATIONALE: Only some allergists/immunologists provide care throughout the lifespan, despite their training. Research, evidence-based guidelines, and resources on transition of care (TOC) for pediatric primary immunodeficiency (PID) patients are lacking.

METHODS: A needs assessment survey adapted from an existing pediatric rheumatology TOC survey was used to evaluate TOC perspectives from allergists/immunologists. The 15-minute online survey was emailed to American Academy of Allergy Asthma and Immunology (AAAAI) and Clinical Immunology Society (CIS) members. Responses were combined and analyzed via SAS.

RESULTS: 60 of 1250 eligible AAAAI and 79 of 698 eligible CIS participants completed the survey (5% & 11% participation rate). Most (60%) providers transition patients to adult care. The groups were comparable in terms of accepting transition patients (P=0.522) or transitioning patients to adult care (P=0.38). Only 3% of providers have a written transition statement, and 26% had a standard protocol. However, 33% expressed interest in creating a policy. Only 38% are satisfied with current TOC practices and 72% feel that time is a barrier. About half (44% and 53%) would like written and online TOC materials, respectively.

CONCLUSIONS: TOC remains overlooked in our specialty. Pediatric PID patients are transitioned despite inadequate time and resources. The impact of suboptimal TOC on patient outcomes and quality of life is unclear. Our findings underscore the need to develop and evaluate the effectiveness of evidence-based TOC guidelines, resources, and best practices for PID patients.

Rai S et al. J Allergy & Clin Immunol 2022

Do we pay enough attention?

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transitioning patients to adult care (P=0.38). Only 3% of providers have a written transition statement, and 26% had a standard protocol. However, 33% expressed interest in creating a policy. Only 38% are satisfied with current TOC practices and 72% feel that time is a barrier. About half (44% and 53%) would like written and online TOC materials, respectively.

Rai S et al. J Allergy & Clin Immunol 2022

Important aspects

Transition of care is warranted to ensure long-term follow-up and best management for patients with PID

Psychological support is recommended

Should be planned during adolescence (age around 14?)

Transition phase should take a few years

Cirillo E et al. J Allergy & Clin Immunol 2020

Who should be involved?

Pediatric-Immunologist

Internist-Immunologist

Designated case-manager; Nurse specialist?

Dedicated team with expertise

Cirillo E et al. J Allergy & Clin Immunol 2020

Outcome measures

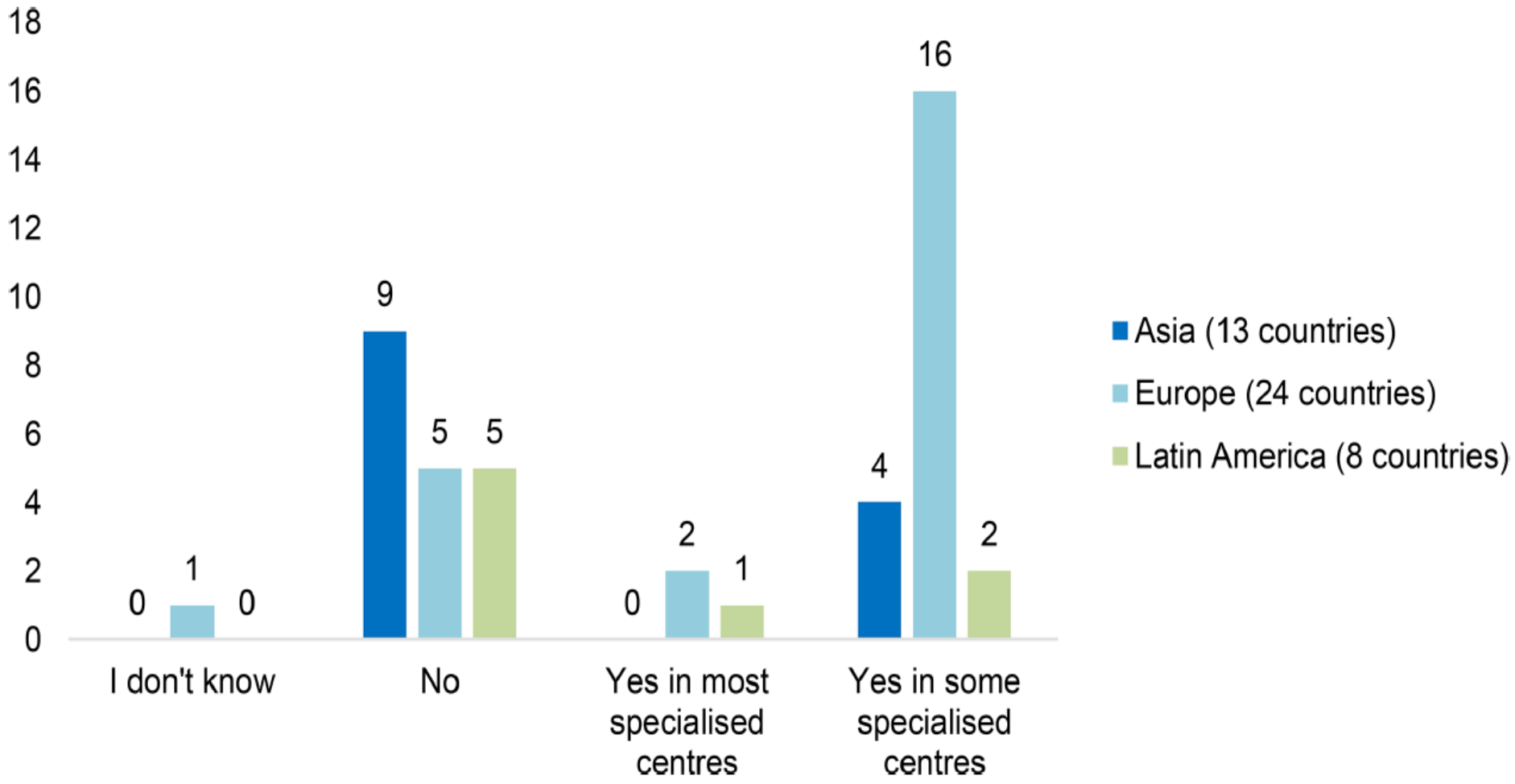
Adherence to follow-up

Adherence to therapies

Patient and family satisfaction

Cirillo E et al. J Allergy & Clin Immunol 2020

Is transition care available everywhere?



Nordin J et al. Front Immunol 2021

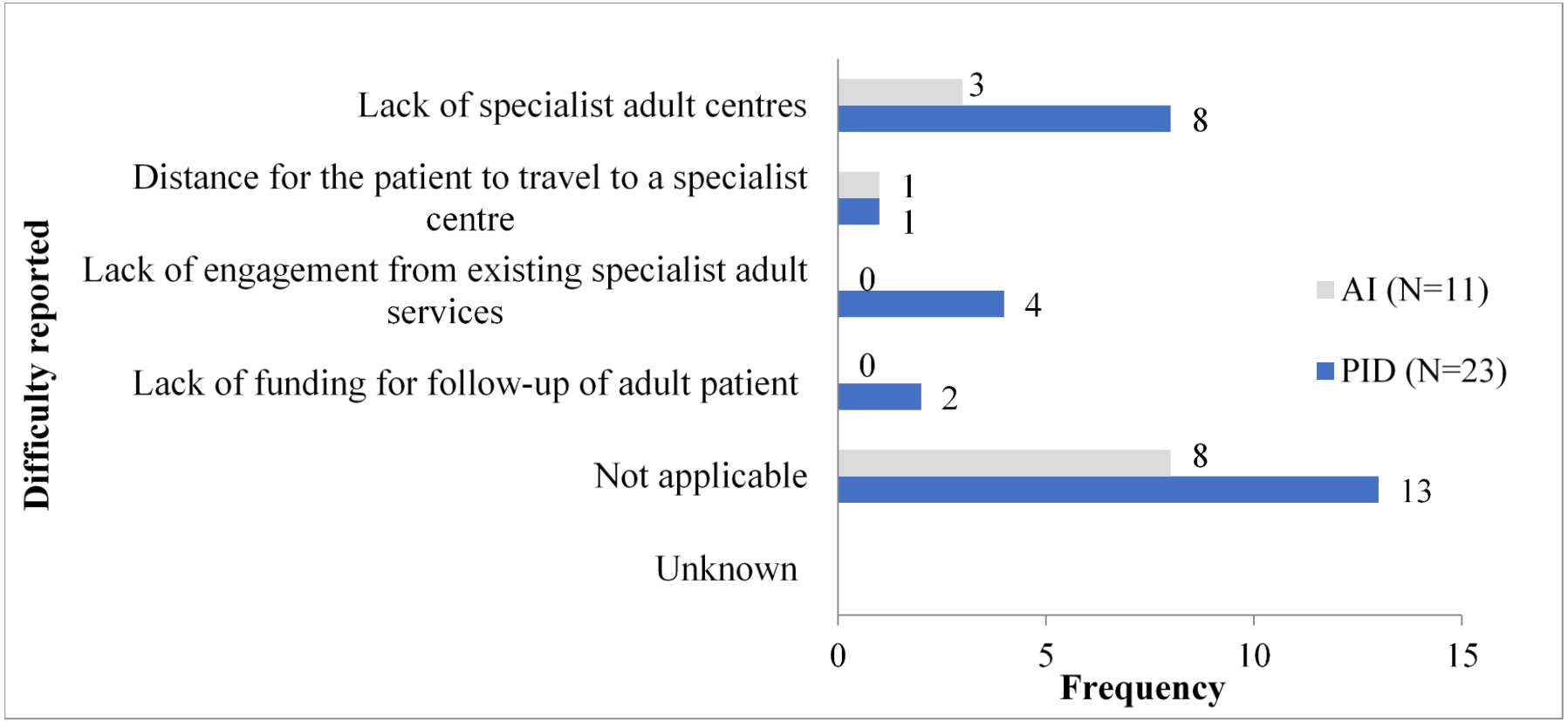
Transition Care : ERN RITA survey

Contacted sites Response sites

Israni M et al. J Clin Immunol 2022

Difficulties in finding adult centers

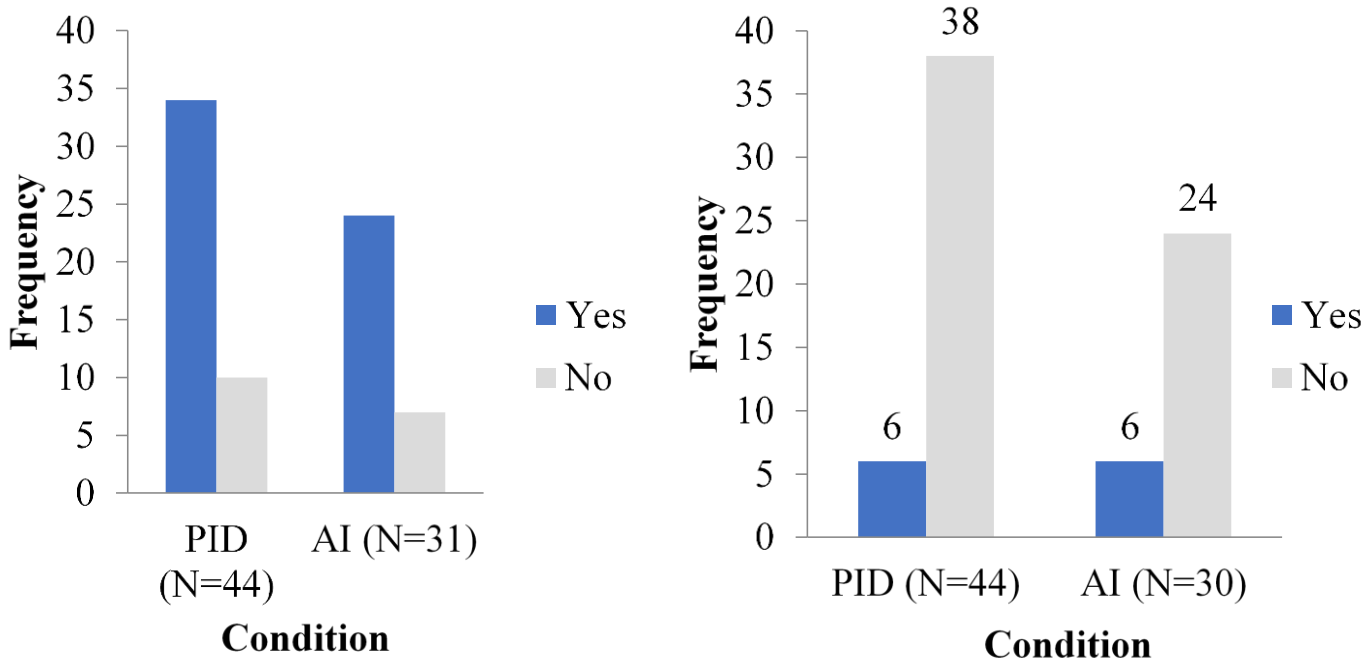
Supplementary Figure 3: Difficulties in identifying adult centre for transfer of care



Israni M et al. J Clin Immunol 2022

Use of defined transition processes

Figure 3: Use of defined transition processes (a) and access to national disease-specific guidelines for transition (b).



Tools for transition care

Name: Date:

Knowledge and skills	Yes	I would like some help	Comment
KNOWLEDGE - WHAT I KNOW			
 I can describe my condition - this means you know why you are seeing your doctors, nurses or therapist			
 I know about my medicines and treatments			
 I know who looks after me and my condition			

Name: Date:

Knowledge and skills	Yes	I would like some help	Comment
KNOWLEDGE - WHAT I KNOW			
 I understand the medical words and procedures relevant to my condition			
 I understand what each of my medications are for and their side effects			
 I am responsible for my own medication at home			
 I order and collect my repeat prescriptions and book my own appointments			

Tools for transition care

Recommendations for Transition of Young Patients with Inborn Errors of Immunity

Inborn Errors of Immunity (IEI) refer to a varied group of rare disorders characterised by ~~elevated~~absent, poor, or ~~absent~~ elevated function in components of the innate and/or adaptive immune systems. Primary immunodeficiencies (PID) and autoinflammatory diseases (AID) represent the majority of known IEI[1,2]. Due to the longevity of IEI and the need for long-term follow-up of patients with these disorders, effective transition programmes are required to ensure smooth transfer of care from paediatric to adult health centres. The following practices have been recommended for optimal transition of young patients with IEI to adult care.

Process of transition

1. The transferring centre should organise 'formal transition partners' with integrated care pathways for smooth transition to adult care services.
2. ~~Ideally, the paediatrics team should identify local , national/international networks to support/share care of patients with rare disorders.~~
3. The process of transition should ideally start when patients are between 12

Tools for transition care

Value Based Health Care

General versus disease specific domains

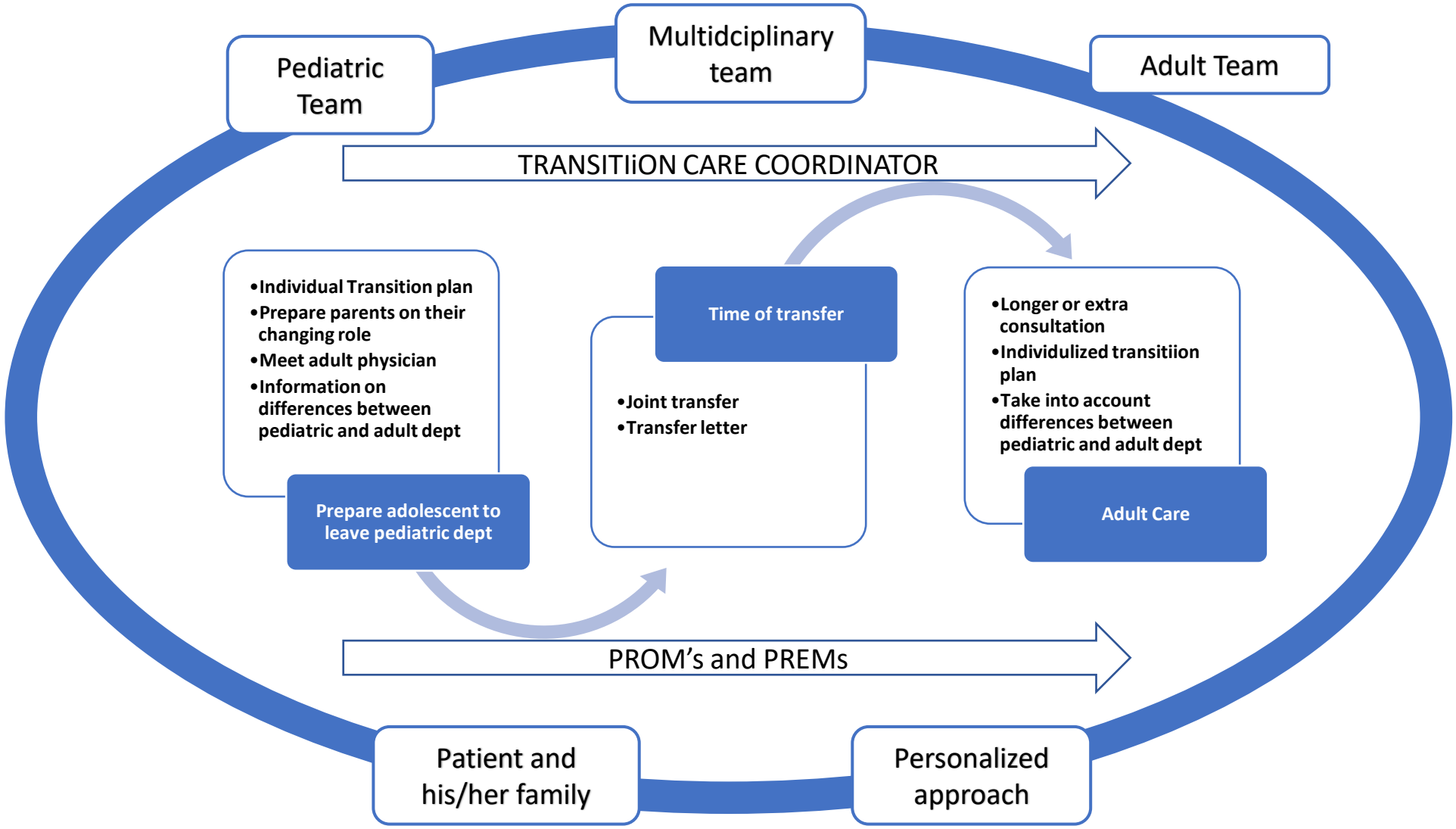
More efficient outpatient clinic visits

More insight in what is important to the patients

Change focus of care? What is important to the doctor and what is important to the patient?

Help patients in more domains

Tools for transition care



Important aspects

Transition care for PID patients should be well organized

Dedicated team

A transition policy should be in place

Role of patient organizations

Thank you

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