

# 8<sup>th</sup> ERN EURO-NMD Annual Meeting

## Transition of care A French center experience

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Marion Masingue

Centre de Référence des Maladies Neuromusculaires Nord-Est-Ile de France, Hôpital Pitié-Salpêtrière, Institut de Myologie, APHP,

Paris, France



# Transition of care



Involves defining a thoughtful, realistic, and adapted adult life plan, that is dignified and consensual.

A moment that is desired and/or feared:

- Gaining autonomy
- Fear of the unknown
- Fear of being "left in the wild," fear of abandonment

# Literature

Two factors that influence the transition process from pediatric to adult medical care:

- The quality of interpersonal and interprofessional relationships maintained by pediatric and adult medical services
- The ability of young patients to envision themselves in an adult project

# Young Adult – Fears and Needs



- **New Medical Issues:** Worsening/ Sexuality/Genetics...
- **Self-reliance**/empowerment
- **Temptation to discontinue** medical follow-up

- Fear of the **unknown**
- **Loss of the privileged and reassuring relationship** established with the pediatric team
- Fear of **not being personally considered** by the new adult medical team

- Relational and care **continuity, visualizing** the service, and **active participation**
- Being able to **project** oneself into the future

# Family— Fears and Needs

- **New care culture:** the adult service prioritizes relationships with the patient perceived as an adult and therefore as more autonomous
- **Organizational changes:** What about the caregiver in adulthood? Change of residence for studies...

- Loss of **control**
- Fear of **less adequate care**

- To be **reassured** in order to facilitate empowerment
- Relational **continuity**
- To **contribute** to their child's care journey during the transition
- To be **supported** in 'letting go'

# Medical/Paramedical Team— Fears and Needs

- **Letting go (pediatrician)**
- **New Patient with a medical history and habits (adult)**

- **What is the right time?**
- **To anticipate**
- **Reassure and connect** with the patient

- Need to be in **contact with their counterpart** from the other department.  
A link that is both **interpersonal** (knowing each other) and **formalized** ('transition file')
- Know the **date** of the first adult consultation and the **name** of the referring myologist
- **Centralize/transfer** medical and paramedical data

# Pitié-Salpêtrière's experience

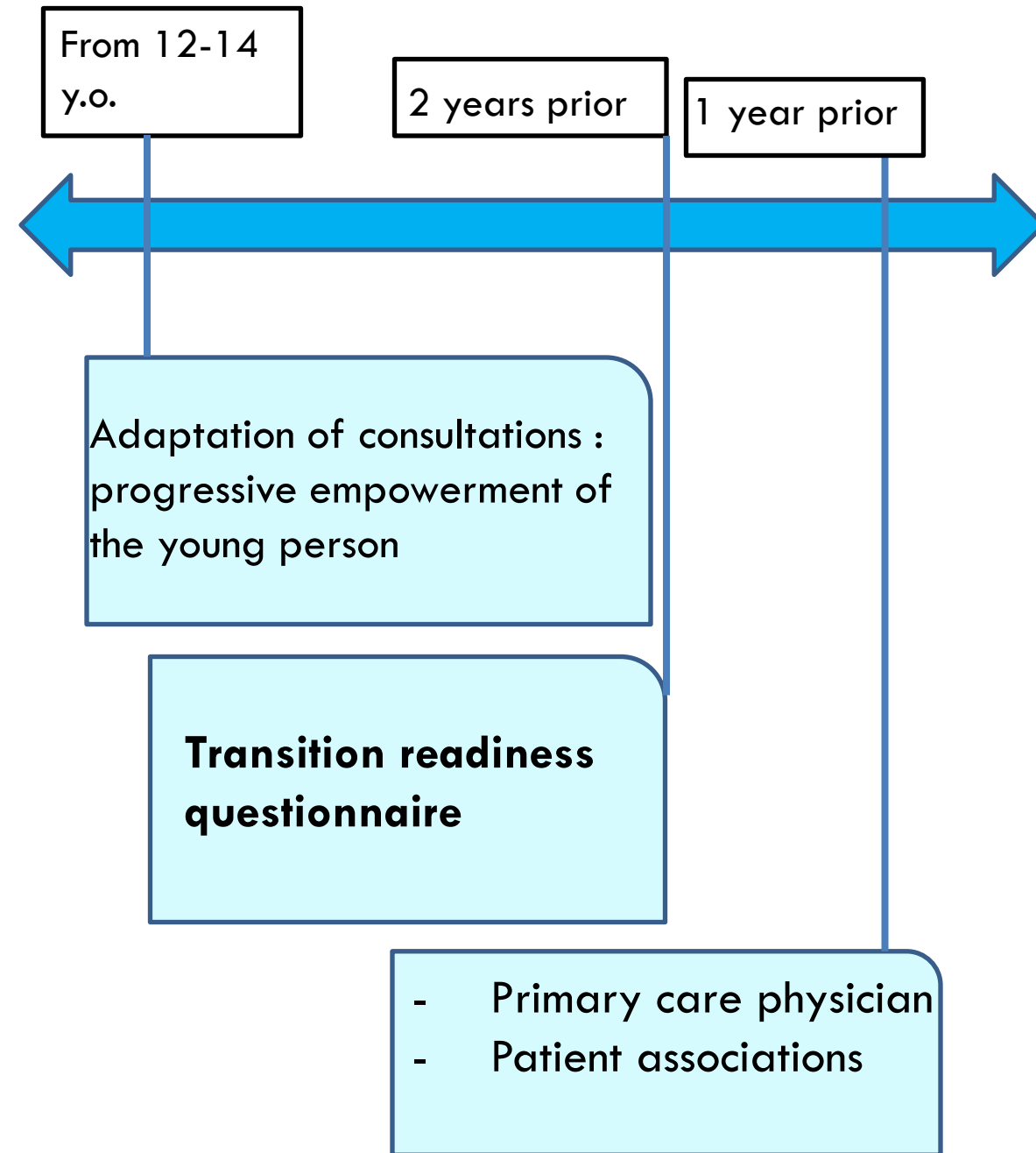
- ~ 30/ year
- One BIG problem...

# Pitié-Salpêtrière's experience





## Preparation for the transition (in pediatrics)



# Transition Readiness Questionnaire

Second-to-last pediatric consult (PC) and at the last PC

## **Knowledge of the illness**

- Diagnosis, mechanisms, treatments, questions...?

## **Taking care of oneself**

- Caregiver, tobacco, alcohol, drugs, sexuality...

## **Manage the constraints of daily life independently**

- How do you see your role and that of your parents in your adult care?
- Administrative tasks

## **Make choices, build one's life plan**

- How do you see yourself in your adult life?
- What are your desires in terms of your professional life?

## **Have confidence in oneself, be oneself**

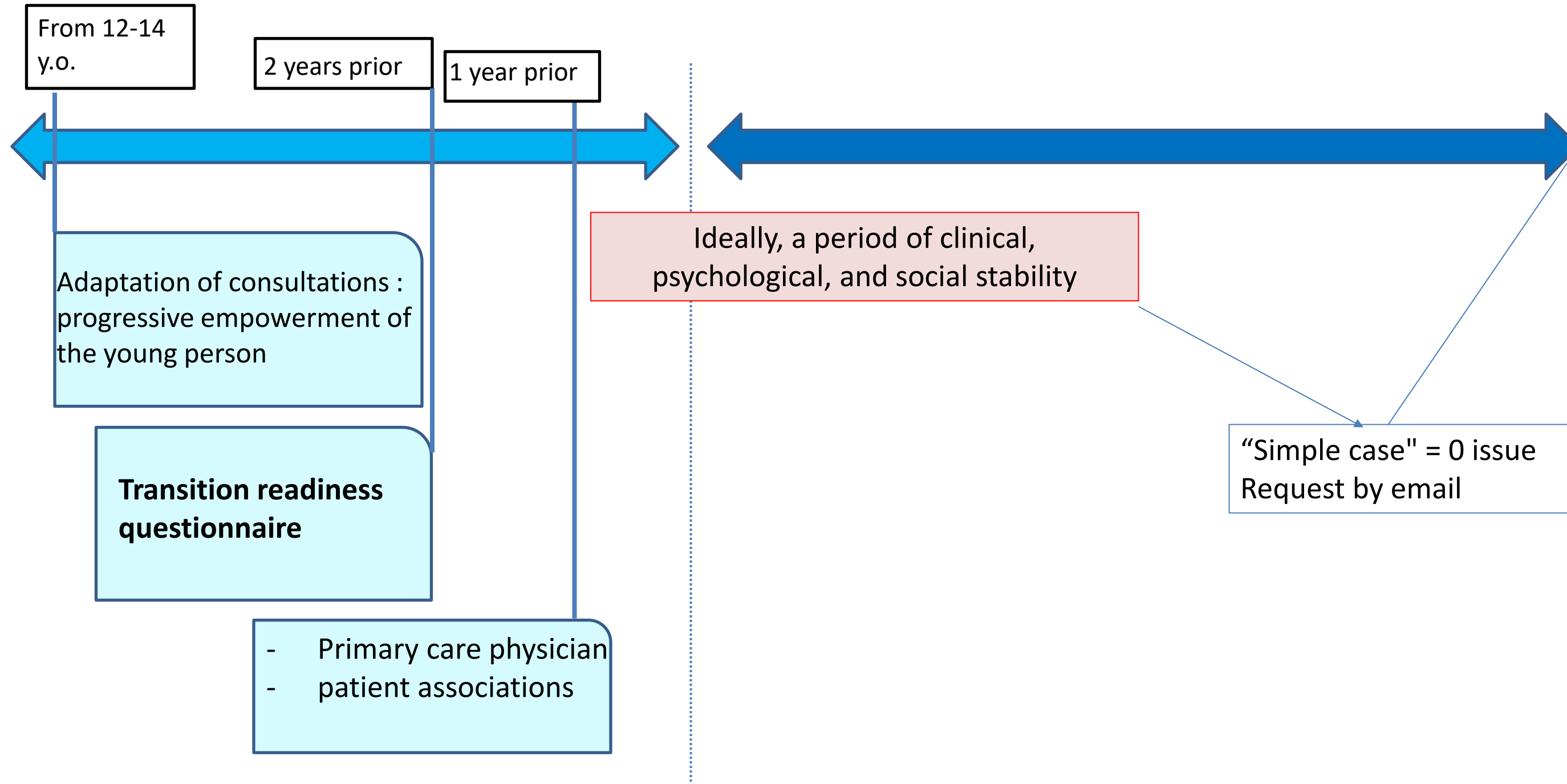
- What is your opinion regarding your follow-up care?
- What would you like to improve?

## **Expectations and needs**

- What are your expectations for the future? (driver's license, living situation, study plans, activities...) Your concerns?
- Would you like to see other specialists (Geneticist, gynecologist, sexologist...)?

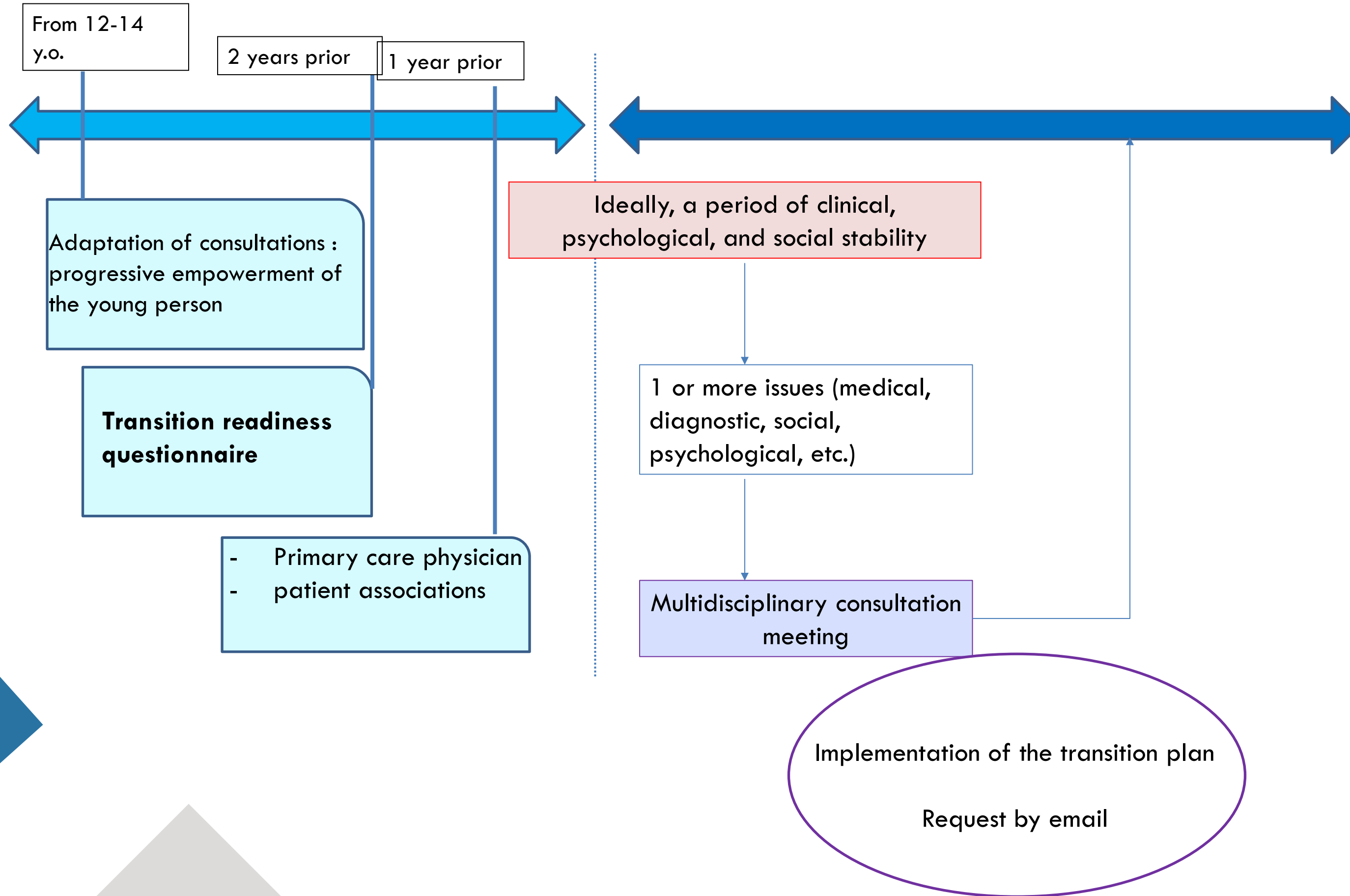
## Preparation for the transition (in pediatrics)

## Transition (adults)

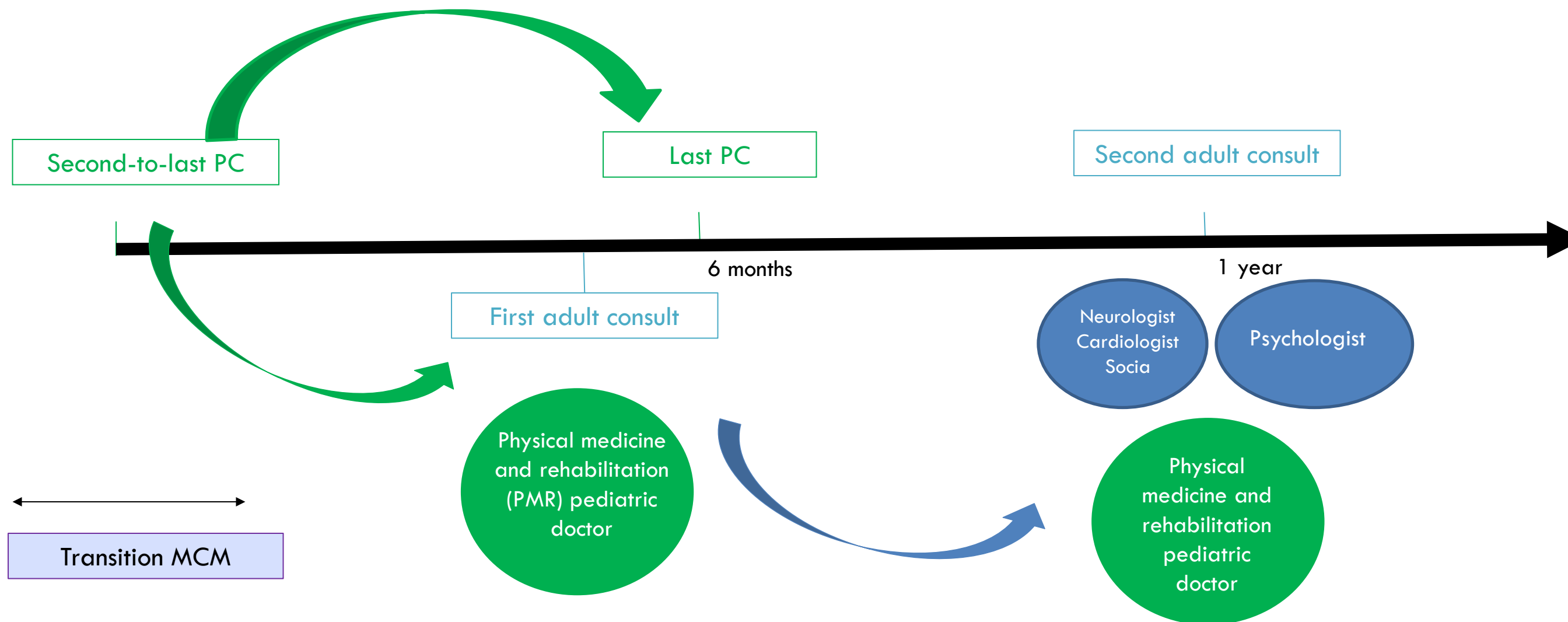


## Preparation for the transition (in pediatrics)

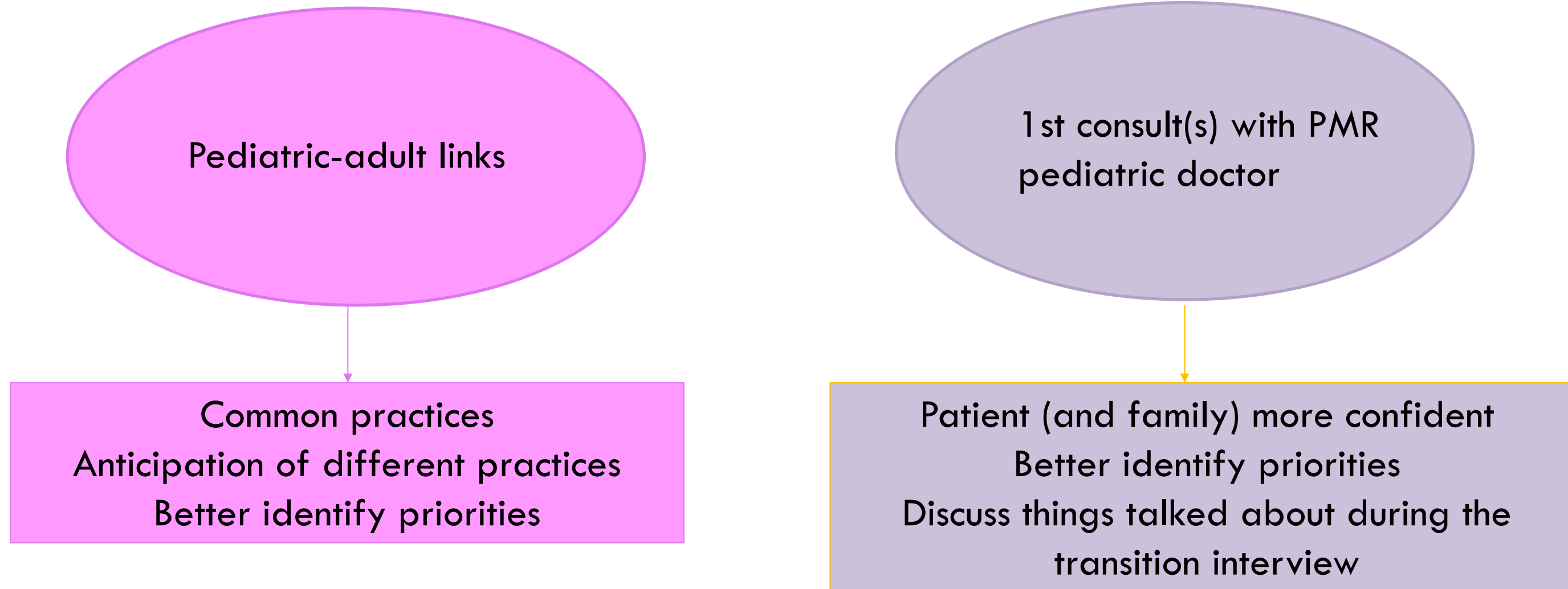
## Transition (adults)



# Transition Plan



# 2 Fundamental Tools



# Acknowledgements

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