



Hôpital
Robert-Debré
AP-HP



PLATEFORME DE TRANSITION
DE L'HÔPITAL UNIVERSITAIRE
ROBERT DEBRÉ - AP-HP

Care Continuity : Transition from childhood to adulthood

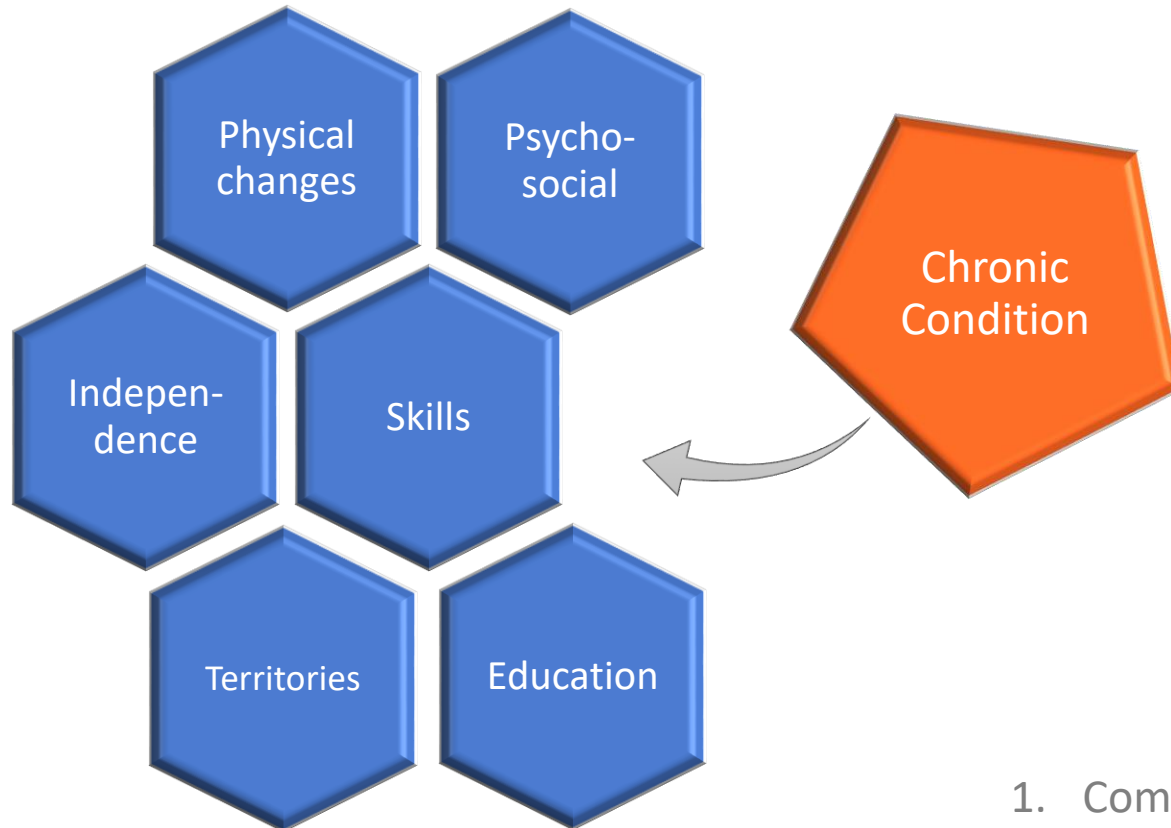
Andrea Limbourg, Hélène Mellerio, Paul Jacquin, Plateforme de transition AD'venir, Paris

ERN Hospital Managers Meeting 21 October 2021

Context :



Adolescence : a time of growth and change



In France: 10-15% of adolescents live with chronic conditions¹

2,25M children and adolescents live with rare diseases²

- Opposed to the priorities of young people
- Can have an impact on all aspects of life

1. Commission nationale de la naissance et de la santé de l'enfant, 2015

2. Plan maladie rare, 2018-2022

The challenges of transition



Leaving the paediatric clinic

- Like a family : protection, understanding, call backs
- Few complications
- Parental presence
- Fear of the unknown & of not being understood in adult clinics

Arriving in the adult clinic : sense of loss

- We don't choose to grow up or to have a CC
- Parents less present even if YP is still very dependent
- Seeing « old » patients, with complications
- Becoming aware of some limits : career, fertility...



Transition : a long process



Transition¹ ≠ simple transfer

- Introduced early
- Planned & structured
- Involving patient and family
- Staff training (specific needs of AYA)
- Coordinated continuity of care



1. Blum et al, J Adolesc Health 1993



Risks² of unplanned transition

- Jeopardy to health of adolescent
- Lost to follow up
- Poor health outcomes
- Increased hospitalisation, morbidity: care consumption, decreased QOL, graft rejection, mortality

2. Rachas et al, Plos one 2018

AD'venir

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AD'venir proposes :



Young people

- Transition-Preparation Consultations (TPC)¹
- « Transition days »
- Group workshops
- AYA committee
- Career guidance, orientation counsellor
- Zoom groups during confinement

Parents

- Support group during « transition days »

Both

- Information about transition (drop-in or phone)
- Psychologist consultations
- Website

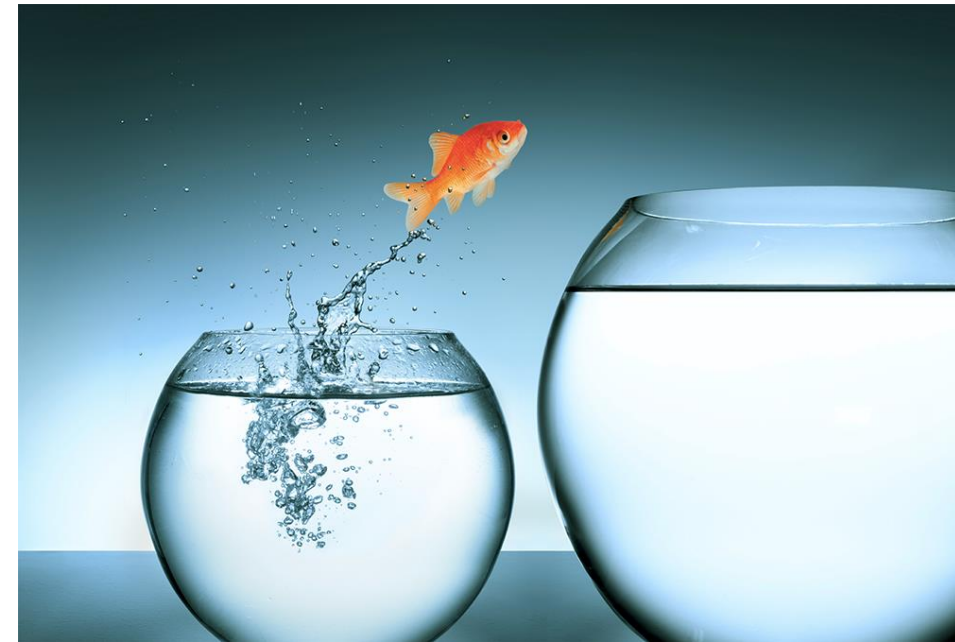
HCPs

- TPC feedback on their patients
- Collaboration on transition processes and research projects
- Information on research, continuing education

Going forward



- **Facilitate change in the health care system** to better take into account the specific needs of AYA:
 - employment – QOL – access to loans – fertility – physical activity
 - increasing awareness of HCPs: paediatric and adult clinics
- Continued work with **Patient organisations**
- **Implicating AYA directly** in driving change
- **Continued research** to evaluate outcomes of different transition strategies





**Thank you for your
attention!**

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