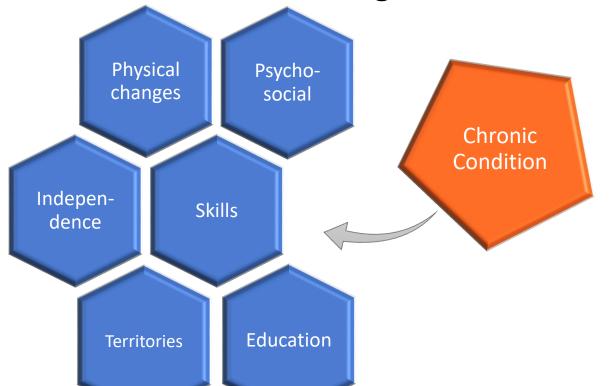


Andrea Limbourg, Hélène Mellerio, Paul Jacquin, Plateforme de transition AD'venir, Paris

## Context:



#### Adolescence: a time of growth and change



In France: 10-15% of adolescents live with chronic conditions<sup>1</sup>

2,25M children and adolescents live with rare diseases<sup>2</sup>

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

- .. 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 traning (specific needs of AYA)
- Coordinated continuity of care



1. Blum et al, J Adolesc Health 1993



#### Risks<sup>2</sup> 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









Adolescent, jeune adulte

pringer comme >



Parent, aidant & accompagnant



Professionnel

procesis son a victorie d'activit. Nide la prépare : con avenir la

Fer Yangmen >

IA 2 ATTROUBLE DE TRANSITION AND PRIS

#### Qu'est-ce que c'est AD'venir?

Unilleu et une équipe dédiés à l'accompagnement des jeunes de 15 à 25 ans vivont avec une malanie. chronique au moment qui passage de la pédiatrie aux services pour adultes.



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#### Pourquoi rejoindre la plateforme de transition AD'venir



je deviens autoname dans le traitement de ma maladie

- prospector is some.
- prospering year extracts shows je caráz i lengrapánez han agrar

Je prépare moit passage vers un hāpital gour adultes.

- Secreto transportante accessed accessos source attach
- utilità i dominica relationa ma internació
- MINISTRUMENT PROPERTY.

- Je prépare man avenir
- Deministration to be accessored
- Historiaa nets dram sacrap.
- Marginato deserbirar

Personal plants

#### Participer à un atelier



# AD'venir proposest

#### Young people

- Transition-Preparation Consultations (TPC)<sup>1</sup>
- « Transition days »
- Group workshops
- AYA committee
- Career guidance, orientation councellor
- Zoom groups during confinement

#### **Parents**

Support
 group during
 « transition
 days »

#### **Both**

- Information

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



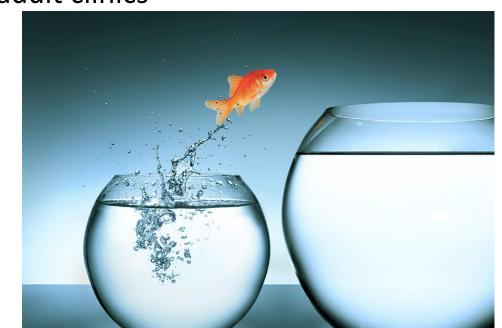
#### **HCPs**

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

1. Mellerio et al, Médecine/Sciences 2021



- 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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