

# THE DEVELOPMENT OF TRANSITION SERVICES IN RENAL CARE IN SYNERGY WITH YOUNG PATIENTS, PARENTS AND THEIR HEALTH CARE PROVIDERS: A CO-CREATIVE DESIGN STUDY

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## BACKGROUND

- Healthcare transition to adulthood = challenge for adolescents and young adults (AYA) with chronic kidney disease (CKD)
- Crucial for successful transition:
  - Fit of transition programme with needs of patients and their parents
  - Involvement of all stakeholders in development of programme

## SETTING

Renal Division of Ghent University Hospital (± 170 patients between 12-18 years old)

## AIM

To co-develop with all stakeholders a transition program that:

- Enhances self management of young persons with CKD
- Enables HCP's to enhance transition outcomes

## FINDINGS

"We have to **strive for independence** and that is a process that **both parents and the adolescent** must go together." (*adult care nephrologist*)

"The success of transition and transfer often depends on **the family situation and context**." (*psychologist*)

"The **timing** of the transfer was determined unilaterally without consulting me. I felt not ready." (*AYA*)

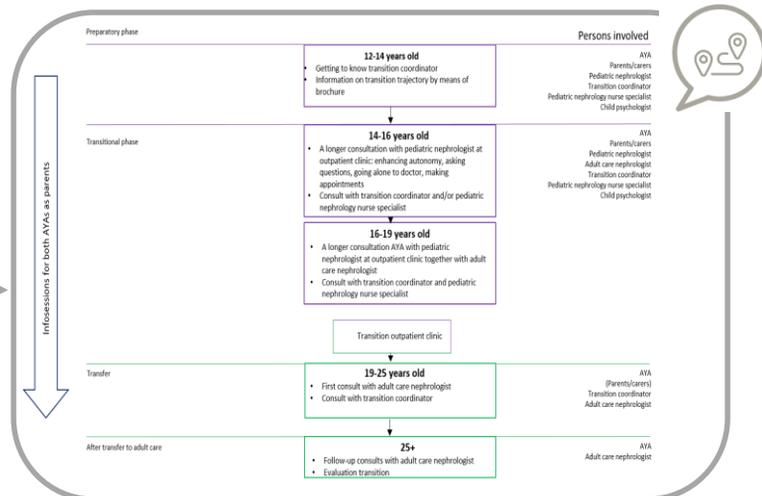
"**Dialogue** with the parents is crucial. You need to be supported in gradually **taking a backseat**." (*parent*)

## CORE ELEMENTS OF TRANSITION PROGRAMME

- The AYA as the main focus
- Involvement of the parents
- Holistic approach
- Flexibility of trajectory
- Forward-looking approach
- Continuity in guidance and follow-up

## METHODS

- Review of best practices and realist review to identify success factors, what works, for whom and in what circumstances
- Understanding the current state of transition practice in the renal division by means of:
  - Semi-structured interviews
  - Focus groups
- Development of a community of practice by means of a working group incorporating HCPs of both paediatric and adult side:
  - Drafting a shared vision statement
  - Co-design of components of transition programme



## CONCLUSION

The development of the transition programme as a multi-actor process was challenging, but worthwhile as it provided much needed insight in experiences of current practice and existing gaps. The bottom-up approach will hopefully contribute to a successful transition and transfer to adult care. Follow-up studies and evaluation of the trajectory post-implementation are underway.