

# Transitional care in the French network for rare malformations of the head, neck and teeth: results of a national survey

Pavan S., de Chalendar M., Ben Aissa I., Medjahed S., Calatayud A-L., Leboulanger N., Members of the TETECOUCO coordination team and patient representatives

Filière de Santé Maladies Rares des Malformations de la Tête, du Cou et des Dents (TETECOUCO)

## 1 Background

The French rare disease network for malformations of the head, neck and teeth (Filière TETECOUCO) is composed of 104 expert centers and covers more than 2,100 conditions, often diagnosed before or at birth. The care pathways mostly take place from birth till the end of growth, but variable impact remains during adulthood and some conditions require follow-up: additional surgery, dental issues, psycho-social support, etc.

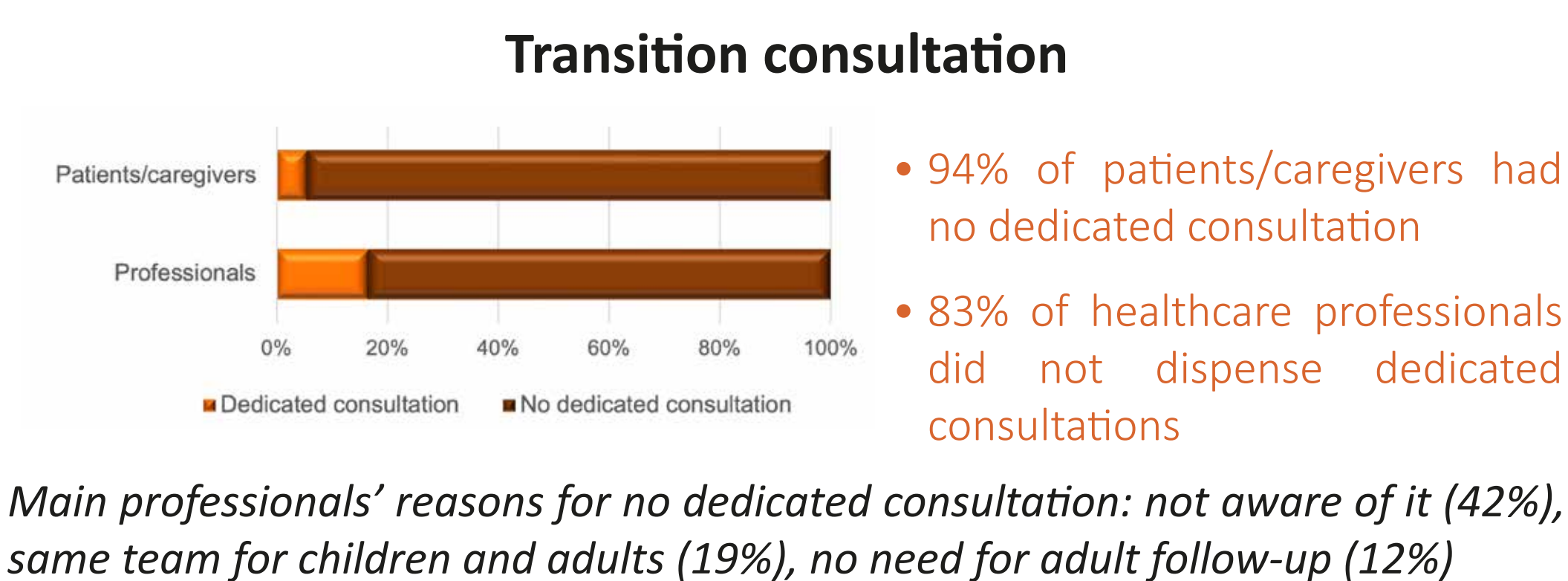
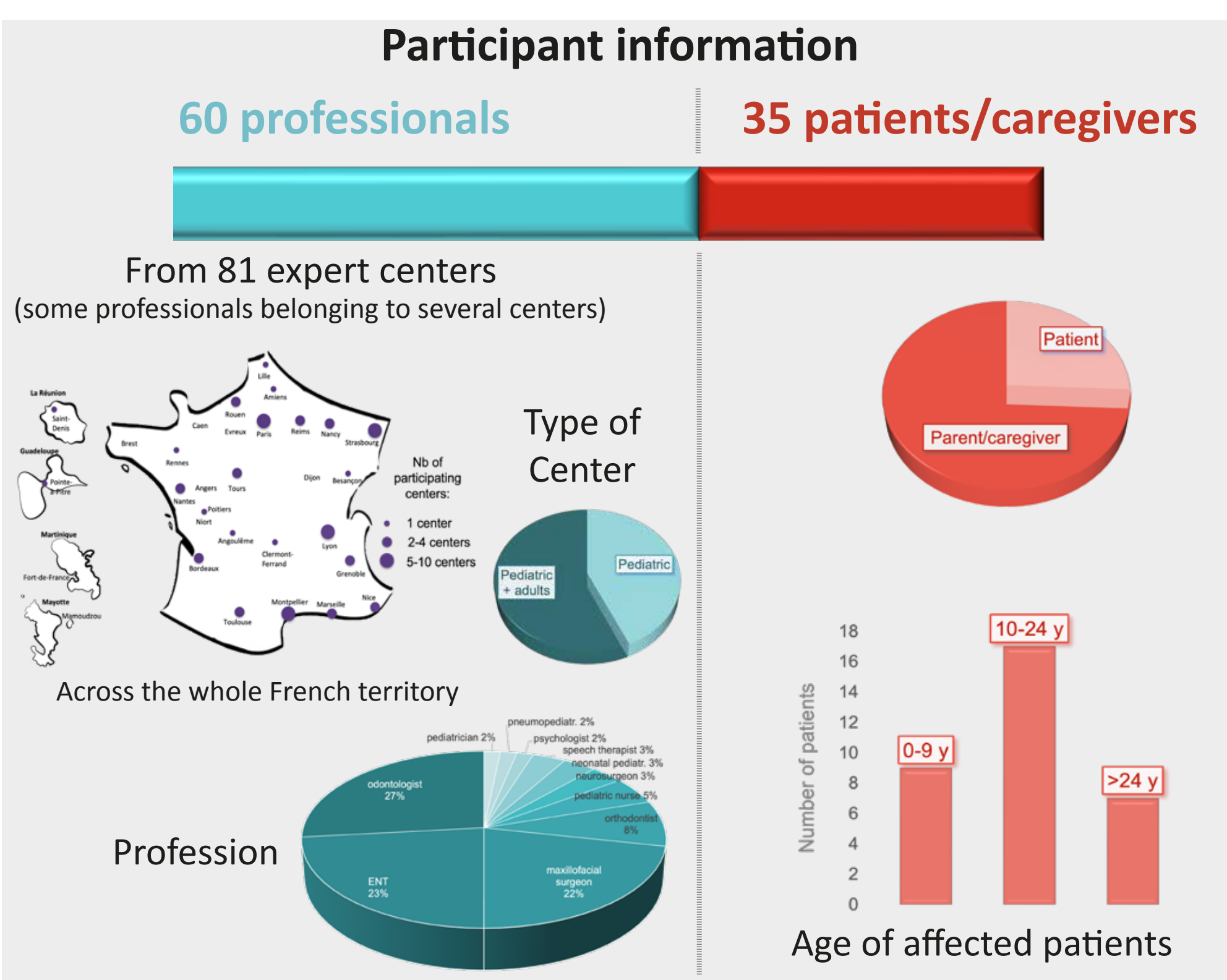
## 2 Purpose

- To characterize patients and caregivers perception, knowledge and needs for the transition period
- To characterize practices and needs of expert healthcare professionals regarding the transition period
- To identify targeted actions that could be carried out to improve the transition care

## 3 Method

- Drafting of two surveys :
  - for healthcare professionals of our expert centers
  - for patients and their caregivers
- Input from representatives of patient organizations
- Circulation by Email campaign and social networks, to healthcare professionals from TETECOUCO expert centers and partner patient organizations
- Answers collected from Aug. 2023 to April 2025
- Results analysis

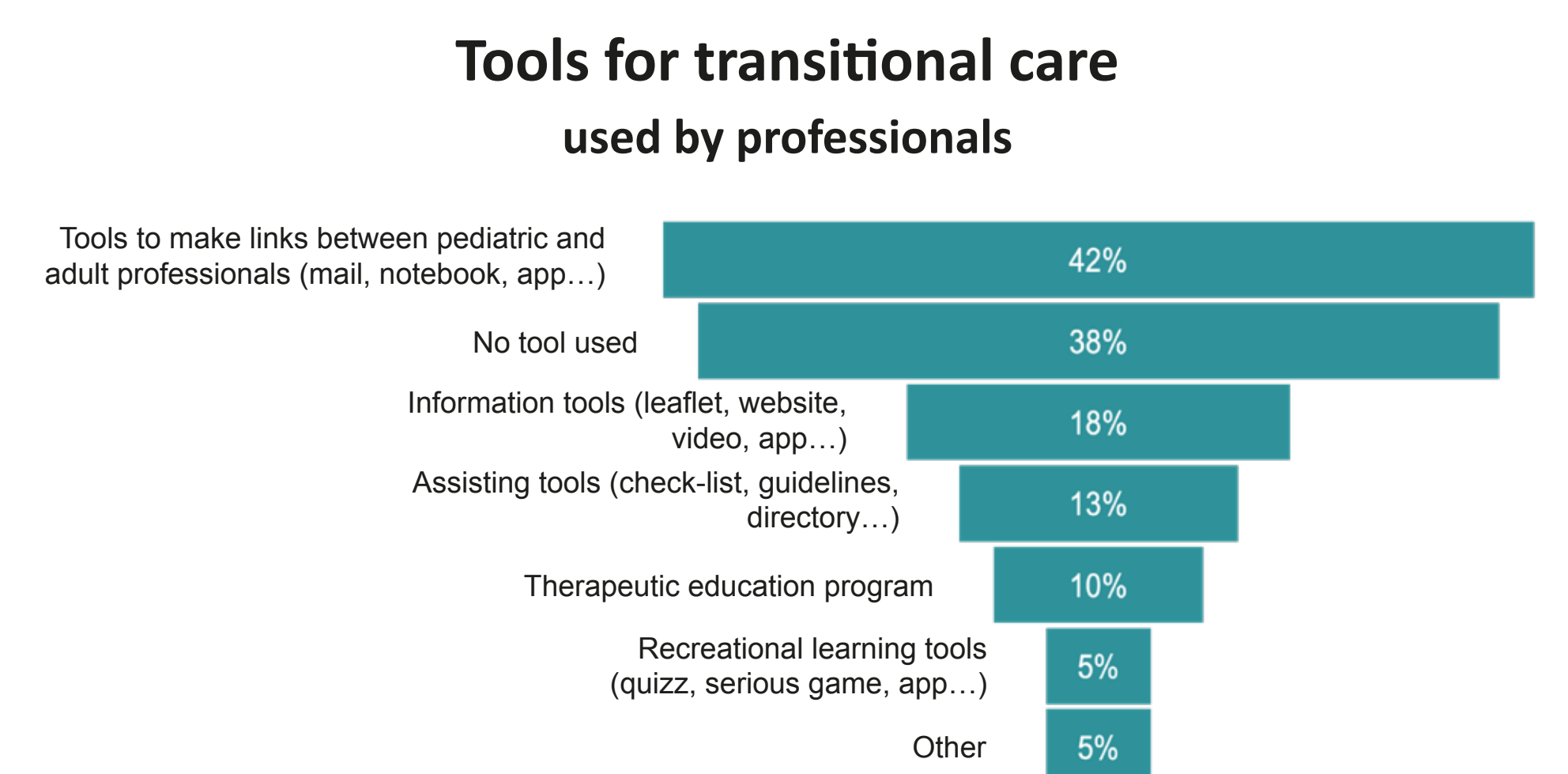
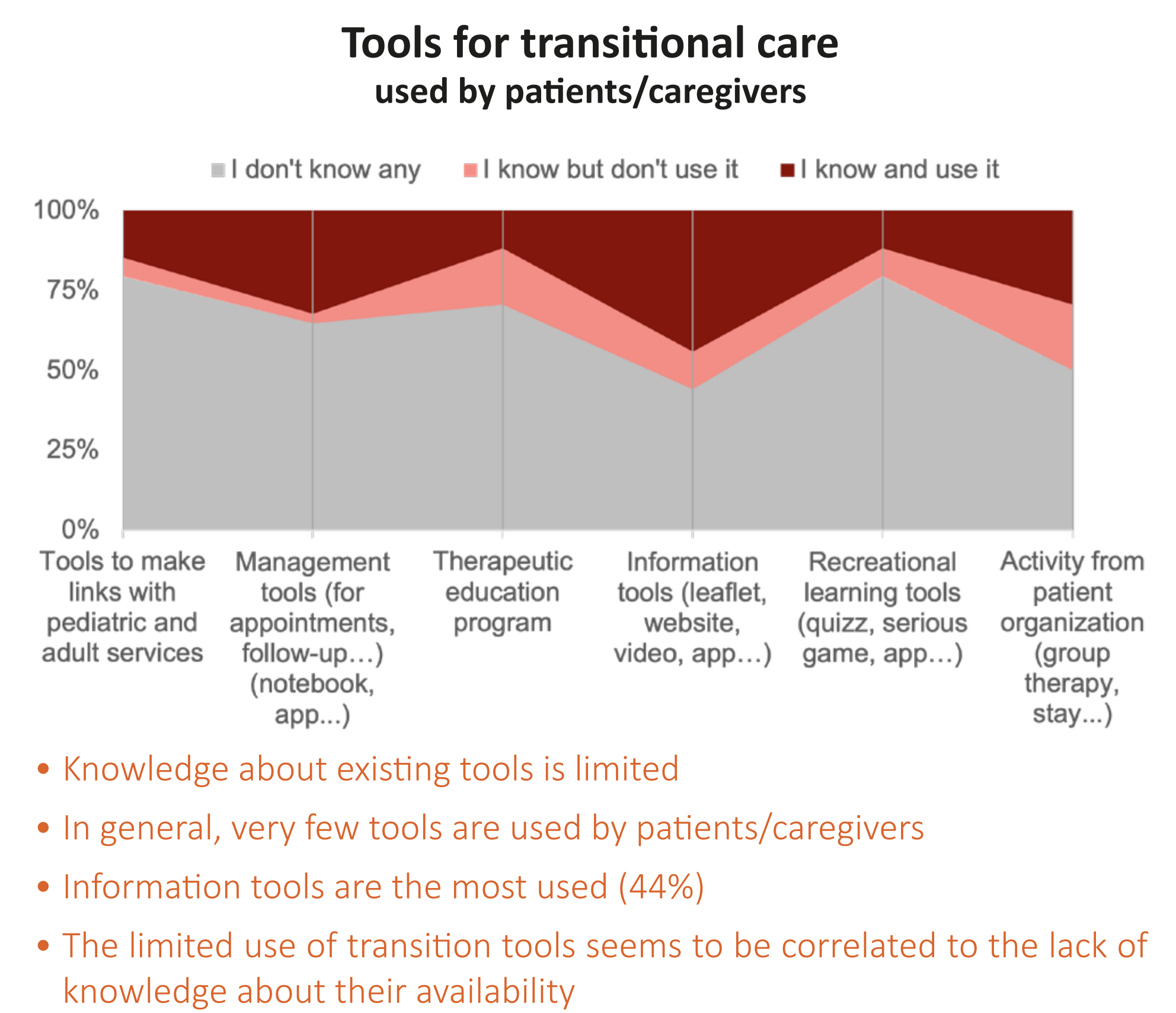
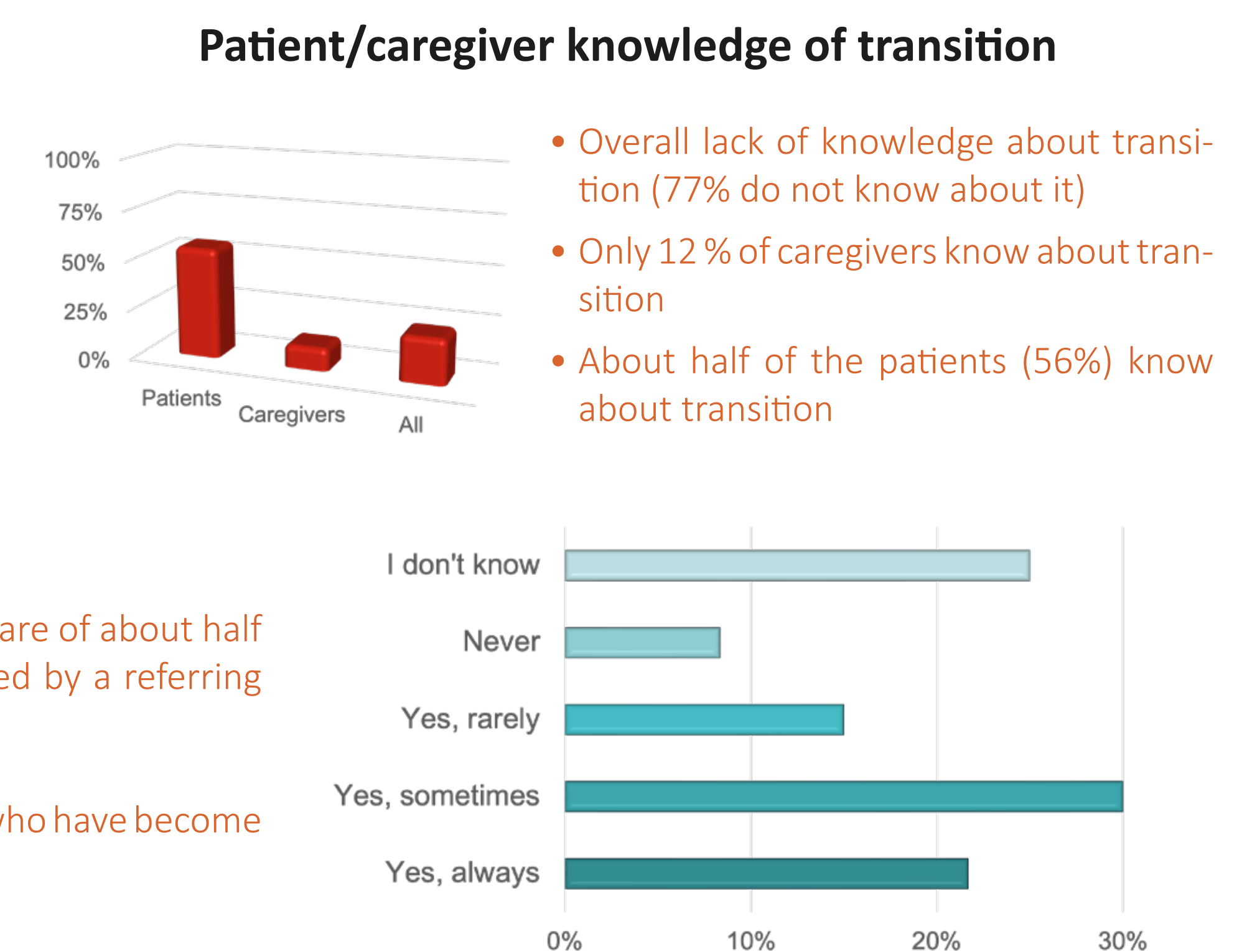
## 4 Results



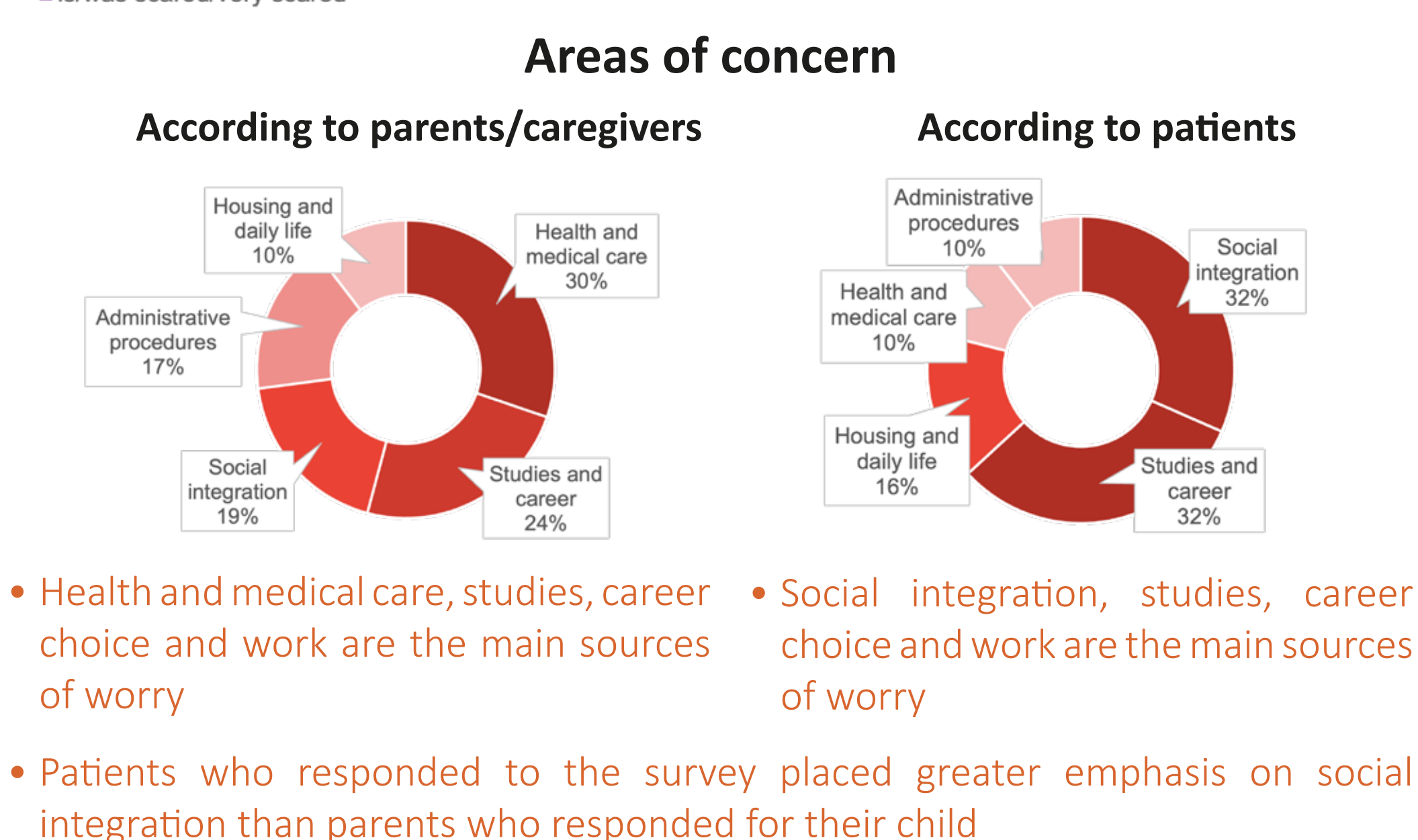
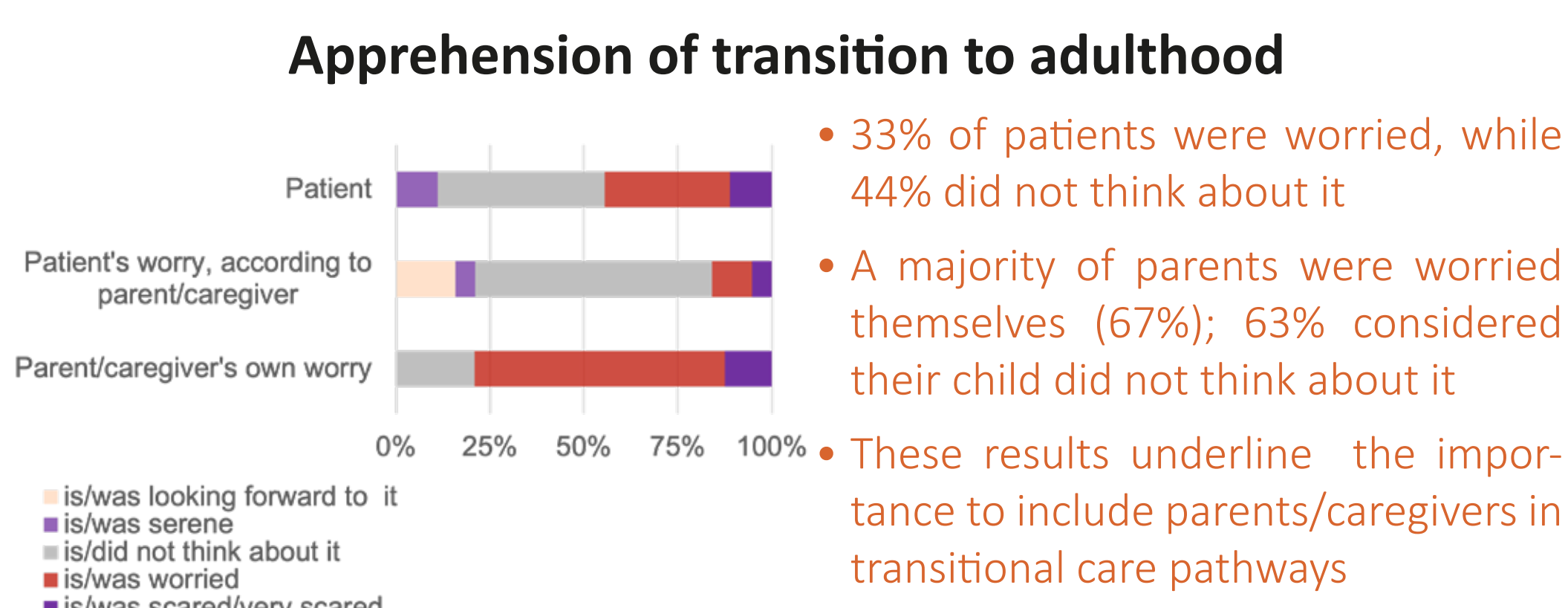
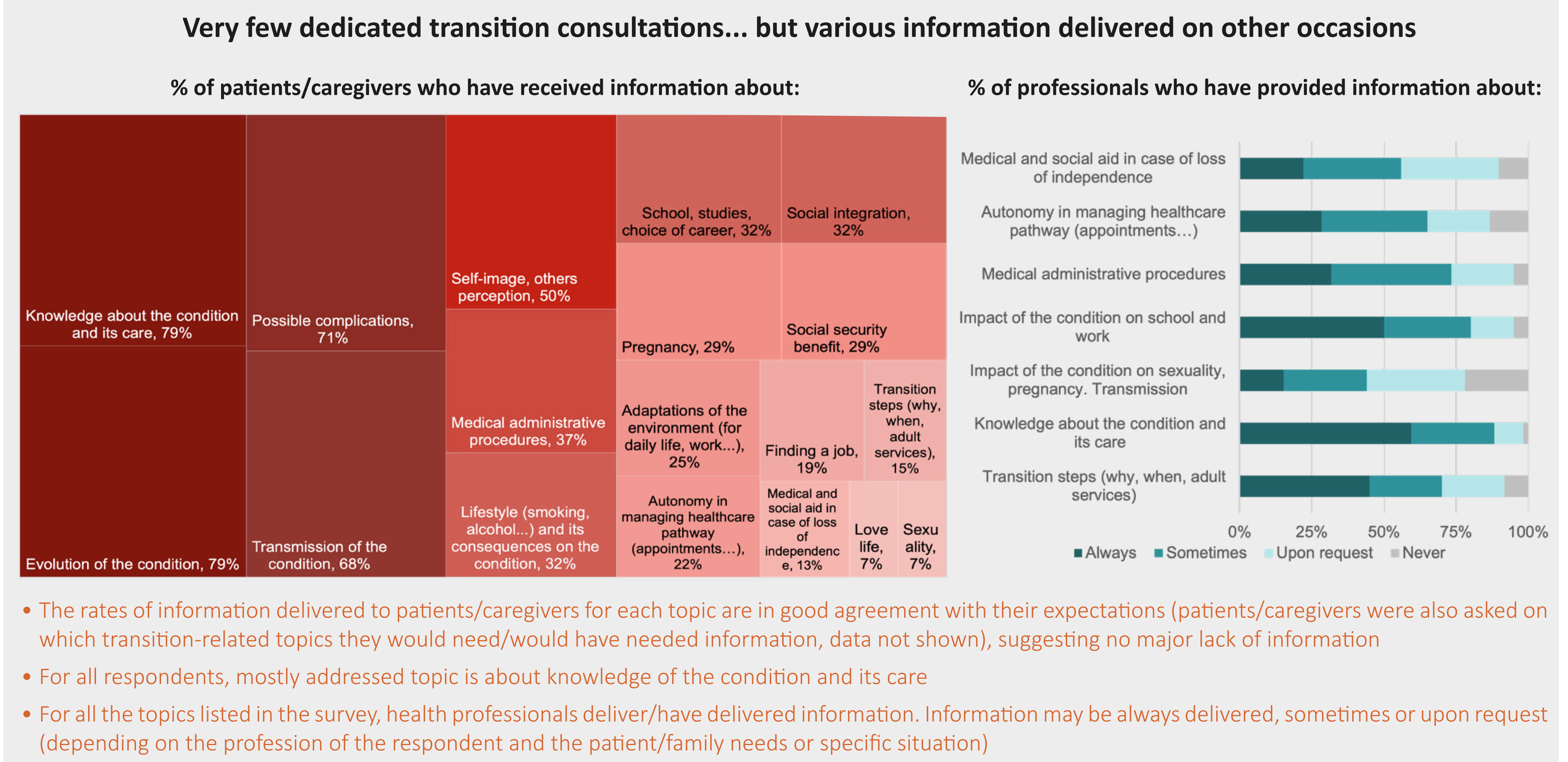
### Adult care coordination

Professionals answers

- According to professionals from pediatric services, the care of about half of their patients who have become adults is coordinated by a referring professional (always 22%, sometimes 30%)
- Additional results (data not shown): 75% of the patients who have become adults declared having no coordinating professional



### Professionals would be interested in...



## 5 Conclusions

For both patients/caregivers and professionals, there is an overall lack of knowledge about the transition process and the available resources. There is a need for additional tools and for more interaction with patient organizations.

These results allowed us to develop new, more targeted, actions. Educational actions have been initiated to raise awareness among professionals, and will continue (seminar, podcast, information on our website...). Impact of these actions will be evaluated in a future survey.

Beyond these results, the survey itself and its restitution during a TETECOUCO national workshop have allowed to raise more awareness among health professionals about all the aspects of the transition process and about the available tools.

