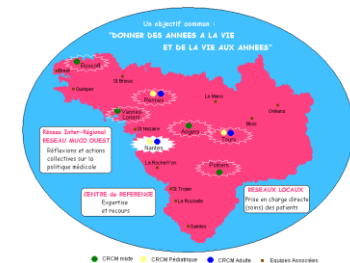


Adolescence and cystic fibrosis

Improving the median FEV1% by reinforcing Therapeutic Patient Education in the course of a quality improvement program

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Introduction

- Adolescence is a period at high risk for FEV1 decline
- As in all chronic diseases, adolescents with CF have more or less serious difficulties for treatment monitoring and have a drop in motivation to take care of themselves
- These difficulties may have a negative effect on their respiratory status.

Nantes CF Centre engaged in the QIP PHARE-M in 2011

- French QIP pilot phase :
 - implement and adapt the CF Foundation LLC QIP
 - explore synergies between TPE and QIP
 - in order to reinforce mutual efficacy
- Therapeutic Patient Education culture is our “pattern” :
 - TPE activities are an essential part of the process of care delivered in the Paediatric CF centre
 - Thus the Team engaged in PHARE-M to sustain the implementation of TPE activities

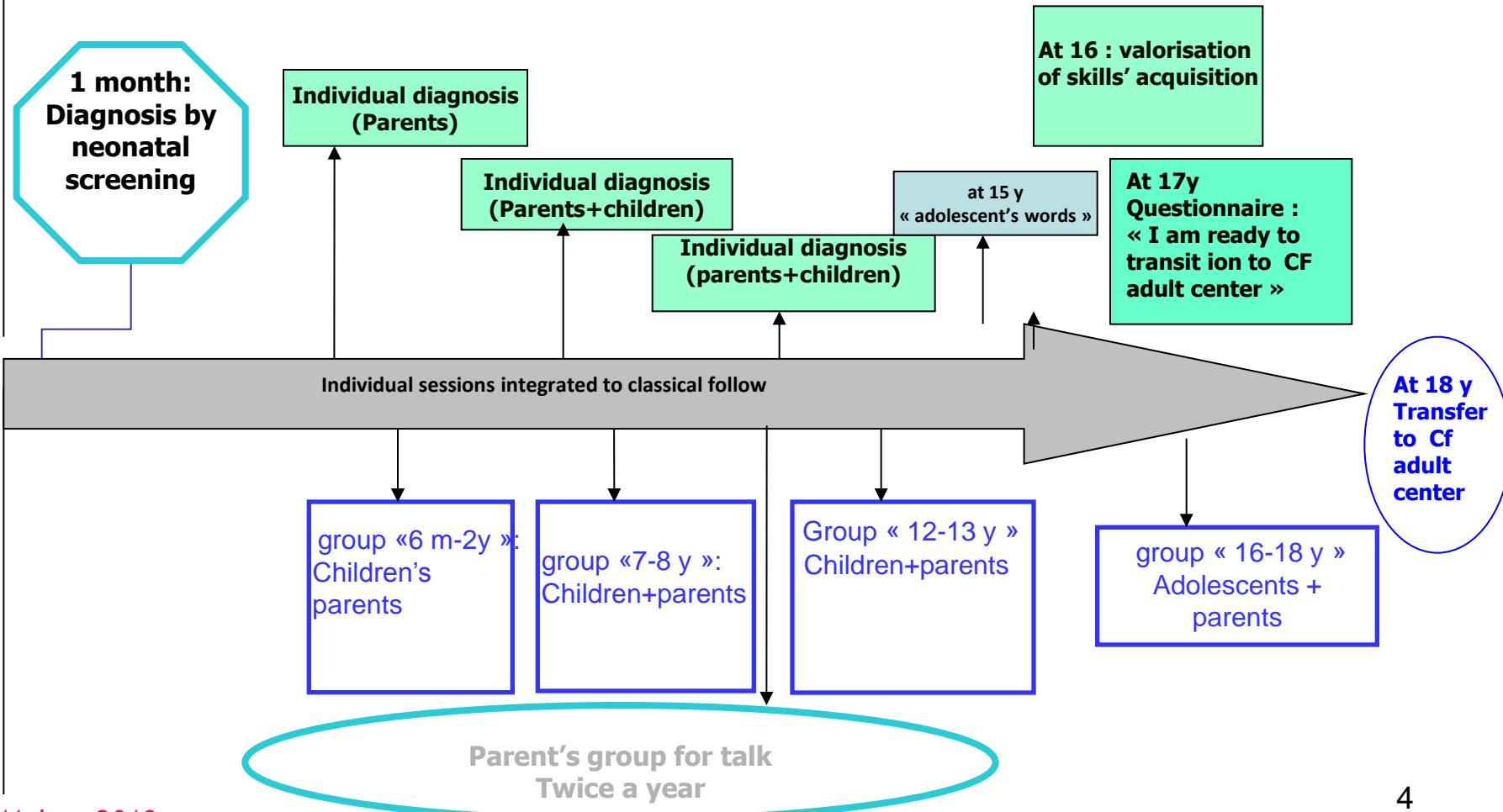
« becoming competent with growing » Therapeutic education program



Interdisciplinary team : physician, nurses, physiotherapist, dietician, psychologist, social worker, art-therapist,

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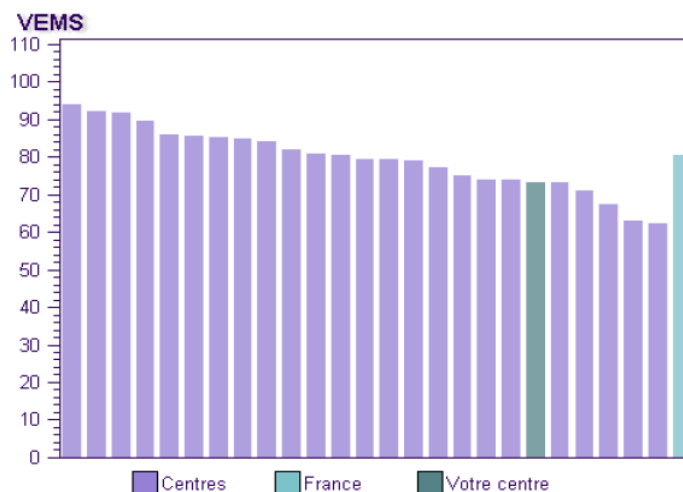


Step 1 : 5P analysis of the CF centre

Patient outcomes : median FEV1 in our center was close to the worst for patients aged 13-18 (*French Patient Registry - data 2010*)

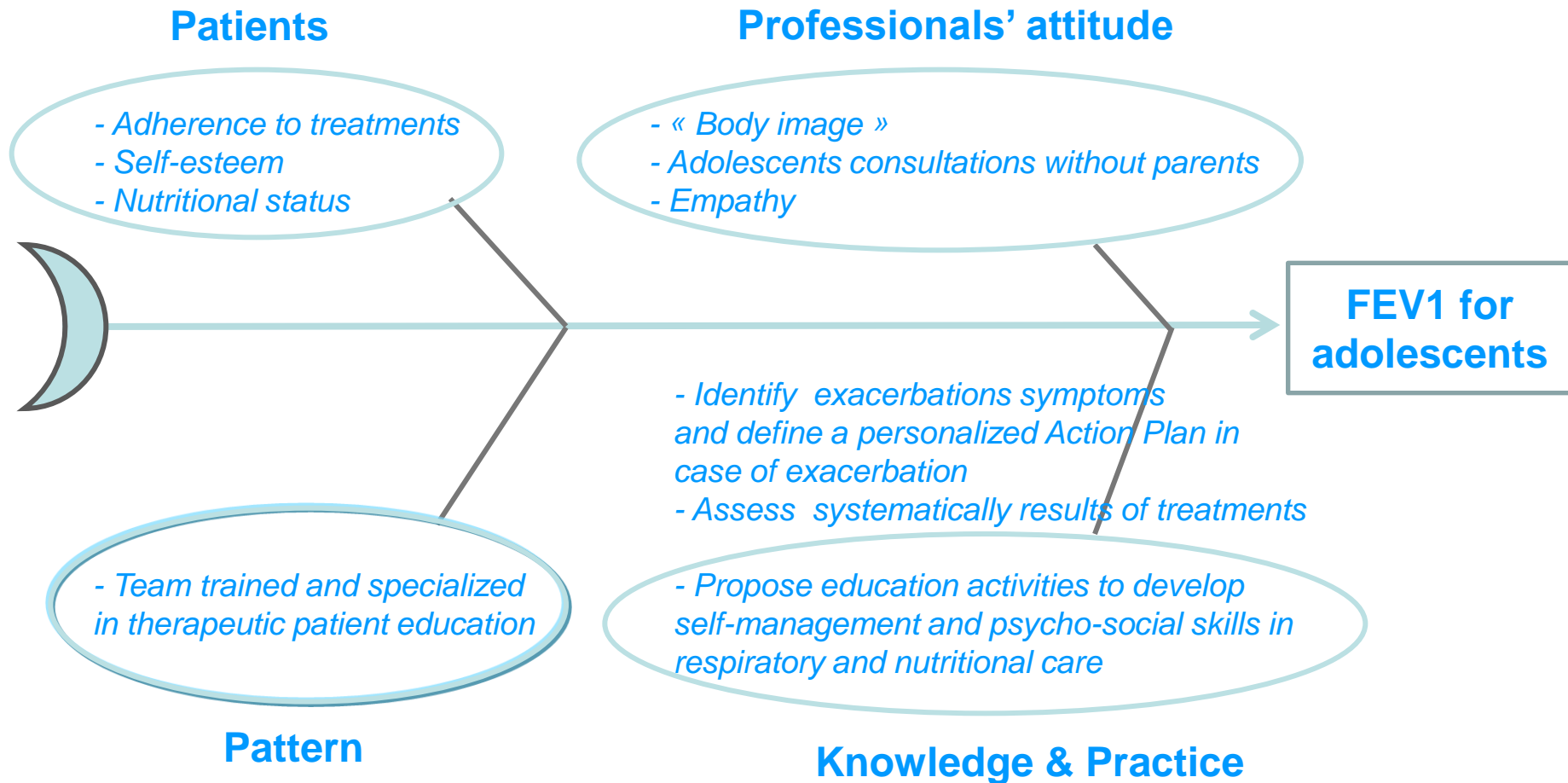
~~~~ VEMS médians - patients de 13-17 ans ~~~~

⊕ Figure 14. VEMS médians par centre



→ **Objective** : Improve the median FEV1 % of adolescents aged 15-18 years by 5% in 4 years (from 78% to 83%)

# Step 2 : fishbone points out the need to pay more attention to the ado's « body image »

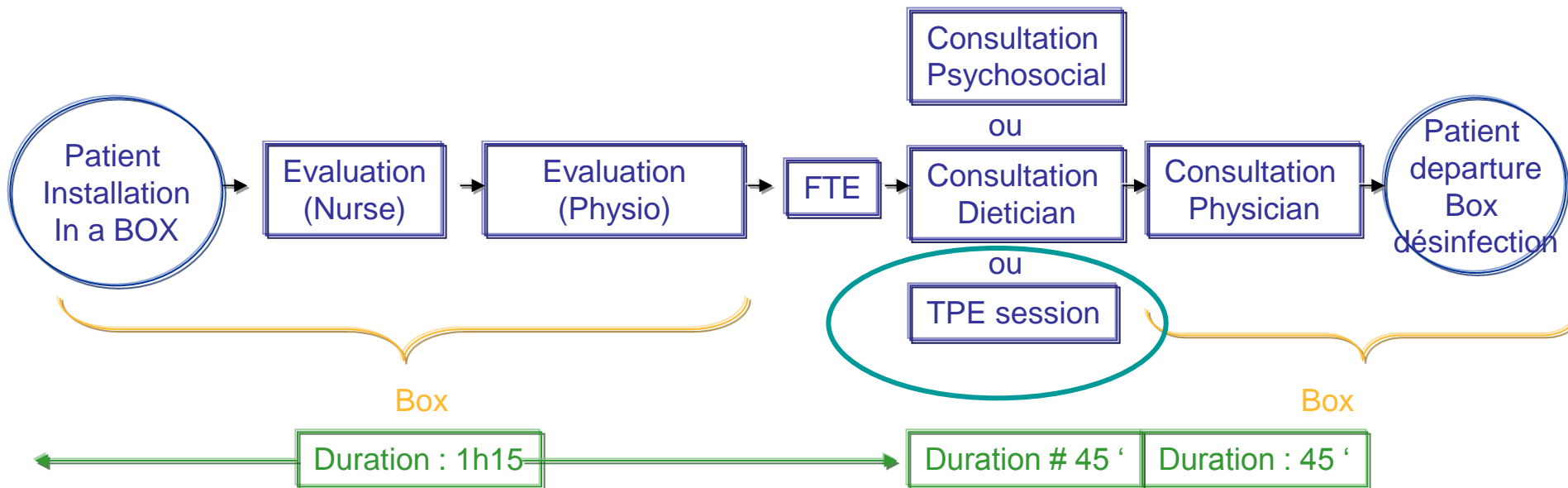


# Step 3 : display “Measures That Matter”

- A systematic multi-disciplinary review of every Ado’s situation allowed to fix priorities for education and health outcomes
- Each Metric and its goal was assigned to a professional in the multidisciplinary team

| Number of patients who:                                                                                                              | Name of the professional               | date | date | date |
|--------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|------|------|------|
| <b>Attended TPE sessions<br/>Have done the “Overall assessment of skills acquired”</b>                                               | <b>nurse</b>                           |      |      |      |
| <b>Have learned lung drainage<br/>Regularly practise exercise</b>                                                                    | <b>physiotherapist</b>                 |      |      |      |
| <b>Use an exacerbation plan<br/>Discussed on topics including alcohol, tobacco, fertility and sexuality, motivation to treatment</b> | <b>doctor</b>                          |      |      |      |
| <b>Filled out a quality of life-anxiety-coping-depression questionnaire</b>                                                          | <b>psychologist</b>                    |      |      |      |
| <b>Have learned the importance of high caloric intake</b>                                                                            | <b>dietician</b>                       |      |      |      |
| <b>Have realised art –therapy(non-verbal expression)<br/>Patient professional project, hobbies, social rights awareness</b>          | <b>art therapist<br/>social worker</b> |      |      |      |

# Step 4 : clinic visit process review





● = I am in the box

● = I have finished and I call the next professional

| Salle       | 3        | 4                           | Bureau psy | HDJ                     | Autres | Indisponibilité                                                                       |
|-------------|----------|-----------------------------|------------|-------------------------|--------|---------------------------------------------------------------------------------------|
| Patient     | Emma     | Océane                      | Lydia.     | JULIETTE                | KFE    |                                                                                       |
| IDEC        | ● ●<br>1 | ● ●<br>1                    | ●<br>3 ←   | ●<br>108F [BA]          |        | <b>Mardi</b><br>KINE : 9 <sup>h</sup> - 10 <sup>h</sup>                               |
| KINÉ<br>EFR | ● ●<br>4 | ● ●<br>3                    |            | Demo Colobreatte        |        | Pauline : 7008A                                                                       |
| PSY         | ● ●<br>2 |                             | ●<br>Maman | ● ●<br>HISTOIRE au P30. |        | <b>Mecredi</b><br>KINE : 13 <sup>h</sup> 30 - 15 <sup>h</sup><br>art-Thérapeute : A-M |
| DIET        | ● ●<br>3 | ●                           |            |                         |        |                                                                                       |
| A.S         | ● ●      | ● ●<br>ETP d's sociaux<br>2 |            | ●                       |        | <b>Vendredi</b><br>KINE : 15 <sup>h</sup> 30 - 16 <sup>h</sup> 30                     |
| Médecin     | ●<br>5   |                             | ● ●<br>4   |                         |        |                                                                                       |
| Stagiaire   |          |                             |            |                         |        |                                                                                       |
| IDE RC ETP  |          |                             |            |                         |        |                                                                                       |
| ART-THERAP  |          |                             |            |                         |        |                                                                                       |
| APA         |          |                             |            |                         |        |                                                                                       |

# Results

The primary objective was met and even exceeded by the end of 2015, as the median FEV1 of patients aged 15-18 years reached 90%

|                        | <b>2011<br/>N=26</b> | <b>2012<br/>N=23</b> | <b>2013<br/>N=23</b> | <b>2014<br/>N=23</b> | <b>2015<br/>N=26</b> |
|------------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| <b>Median<br/>FEV1</b> | 75%                  | 86%                  | 87%                  | 82%                  | 90%                  |

## Other results:

Patient satisfaction with the creative and sports activities offered was high

The team got involved immediately, cohesion around the project was strong, and the psychologist was heavily enlisted

# Conclusion

The monitoring of educational goals was enhanced in the course of the QIP. This helped achieve the objectives in terms of health outcomes and self-management for adolescents before transitioning to the adult program

TPE and QIP, combined for the best, were able to improve the health indicators of CF Ados in our CF center

As Bruce Marshall wrote in the British Medical Journal in 2014: « we suggest that the **aggregate effects** of these **combined efforts** — a widely available and transparent patient registry, benchmarking of best improvement practices, active involvement of patients and their families in improvement initiatives, and dissemination of improvement methodologies among CF healthcare professionals — may be transferrable to improving care for others with serious chronic illnesses »