



# Evaluation of transplantation information delivered to patients and their relatives by the professionals from Cystic Fibrosis centres and Transplant centres and from transplanted peer-patients in France

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# Objectives

Describing when and which transplantation information is delivered by CF teams, by professionals in transplant centres and by peer-patients, to CF patients and their relatives

## Starting from the publication...

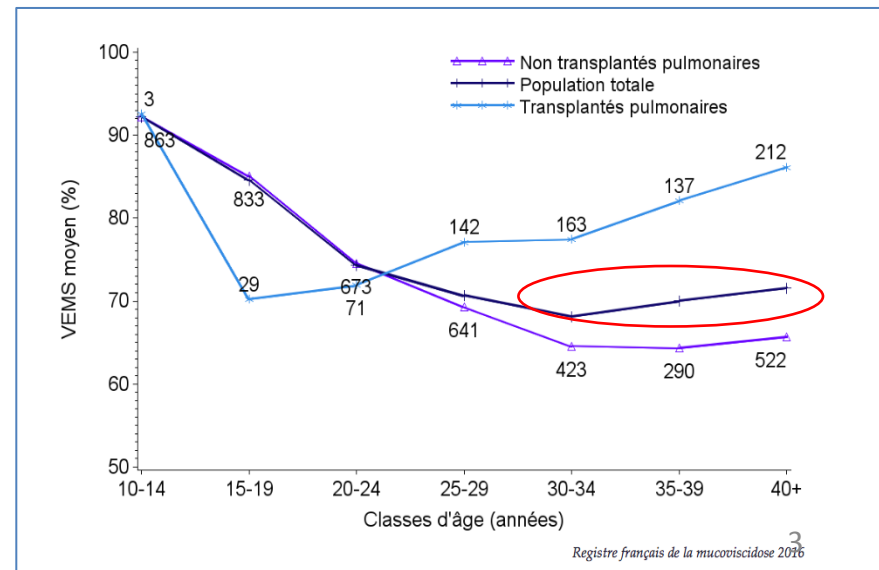
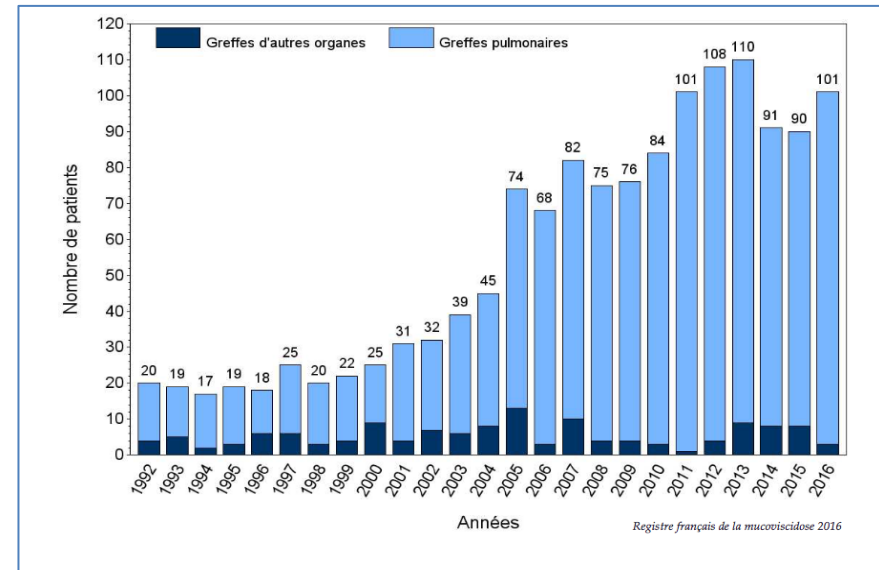
[J Cyst Fibros.](#) 2016 Mar;15(2):204-12. doi: 10.1016/j.jcf.2015.09.002. Epub 2015 Sep 26.

**Causes of death in French cystic fibrosis patients: The need for improvement in transplantation referral strategies!**

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# Context – Patient Registry Data 2016

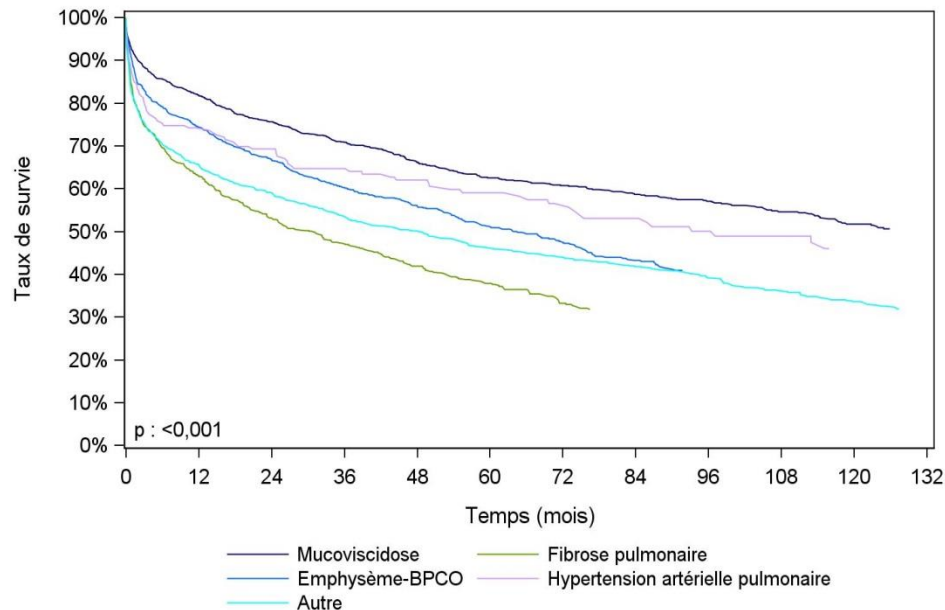
- 6757 patients in the French Registry - **54,5% Adults**
- 807 transplanted patients alive (all organs) - 12%
- **101 pulmonary Transplantation (TxP)**- mean age 31
- 725 TxP Adult Patients - **20% of Adults**
- Impact on mean FEV1 in the French Registry
- 51 CF Patients died in 2016 :
  - 11 deaths post TxP
  - 26 more deaths of TxP Patients
  - **14 deaths of non TxP Patients**



# Context - Transplantation is supported 100% by the French public health system

- All CF patients can be addressed timely to a transplant centre by their CF Team
- All patients can be transplanted if matching the criteria (clinical and mental)
- One transplant centre for CF children and 7 transplant centres for CF adults
- Average waiting time on the national waiting list varies from about 3 months to 3 weeks depending on the transplant centre

Survival Post Transplantation by disease  
France: 1993 – 2015  
(Agence de Biomédecine)



# Methodology

- A multidisciplinary group including professionals in CF centers and in transplant centers, patients and parents and statisticians, defined **three types of questionnaires** aimed at each of the 3 categories of population interviewed :
  1. healthcare professionals
  2. patients and their relatives
  3. peer-patients, defined as patients transplanted within the last 2 years who were solicited to share information with patients on the transition to transplant
- Descriptive and statistical cross-analysis were conducted to compare the information delivered by the professionals and peer-patients and the information received by patients and their relatives.

# Results from all responses to questionnaires

- Based on 217 questionnaires collected from multidisciplinary professionals, 55 questionnaires from patients, 30 from their relatives and 17 questionnaires from peer-patients, it appears that :
  - **little information is provided at the time of newborn or later diagnosis** and it is only in response to questions asked by patients or their relatives
  - **no systematic information is given during the course of the disease**, before the patient's health worsens
  - **Treatments' intensification to avoid transplantation is almost never discussed**
  - Information provided when the patient is referred to the transition to transplant relates to :
    - the expected **benefits** of transplantation,
    - **anti-rejection treatments and their side effects**,
    - **precautions regarding fooding after transplant.**
  - More rarely it addresses **procreation** after transplant, back to **studying / working and social life.**

# Specific results from patients', their relatives' and Peer-Patients' responses to questionnaires

- Patients and families ask for **more comprehensive information** about the course of the disease **including transplantation** and new therapies, soon after the diagnosis is given and as and when the evolution of their health status
- **Meetings with peer-patients are recognized very important by patients entering the transition to transplant** but should be more prepared and organized, including **support for the peer-patient**.

# Discussion

Recommendations are being prepared **to improve the information process to patients and their relatives about transplantation** at key moments in the course of the disease, addressing Professionals' attitudes and representations and supporting Peer-Patients interventions.



# Need for **general information**

## 1. Professionals should all have minimum knowledge about transplantation

- a **booklet** specifically on TxP distributed to all professionals in all CF centers
- **e-learning for professionals is being prepared**
- a **CF specific University Degree** (for both patients and professionals) will include global knowledge on the disease from neonatal screening to transplantation and patient education

## 2. Patients should be given information on the treatments

- the booklet called “**Registry, a tool for Quality Improvement**” (providing information on transplantation, anticipated decisions on new therapies) **should be largely distributed to patients and discussed with the care team**
- **A Mooc for patients and families is under consideration**



# Need for individualized specific information given during the course of the disease since pediatrics

3. Opportunities should be regularly offered to the patient and their relatives to ask questions about transplantation :

→ 1st tool to help the patient express his fear or need for information

4. The delivery of information on transplantation should be anticipated from the first identified warning signs.

→ 2nd tool to help the patient and the CF doctor share the same representation of the patient health status when worsening

→ 3rd tool to help the patient understand the criteria for transplantation and discuss the transition process

**GETHEM**

**Symptômes**

**Traitements pour la nutrition**

**Traitements respiratoires**

**Des mots pour le dire**

Date : .....  
 Nom du médecin : .....  
 Etiquette patient

Parmi les thèmes suivants, cochez ceux que vous aimeriez aborder lors de vos prochaines consultations avec le médecin. Parmi les mots cochés, entourez les 3 auxquels vous donnez le plus d'importance.

**VIE SOCIALE ET FAMILIALE**

- ☐ Famille
- ☐ Couple
- ☐ Enfants
- ☐ Amis
- ☐ Rencontres amoureuses
- ☐ Conduites à risque
- ☐ Avoir un enfant
- ☐ Parler de la maladie

**VIE SOCIOPROFESSIONNELLE**

- ☐ Études / Travail
- ☐ Stage à l'étranger
- ☐ Absentéisme
- ☐ Droits sociaux
- ☐ Revenus
- ☐ Mutuelle
- ☐ Transports

**VIE SEXUELLE**

- ☐ Libido
- ☐ Image du corps
- ☐ Essoufflement
- ☐ Contraception
- ☐ Positions de confort
- ☐ Maladies sexuellement transmissibles / VIH
- ☐ Douleurs

**RESSENTI PSYCHOLOGIQUE**

- ☐ Moral
- ☐ Estime de soi, regard de l'autre
- ☐ Sentiment d'efficacité
- ☐ Motivation
- ☐ Anxiété
- ☐ Ras le bol

**SYMPTÔMES GÉNANTS LIÉS À LA MALADIE**

- ☐ Douleurs
- ☐ Fatigue
- ☐ Qualité du sommeil
- ☐ Fuites urinaires
- ☐ Gaz
- ☐ Selles odorantes
- ☐ Constipation/diarrhée
- ☐ Toux
- ☐ Crachats
- ☐ Mycoses

**LA VIE QUOTIDIENNE**

- ☐ Courses, tâches ménagères
- ☐ Temps de repos
- ☐ Planification activités/soins
- ☐ Hygiène
- ☐ Autonomie
- ☐ Temps de repas

**LOISIRS**

- ☐ Activités
- ☐ Sports
- ☐ Coûts
- ☐ Vacances
- ☐ Séjour à l'étranger

**Traitement**

- ☐ Difficultés de suivi/oubli
- ☐ Arrêt
- ☐ Allègement des soins
- ☐ Organisation de l'approvisionnement
- ☐ Efficacité
- ☐ Effets secondaires
- ☐ Évolution de la maladie et devenir
- ☐ Aide médicale à la procréation
- ☐ Transplantation
- ☐ Avancées médicales, recherche

**PROJET**

- ☐ Personnel
- ☐ Professionnel
- ☐ Autre

**AUTRES**

Quels sont les thèmes abordés par les soignants que vous trouvez inutiles/répétitifs ?  
 .....  
 Objectif(s) à travailler la(s) prochaine(s) fois : .....

Cela peut être aussi gestion.

Document créé par le GEM. Journal of Cystic Fibrosis 2013 (Communication orale, 3e ECTS Conférence, Ljubljana, Novembre 2013)

# Need for **individualized specific information** given during the course of the disease

- 5. At the same time as treatment intensification is discussed with the patient psychosocial issues should be addressed to take in account the patient life project and preferences**
- 6. Exchange days between transplant centres and CF centers that refer patients for transplantation ("satellite to Transplant centres") must be organized to**
  - reinforce communication between the teams about the referral process**
  - specify the role of each team in the information given to the patient**
  - integer Peer-Patients, their role in the information to patients and the support given to them**

# Conclusion : need for improvement in information and education strategies!



Thanks to Patients and Professionals in the GETHEM  
&  
Thank you for your attention...

...If you have any questions we'll be happy to answer them!

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