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# Involving patients and healthcare professionals in intervention development: a participatory approach to improving medication adherence in cystic fibrosis



F. Mougeot<sup>1</sup>, M. Viprey<sup>2,3</sup>, P. Occelli<sup>2,3</sup>, I. Durieu<sup>3,4</sup>, H. Rouzé<sup>2</sup>, A. Dima<sup>3</sup>, Q. Reynaud<sup>3,4</sup>, S. Touzet<sup>2,3</sup>

<sup>1</sup> Centre Max Weber, UMR 5283, Lyon, France; <sup>2</sup> Hospices Civils de Lyon, Public Health Department, Lyon, France;

<sup>3</sup> University Claude Bernard Lyon 1, HESPER Lab - EA 7425, Lyon, France; <sup>4</sup> Hospices Civils de Lyon, Centre Hospitalier Lyon Sud, Adult Cystic Fibrosis Care Center, Pierre Bénite, France

## Background and aim

Cystic fibrosis (CF) is an inherited and life-shortening disease involving significant treatment burden. Few interventions have been developed to improve medication adherence of CF patients with limited results. Involving patients and providers in intervention development is recommended for improving effectiveness and intervention adoption in routine care.

## Purpose

A participatory approach involving patients, health care professionals (HCP) and researchers was used to co-construct an adherence-enhancing intervention program in the CF reference medical center of Lyon (France).

## Methods

- **6 focus groups** were conducted at 4-week intervals
  - 2 initial sessions focused on **sharing experiences of CF treatments** to identify determinants of adherence
  - 4 subsequent sessions to **develop solutions and tools to target key determinants**
- Participants: **1 physician, 1 nurse, 1 physiotherapist, 7 patients and 2 researchers** (sociologist, public health pharmacist)
- Researchers produced supporting materials and discussion logs to guide co-construction according to research evidence and record qualitative results
- A qualitative analysis of group dynamics during intervention development was performed

## Results

- **Participatory approach**
  - All participants attended each session, except for 2 sessions where 1 patient was absent
  - Patients, HCPs and researchers contributed equally to the focus groups: the exchanges were balanced in terms of time and content
  - The process created a cohesion in the group and members expressed their wish to continue to exchange between each other after the intervention development
- **Barriers to adherence** identified by the group and **tools and solutions co-constructed** in response to each of these barriers are presented in the table below

Barriers to adherence	Tools and solutions
<b>Adherence not systematically questioned</b> by HCP	Completing a <b>questionnaire on barriers to adherence before consultation</b>
<b>Planning medication intake schedules for multiple medications</b>	Completing a <b>breath diary</b> to plan the time slots dedicated to activities and treatments
<b>Maintaining adherence during periods of significant life changes</b> (entry into professional or student life, pregnancy, transplantation...) needs information and guidance	Accessing <b>support from peers or consulting adherence support tools</b> when significant life changes occurred
<b>Adjusting routines after new medication initiation</b>	<ul style="list-style-type: none"><li>- Completing a <b>breath diary</b> to plan the time slots dedicated to the new medication</li><li>- <b>Contact with the patient by email or SMS one month after treatment initiation</b> to ensure that he/she does not encounter any difficulties</li></ul>
<b>Lower adherence to aerosols and respiratory physiotherapy</b> because they are constraining and time-consuming	<ul style="list-style-type: none"><li>- Concerning aerosols: patient might seek <b>help from caregivers to clean the aerosols</b></li><li>- Concerning respiratory physiotherapy: <b>visit of physiotherapists at home or in the workplace</b></li></ul>
<b>Lower adherence to vitamins</b>	<ul style="list-style-type: none"><li>- Use of an <b>electronic diary combined with a recall system</b></li><li>- <b>Administration of vitamins</b> taken every 3 months <b>during the quarterly visit to the specialized centre</b></li></ul>
<b>Difficulty to initiate physical activity</b>	<b>Follow-up by a sports coach</b> available in the specialized centre to facilitate the integration of physical activity into daily life
Patient express <b>concern about receiving care from the same HCP over time</b>	Organization of <b>interaction with different professionals</b> from the same profession within the specialized center
Patients report that their <b>family and friends experience anxiety in relation to CF</b> , which prevents them from performing certain treatments in their presence	<b>Inviting more frequently the patient's family to the consultation</b>

## Conclusion

A 6-session focus group format is a **feasible participatory approach to intervention development**. The co-constructed intervention will be tested in a multicenter, open-label study in 3 centres in France.

