

# HIV cure trials acceptability, representations and ethical issues among patients living with HIV: A qualitative study

## BACKGROUND AND OBJECTIVES

## METHODS

Literature on the acceptability of HIV cure-related clinical trials (HCRCTs) highlights the importance of integrating people living with HIV (PLHIV) into the development and recruitment strategies of HCRCTs. However, existing studies have rarely questioned PLHIV who have ever participated in an HCRCT. Decision-making processes, as well as social and emotional components of HCRCTs acceptability, have also rarely been examined so far. We propose to fill in these gaps considering the Health Belief Model (HBM) and the social representation approach.

### Objectives

1. To explore social representations of PLHIV about therapeutic trials
2. To understand the processes involved in the decisions of whether or not to participate in a therapeutic trial
3. To compare perceptions and decision-making processes based on participants' characteristics
4. To identify ethical issues

**Design:** 2-phase semi-structured interviews: 1) free speech to talk about their knowledge/perceptions on HIV related research and experiences; 2) discussion on a fictive but typical information letter for a HCRCT

**Population:** 15 French speaking adults PLHIV from 2 HIV Swiss university clinics

**Table 1. Participants' characteristics (N=15)**

Males	9
Females	6
>5 years since diagnosis	9
<5 years since diagnosis	6
<b>Participation in a previous HIV HCRCT</b>	
Yes	9
No	6

**Data collection and analyses:** Interviews were audiotaped and transcribed. Textual analyses were performed using 2 complementary methods:

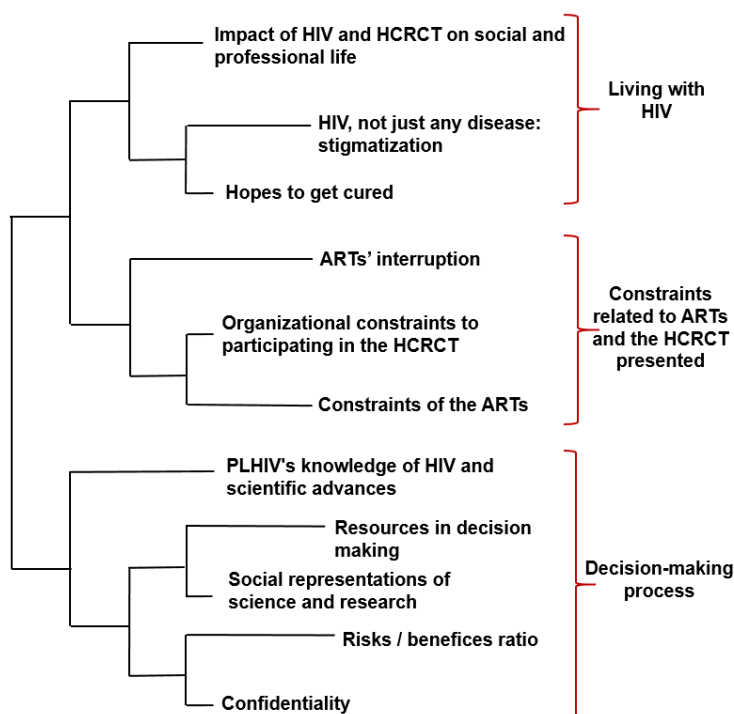
- classic thematic analysis (CTA)
- lexicographic analysis assisted by the software IRaMuTeQ

## RESULTS

### KEY RESULTS

The 10 emerging themes were classified into 3 broad categories: 1) living with HIV, 2) constraints (ARTs and HCRCT) and 3) decision-making process

**Figure 1. Thematic classification**



#### Willingness to participate

- **Perception of participants' own health status**  
Perception of poor health status → lower acceptability  
Perception of strong health → higher acceptability
- **Past experiences with ARTs**  
Experience with the first HIV treatments (e.g., AZT) → more concerns with side-effects
- **Experienced or perceived stigmatization**  
Main patients' expectation = to be cured to escape social stigmatization, but participating in a HCRCT can be perceived as potentially stigmatizing: repeated absences from work, visible side effects, failure of confidentiality, etc.
- **Confidence in research, researchers and referring physicians**

#### Main perceived benefices

- Curing and get rid of HIV related stigmas. No longer take ARTs

#### Main perceived barriers

- Impacts on professional and social life and perceived risks (effects sides, irreversible damages and ARTs' interruption)

#### Information needs to make a decision

- HCRCT's total duration and frequency of appointments
- Be informed about preliminaries HCRCT's results (first phases)
- Be informed of the consequences of ARTs interruption

## CONCLUSION AND RECOMMANDATIONS

- It is important to take into account the experience of PLHIV and adopt more person-centered recruitment and design strategies for future HCRCTs
- While recruiting, it is necessary to inform individuals about the social risks of participating in a HCRCT and not only the clinical ones
- It is ethically fundamental to understand the real people's motivations to participate in HCRCTs. Indeed, while all respondents were conscious that they would not directly benefit from participation, their main motivations were to heal and get rid of social stigma
- Strengthening people's trust in research through more transparent and accessible communication is key
- Given the key role of referring physicians in the HIV management of PLHIV, integrating them into recruitment strategies and designs of HCRCTs would certainly be advisable. Whether it is ethical for the latter to act as recruiters is questionable. Patients may in fact not dare to refuse to participate in a trial when it is proposed by their treating physician