

Epidemiología y Prevención  
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XXXVII REUNIÓN ANUAL DE LA SEE  
XIV CONGRESO DA APE  
XVIII CONGRESO SESPAS

# Baseline predictors for being lost to follow-up in OKAPI prospective cohort study



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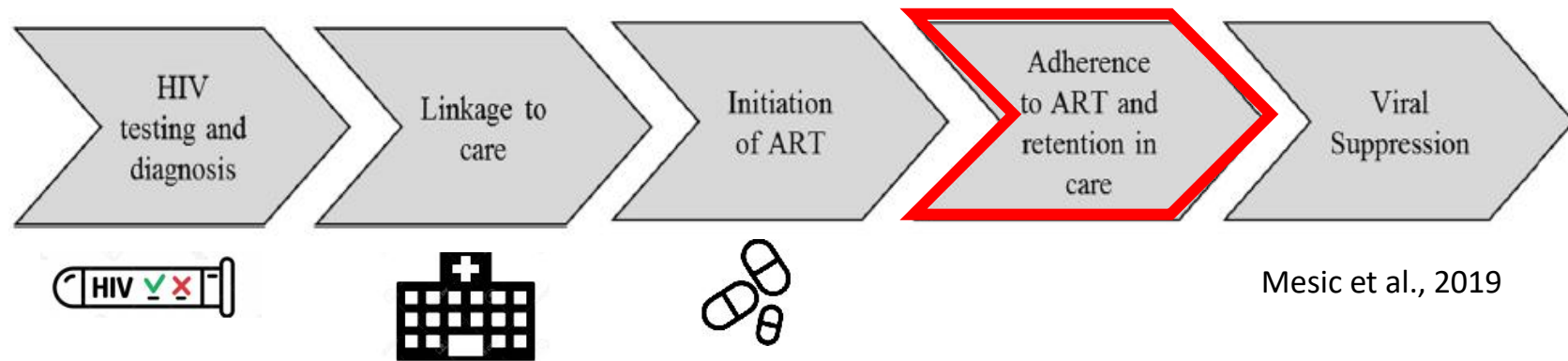
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\*No conflict of interests



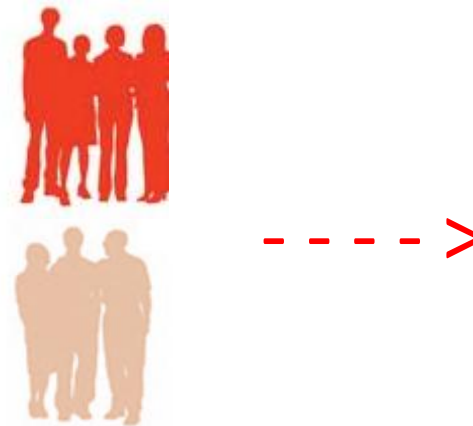
# 1. Background. HIV - Follow-up

## ■ HIV continuum of care



## ■ HIV Longitudinal studies:

- Clinical trials
- Prospective cohorts





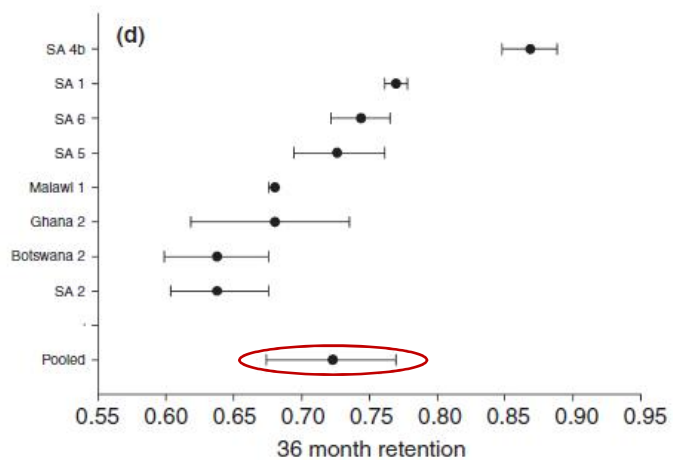
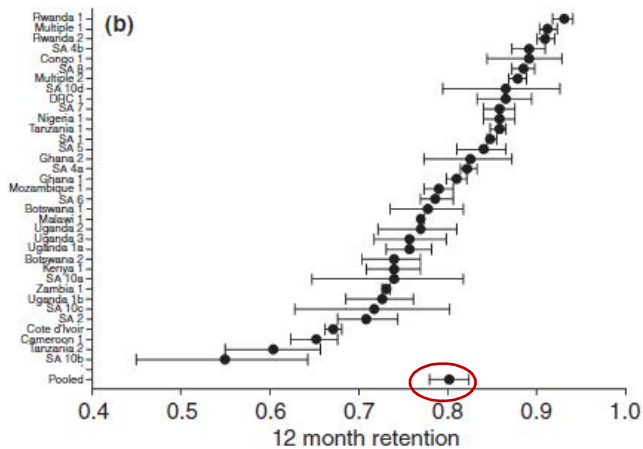
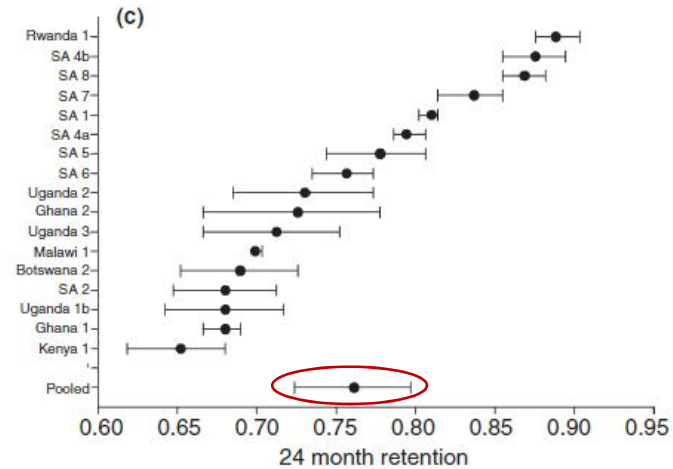
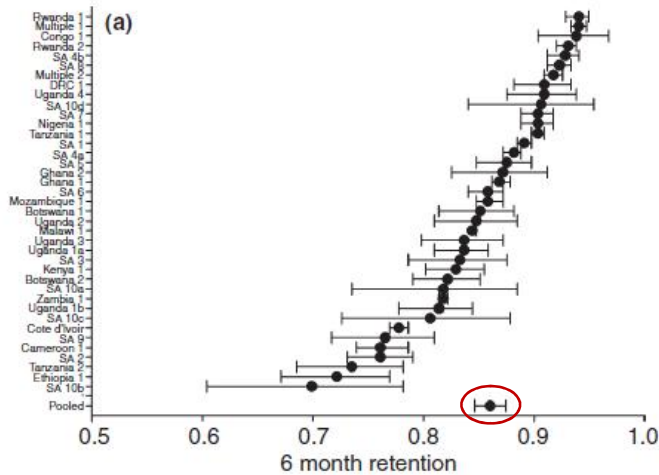
# Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007–2009: systematic review

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# 1. Background. HIV - Follow-up

## ■ Clinical trials



Int Health 2017; 9: 243-251  
doi:10.1093/inthealth/ihx023 Advance Access publication 14 July 2017

### HIV status disclosure, facility-based delivery and postpartum retention of mothers in a prevention clinical trial in rural Nigeria

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**Background:** Within the context of a cluster randomized prevention of mother-to-child HIV (PMTCT) trial, we evaluated the impact of disclosure on selected PMTCT continuum of care measures.

**Methods:** In 12 rural matched-pair clinics randomly assigned to an intervention package versus control, we enrolled 372 HIV-infected pregnant women from April 2013 to March 2014. This study included 327 (87.9%) women with unknown HIV status or who were treatment naive at prenatal care. We employed mixed effects logistic regression to estimate impact of disclosure and postpartum retention in HIV care at 6 and 12 weeks.

**Results:** Fully 86.5% (283/327) of women disclosed their HIV status to their partner, 99.2% of women who disclosed were more likely to deliver at a health facility (OR 3.17, 95% CI 1.39-7.23). Adjusting for intervention arm, maternal age and family relocation were more likely to be retained in care at 6 weeks (OR 2.72, 95% CI 0.79-9.41 and 2.46, 95% CI 0.70-8.63, respectively).

**Conclusions:** HIV status disclosure at 6 weeks' postpartum was positively associated with retention of mothers in HIV care, but not with early postpartum retention. Facilitating HIV status disclosure at 6 weeks' postpartum was positively associated with retention of mothers in HIV care, but not with early postpartum retention of facility obstetric services.

### Retention of South African Adolescents in a 54-Month Longitudinal HIV Risk Reduction Trial

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**Abstract** Retention of participants in clinical trials is a central concern of HIV/STI behavioral researchers and research sponsors. This article describes the strategies used for addressing the challenges in retaining South African adolescents for a 54-month longitudinal study. The objective of the South African adolescent health promotion long-term follow-up trial was to test the sustainability of the effects of an HIV/STI risk reduction intervention, "Let Us Protect Our Future," on young adolescents as they aged into middle and late adolescence. Inaccurate contact information, invalid mobile telephone numbers, lack of transportation, transitory family addresses, and family relocation were among the challenges to retaining participants. Despite a significant gap in time of 36 months between the main trial and the long-term follow-up study, 99.2% of 1057 participants were retained. Solutions used for retaining the adolescents are discussed with suggestions offered for retaining adolescents in longitudinal HIV/STI prevention clinical trials in low resource countries.

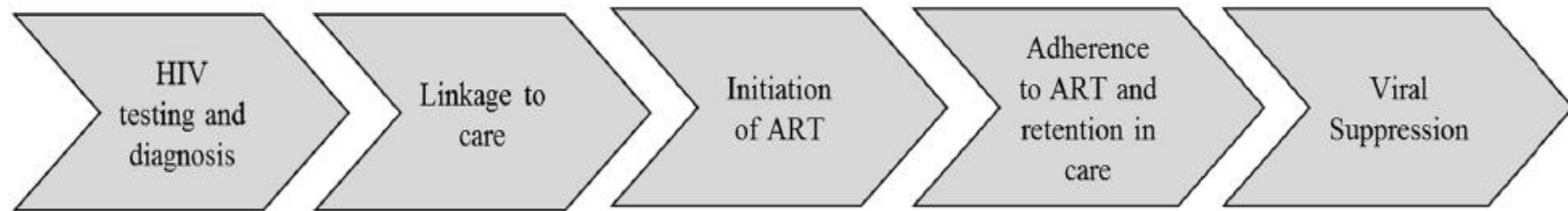
#### Keywords

Adolescents · HIV clinical · Trial retention · South Africa

The retention of adequate numbers of study participants in clinical research is vital for maintaining the internal and external validity of a study. The conclusions drawn from studies with low retention rates are questionable because non-participants may respond differently from participants (Bender et al. 2003; Campbell and Stanley 1963). Failure to retain the projected number of participants can also prolong the time required to complete a study and drain limited resources. Several factors have been identified affecting the retention of adolescents in research studies including caring staff, flexibility of the study time, participant age and gender, and contact information (Davis et al. 2002; Jones and Broome 2001; Stanford et al. 2003). Using text messages for reminders, providing food and time for socialization has also been suggested for retaining

# 1. Background. HIV - Follow-up

- HIV continuum of care



Mesic et al., 2019

- Longitudinal studies:

- Clinical trials

- Prospective cohorts → LTFU: validity & sample size

# 1. Background. Follow-up in the DRC

Carlos et al. *BMC Public Health* (2016) 16:606  
DOI 10.1186/s12889-016-3285-5

BMC Public Health

STUDY PROTOCOL

Open Access

## Factors that lead to changes in sexual behaviours after a negative HIV test: protocol for a prospective cohort study in Kinshasa



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### Abstract

**Background:** Considering the high percentage of couples in which one or both members are HIV negative, the frequency of transmission among non-regular partners and the probabilities of non-disclosure, attention should be paid to people getting a negative HIV test at the Voluntary Counseling and Testing (VCT). Research has shown that a negative HIV test may be followed by a change in sexual behaviours. In Sub-Saharan Africa, where most HIV infections occur, there are few studies that have analysed the factors associated with changes in sexual risk behaviours after a negative HIV test at the VCT clinic. The aim of this project is to evaluate the specific factors associated with changes in sexual behaviours, three months after a negative result in an HIV test, and to analyse the effect of counseling and testing on HIV-related knowledge of participants in an outpatient centre of Kinshasa (Democratic Republic of Congo).

**Methods and design:** Prospective cohort study from December 2014 until March 2016. People 15–60 year old that received VCT at Monkole Hospital (Kinshasa) were followed three months after they got a negative HIV test. In a face-to-face interview, participants replied to a baseline and a follow-up research questionnaire on HIV-related knowledge, attitudes and behaviours. At follow-up respondents were also offered a new HIV test and additional HIV counseling. Four hundred and fifteen participants completed the baseline questionnaire and 363 (87 %) came back for their 3-month follow up.

**Discussion:** This is the first longitudinal study in the DRC that evaluates the factors associated with changes in sexual behaviours after a negative HIV test at the VCT. Participants attending the VCT services within a clinical setting are a good study population as they can be good transmitters of preventive information for other people with no access to health facilities.

**Keywords:** HIV, Voluntary Counseling and Testing (VCT), Negative test, Sexual, Behaviour, Knowledge, Cohort, Africa

### Follow-up

For all the respondents with a negative HIV test at baseline, an appointment was set to go back to Monkole after a 3-month period for the follow-up. One week before the follow-up visit they received a reminding call.

In order to assure a high retention rate, participants received a transportation fee when they arrived at the hospital for the follow-up.

Eighty-seven percent of participants scheduled for a follow-up visit returned to Monkole for their appointment.

## Effect of HIV-1 Infection on Tuberculosis and Fertility in a Large Workforce in Kinshasa, Democratic Republic of the Congo

To determine the effect of an HIV counseling service on the incidence of HIV and tuberculosis infection and on the fertility rate in a large workforce cohort of adult men and women from Kinshasa, Democratic Republic of Congo (formerly Zaire), we conducted a 2-year prospective longitudinal cohort study, two large Kinshasa businesses (a commercial bank and a textile factory). We determined baseline HIV-1 seroprevalence, HIV-1 and tuberculosis mortality/morbidity, and fertility rates during 24 months of follow-up on 8866 employees and

TABLE 1. ENROLLMENT AND PARTICIPATION RATES

	<i>Business</i>	
	<i>A</i>	<i>B</i>
Enrollment window	7/87–12/87	12/87–4/88
Number of employees:		
Invited	6589	1652
Participating (% total)	6016 (91.3%)	1600 (96.9%)
Number of wives:		
Invited	4369	1217
Participating (% total)	3621 (82.9%)	1127 (92.6%)
Year one follow-up window	7/88–12/88	2/89–7/89
Number of employees:		
Invited	6016	1600
Participating (% total)	5139 (85.4%)	1482 (92.6%)
Number of wives:		
Invited	3621	1127
Participating (% total)	3004 (83.0%)	1026 (91.0%)
Number of newly enrolled:		
Employees	573	52
Wives	738	87
Year two follow-up window	11/89–7/90	2/90–8/90
Number of employees:		
Invited	5712	1534
Participating (% total)	4732 (82.8%)	1454 (94.8%)
Number of wives:		
Invited	3742	1113
Participating (% total)	3120 (83.4%)	980 (88.0%)

# 1. Background. Follow-up in the DRC



## HHS Public Access

Author manuscript

*Lancet Glob Health*. Author manuscript; available in PMC 2017 September 12.

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*Lancet Glob Health*. 2017 September ; 5(9): e936–e947. doi:10.1016/S2214-109X(17)30267-X.



## Cognitive and motor performance in Congolese children with konzo during 4 years of follow-up: a longitudinal analysis

Michael J Boivin, Daniel Okitundu, Bumoko Makila-Mabe, Marie-Therese Sombo, Dieudonne Mumba, Alla Sikorskii, Banea Mayambu, and Desire Tshala-Katumbay

Department of Psychiatry and Neurology & Ophthalmology, Michigan State University, East Lansing, MI, USA (Prof M J Boivin PhD); Centre NeuroPsychopathologique (CNPP) (D Okitundu MD, B Makila-Mabe MD, M-T Sombo MD, Prof D Tshala-Katumbay PhD), Department of Tropical Medicine (Prof D Mumba PhD), University of Kinshasa, Kinshasa, Congo; Ministry of Health National Program on Nutrition (PRONANUT), Kinshasa, Congo (Prof B Mayambu PhD); National Institute for Biomedical Research (INRB), Kinshasa, Congo (Prof D Mumba, Prof D Tshala-Katumbay); Department of Psychiatry and Department of Statistics and Probability, Michigan State University, East Lansing, MI, USA (Prof A Sikorskii PhD); and Department of Neurology and School of Public Health, Oregon Health & Science University, Portland, OR, USA (Prof D Tshala-Katumbay)

## Results

56% - 2years

210 children (median age 8.38 years, IQR 6.92–10.58) completed the first neurocognitive assessment, 117 completed a follow-up assessment approximately 2 years later (median age 10.09 years, IQR 8.67–12.27), and 89 completed another follow-up assessment 2 years later (median age 11.97 years, IQR 10.55–14.14). Results of a diagnostic neurological exam for

RESEARCH ARTICLE

# The World Health Organization Fetal Growth Charts: A Multinational Longitudinal Study of Ultrasound Biometric Measurements and Estimated Fetal Weight

Torvid Kiserud<sup>1,2\*</sup>, Gilda Piaggio<sup>3,4\*</sup>, Guillermo Carroli<sup>5</sup>, Mariana Widmer<sup>6\*</sup>, José Carvalho<sup>4</sup>, Lisa Neerup Jensen<sup>7</sup>, Daniel Giordano<sup>5</sup>, José Guilherme Cecatti<sup>8</sup>, Hany Abdel Aleem<sup>9</sup>, Sameera A. Talegawkar<sup>10</sup>, Alexandra Benachi<sup>11</sup>, Anke Diemert<sup>12</sup>, Antoinette Tshetu Kitoto<sup>13</sup>, Jadsada Thinkhamrop<sup>14</sup>, Pisake Lumbiganon<sup>14</sup>, Ann Tabor<sup>7</sup>, Alka Kriplani<sup>15</sup>, Rogelio Gonzalez Perez<sup>16</sup>, Kurt Hecher<sup>12</sup>, Mark A. Hanson<sup>17</sup>, A. Metin Gülmezoglu<sup>6</sup>, Lawrence D. Platt<sup>18,19</sup>



**Table 1. Number of women recruited to the study by country, with withdrawals and discontinuations.**

Country	Number of Women Recruited	Consent Withdrawal		Discontinuation		Miscarriage/Intrauterine Death*	
		n	Percent	Lost to Follow-Up		n	Percent
				n	Percent		
Argentina	143	0	0.0	2	1.4	1	0.7
Brazil	157	4	2.5	2	1.3	3	1.9
D. R. Congo	157	15	9.6	6	3.8	10	6.4
Denmark	142	2	1.4	3	2.1	1	0.7
Egypt	180	25	13.9	11	6.1	9	5.0
France	109	1	0.9	9	8.3	2	1.8
Germany	141	0	0.0	2	1.4	0	0.0
India	146	0	0.0	7	4.8	3	2.1
Norway	140	2	1.4	1	0.7	1	0.7
Thailand	124	3	2.4	3	2.4	4	3.2
<b>Total</b>	<b>1,439</b>	<b>52</b>	<b>3.6</b>	<b>46</b>	<b>3.2</b>	<b>34</b>	<b>2.4</b>

\*Two medical abortions, 29 miscarriages, and three intrauterine deaths.

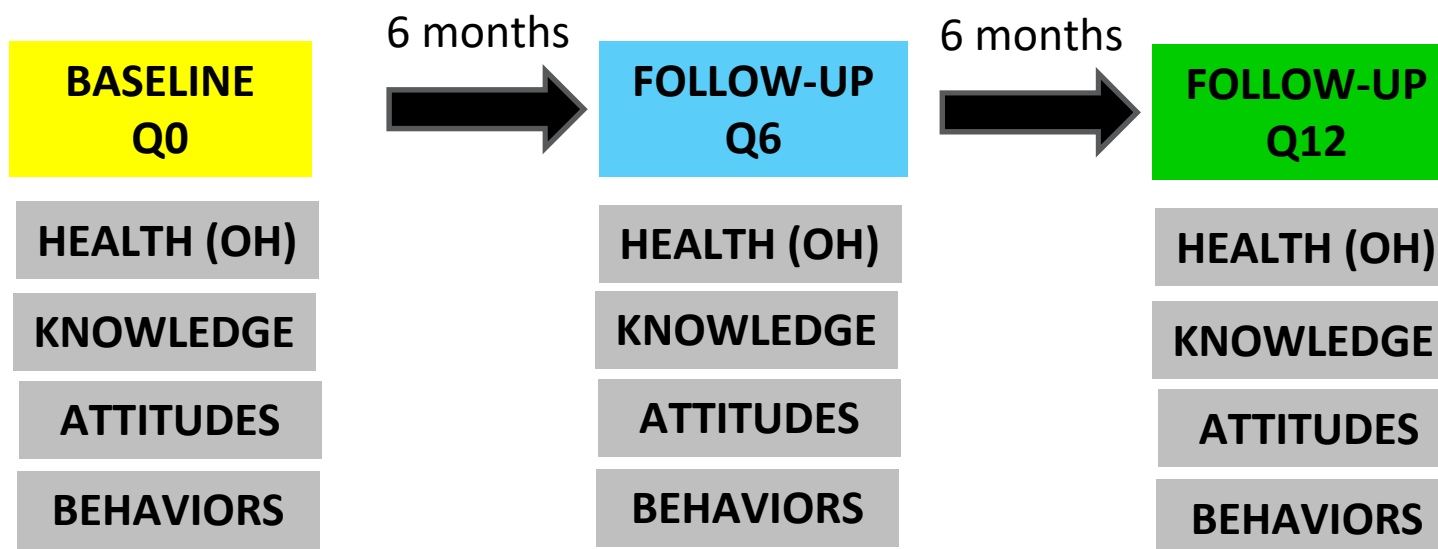
D. R. Congo, Democratic Republic of the Congo.

## 2. Objectives

1. To analyze the retention rates at 6- and 12-month follow-ups in an African HIV-related cohort study.
2. To evaluate the factors associated with being lost to follow-up (LTFU).

### 3. Methods. Study design and population

- OKAPI (Observational Kinshasa AIDS Prevention Initiative) project
- Prospective cohort study (April 2016 - April 2018)
- Monkole Hospital, Kinshasa (D.R.Congo)
- Participants aged 15-59 yr.
- HIV Voluntary Counseling and Testing (VCT)



### 3. Methods. Data collection

- **HIV test**



- **Interviews** - questionnaires Q0, Q6, Q12



- **Statistical analyses:** Descriptive and multivariate analyses (Stata 12.0).

### 3. Methods. Follow-up

#### CONSENTEMENT ÉCLAIRÉ

Je soussigné, Mr/Mme\* : .....

accepte de répondre au questionnaire sur les connaissances, attitudes et comportements liés au VIH/SIDA. J'accepte également de me faire dépister et de **revenir ensuite dans 6 mois et 12 mois** pour répondre de nouveau à un bref questionnaire de suivi sur les connaissances, comportements et attitudes en rapport avec le VIH/SIDA. En cas d'un résultat négatif au premier test, j'accepte de me **faire à nouveau tester dans 6 mois ou 12 mois**, et autorise que d'autres tests de confirmation ou de recherche d'autres virus ou agents infectieux soient réalisés en Espagne sur mon échantillon de sang. En cas de positivité, j'autorise également que des analyses spéciales sur mon échantillon de sang soient réalisées en Espagne pour déterminer les types de virus qui circulent en moi, et dans le cas où cela s'appliquera, les mutations génétiques à la base d'un quelconque échec thérapeutique.

\* En cas de mineur, le responsable légal : Mr/Mme. ....

Kinshasa, le .....

# 3. Methods. Follow-up



## OKAPI Project. QUESTIONNAIRE Q1

Numéro d'identification: _____ <b>-Q1</b>	Date Q1: ___ / ___ / ___
Date de naissance: ___ / ___ / ___ (jour / mois / année)	Date Q6 (6 mois après): ___ / ___ / ___
Sexe: <input type="checkbox"/> Homme <input type="checkbox"/> Femme	Date ☎️ (1 semaine avant): ___ / ___ / ___
NUMERO OKAPI DU PARTICIPANT: _____	
N° d'identification du laboratoire : _____	

N° d'identification OKAPI du partenaire : \_\_\_\_\_

Nom : \_\_\_\_\_

Adresse de la rue : \_\_\_\_\_

Numéro de téléphone -I : \_\_\_\_\_

Numéro de téléphone -II : \_\_\_\_\_

Numéro de téléphone -III : \_\_\_\_\_

Nom personne de contact-1 : \_\_\_\_\_

Adresse de la personne de contact-1 : \_\_\_\_\_

Numéro de téléphone de la personne de contact-1: \_\_\_\_\_

Nom personne de contact-2 : \_\_\_\_\_

Adresse de la personne de contact-2 : \_\_\_\_\_

Numéro de téléphone de la personne de contact-2: \_\_\_\_\_



### 3. Methods. Follow-up

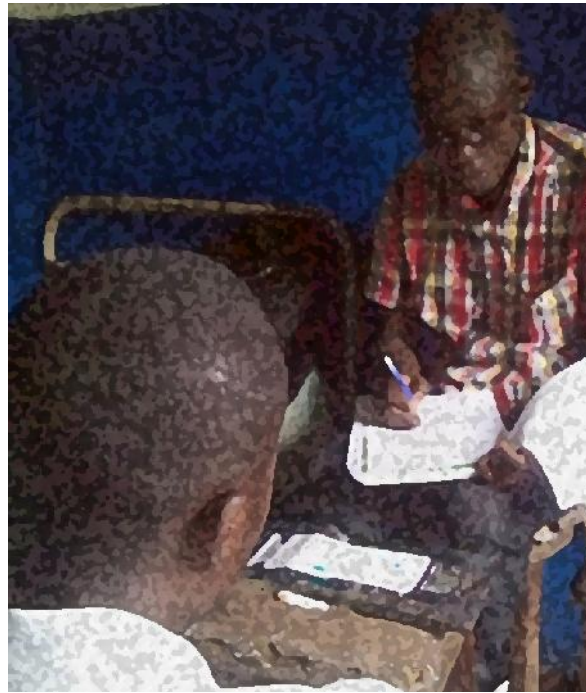
Liste des participants venus au rendez-vous pour le Q6 et remboursement des frais de transport  
(4€ approx, 5000 Francs Congolais)

N°	Date	Numéro d'identification	Montant reçu	Signature
02	02/03/18	BHM HT 25-12-1990	1000fc	[Signature]
02	07/03/18	ATNPP2511 1986 F	1000fc	[Signature]
03	07/03/18	ATNPIF 06 03/1994 M	1000fc	[Signature]
04	07/03/18	AMN2KJ 2505/1986 F	1000fc	[Signature]
05	07/03/18	ATN.176-93 03/1980 M	1000fc	[Signature]
06	08/03/18	AMKEB 0808 1984 F	5000fc	[Signature]
07	08/03/18	AMKCP 2404/1985 M	1000fc	[Signature]
08	08/03/18	AMN12 12 12 1988	1000fc	[Signature]
09	08/03/18	AMN111 2008 1967	1000fc	[Signature]
10	08/03/18	AMMBIE 18/10/1998	1000fc	[Signature]

4€ = 5,000 Congolese francs



### 3. Methods. Follow-up



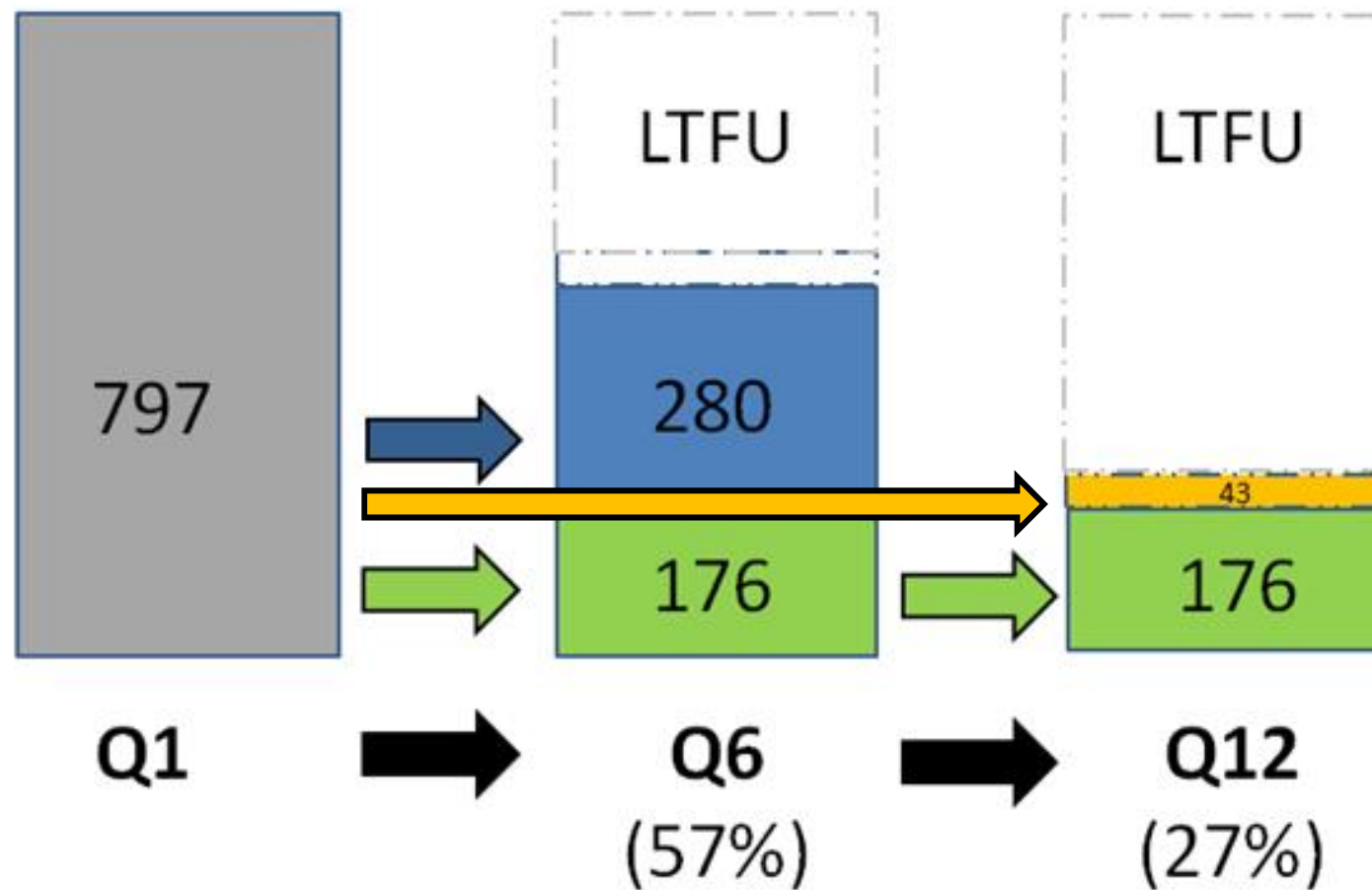
## 4. Results. OKAPI participants: baseline characteristics

- April 2016-April 2018:

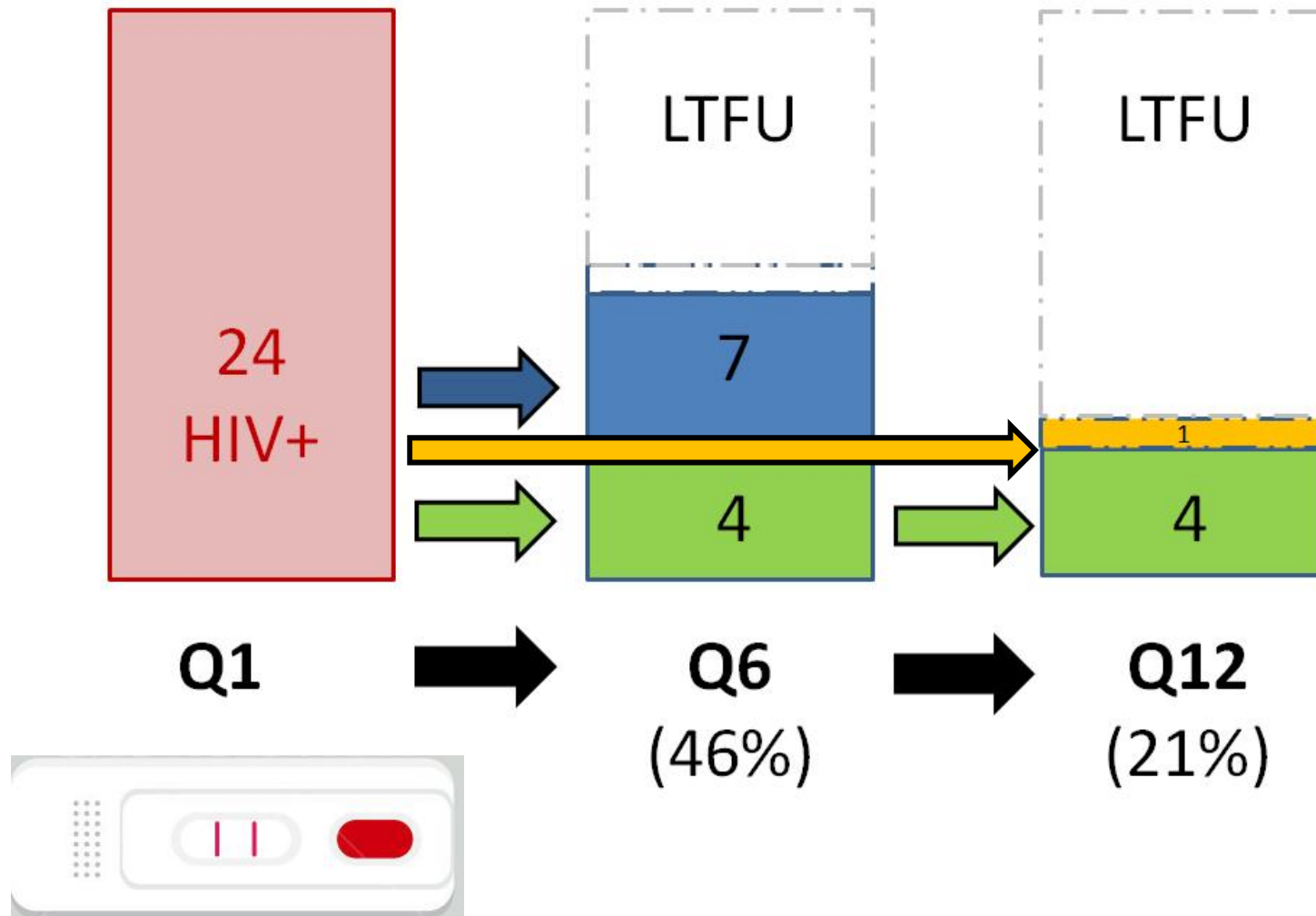


	Baseline (N=797)
<b>Sociodemographics (%)</b>	
Sex (female)	58
Age (years) (mean, SD)	30.2 ± 9.4
University studies	67
Perceive medium economic level	76
Religion	
Église de réveil	51
Catholic	27
Married	18
Media access (weekly/daily)	
Mobile phone	99
The Internet	78
<b>Health (%)</b>	
Perceived good health status	66
No/low HIV risk perception	77
HIV+ test	3

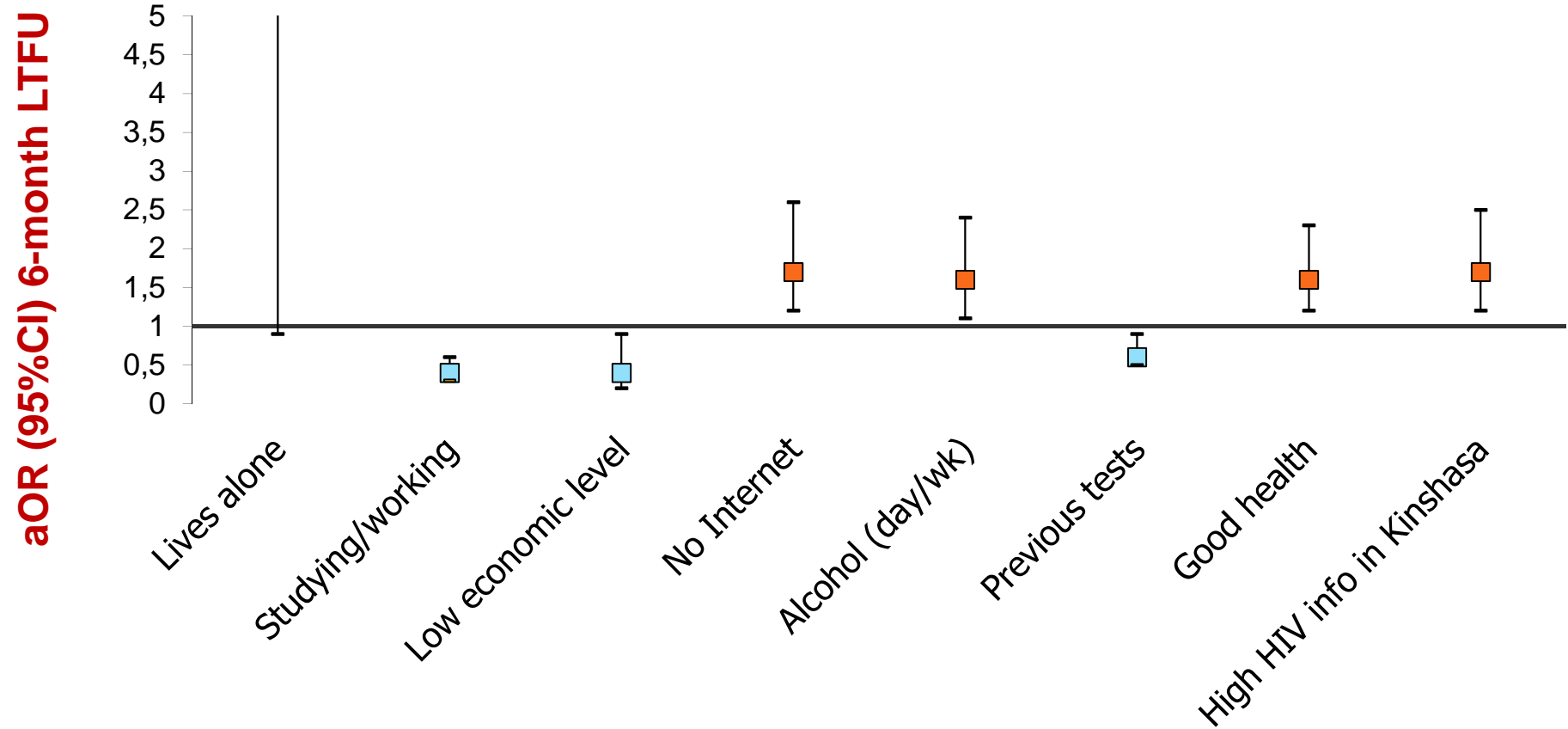
## 4. Results. Retention at 6- and 12-month follow-up



## 4. Results. Retention at 6- and 12-month follow-up

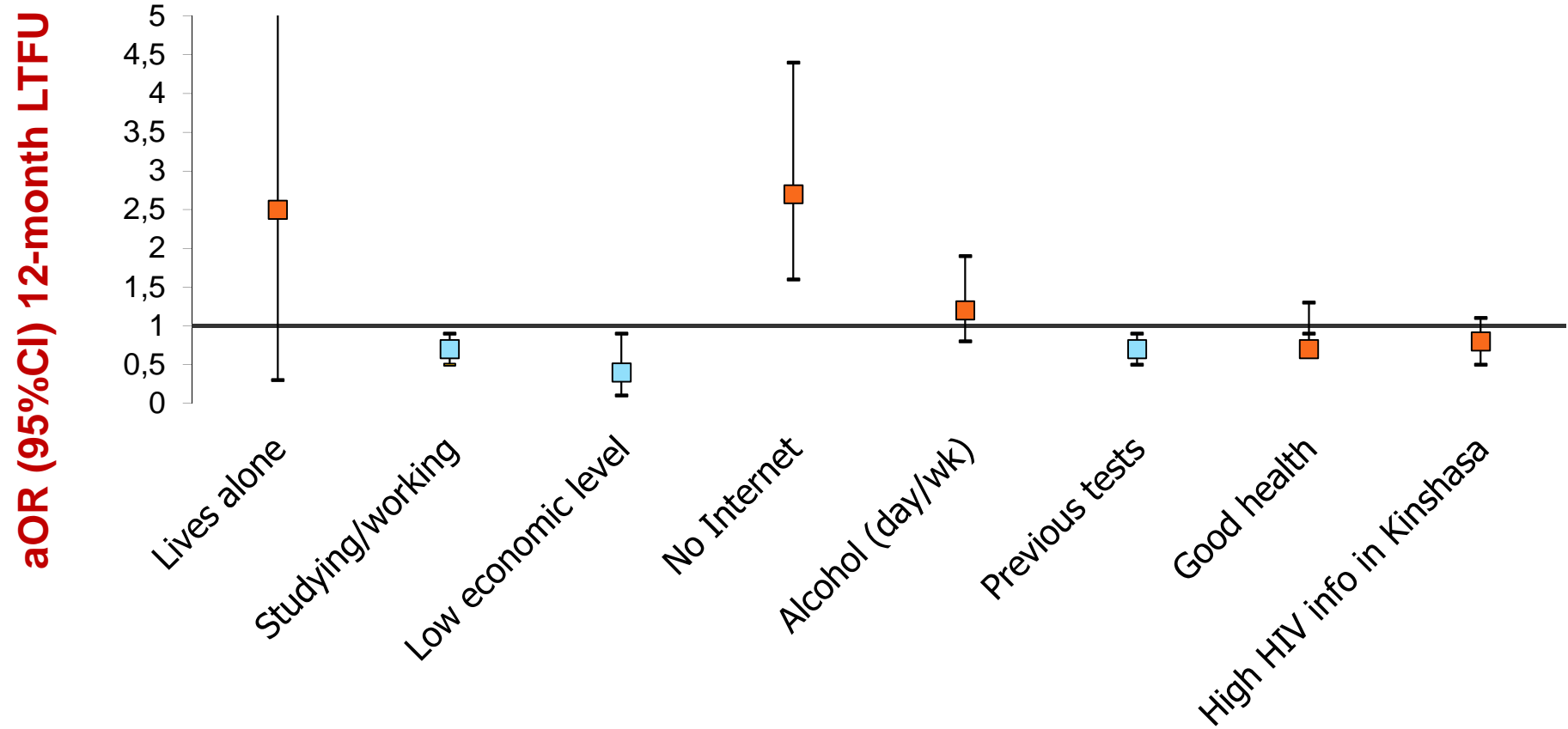


## 4. Results. Lost-to-follow-up (6-months)



\*All variables were included in the multivariate regression model.

## 4. Results. Lost-to-follow-up (12-months)



\*All variables included in the multivariate regression model.

## 5. Limitations.

### Unknown Competitive causes:

- Disease
- Death
- Psychological factors
- Migration
- Social barriers



## 5. Conclusions

- Not having a daily/weekly access to the Internet was significantly associated with being LTFU at 6 and 12-month follow-up.
- Being studying/working, reporting a low economic level and having been previously tested were inversely associated with being LTFU at 6 and 12-month follow-up.
- Considering the high prevalence of LTFU in cohort studies in DRC, it is important to look for efficient strategies that improve retention in longitudinal studies, as well as in clinical care of people attending VCT.

