Volunteers in preventive HIV vaccine trials. Motivations, determinants and biographical consequences in a longitudinal perspective (France, 1992-2001)

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Background

Starting from the mid nineties, the fight against Aids has faced a tremendous demobilisation, due to the after effect of its substantial growth during the eighties, along with therapeutic progresses (development of HAART). Voluntary groups have experienced a dramatic decrease in terms of resources and constituency. In such a depressed context, it is particularly important to investigate the rationale underlying volunteering to preventive HIV vaccine trials in order to secure the engagement of new volunteers in the years to come and to assure better recruitment.

Methods

The research relies on data collected by the ANRS (National Research Agency on AIDS) which is in charge of organising and follow up studies of the French network of volunteers for preventive HIV vaccine trials. All material gathered at each step of the recruitment process is put under scrutiny. We first propose a global statistical analysis of the 4882 recruitment procedures that were held since 1992. We then turn to an in-depth lexical analysis of initial 'motivation' letters, using ALCESTE software ; As an initial step of a work in progress, we explore here the possible temporal evolution in the dominant reasons invoked for applying.

Results :

If volunteering to preventive HIV vaccine trials is undoubtedly part of the larger field of social mobilisation against Aids, it however distinguishes itself by many features from the rest of the voluntary sector. To mention only the most important, participation to trials is the result of an individualistic motivation and do not implies any direct expression of solidarity or confrontative attitudes.

In a sociological and anthropological perspective, our research on preventive HIV vaccine volunteers aims at articulating the analysis of the reasons invoked for committing oneself with the study of the factors and biographical consequences of volunteering.

Table 1 gives a general overview of the selection process. One should note that the figures for 2001 are higher due to a change in the recruitment campaign. **Table 2** summarises the cohortal analysis of the volunteers' network. It allows us to better understand the evolution across time of the selection process. The two main results are 1/that the proportion of drop outs at each step of the selection process is low, which tends to indicate the accuracy of the selection criterions ; 2/ that the contribution of each cohort to the network in 2003 is relatively stable across time (when controlled by the age of the cohort and the total number of people admitted in the network each year), which indicates the persistence of volunteers motivation to participate across time.

Table 3 points out the main characteristics that help to understand the entry in the network, due to the selection process (from the first selection of initial motivations to the final admission) as well as to individual consistency of initial motivations. Potential participants were recruited through

specialised and mainstream media. People interested were provided an informative leaflet about the trials and the ones willing to volunteer had to write a letter showing their motivation and to complete a questionnaire. On the basis of this material a first selection occurs, where about 40% of the applicants are invited to take an appointment at a testing centre where they are submitted to serological and clinical exams and had an interview with a psychologist. In brief, people were not eligible to participate if they were aged under 21 and above 55 years, (except for the women who could procreate), tested HIV-positive, presented clinical problems or were at epidemiological risk (like having an HIV positive partner, or sexual erratic behaviour). The ones who couldn't be available during the whole trials (like students or unemployed persons) were rejected as well as the ones showing unapropriate motivations like wanting to receive financial incentives or some protection from the vaccine or no motivation at all. These selection criteria were not softened until 2001 when woman able to procreate were eligible for some trials as well as people presenting a risk of allergy.

A logistic regression was ran that intends to highlight the role of socio-demographic as well as socio-professional status in predicting the admission in the network.

Concerning socio-demographic variables, it appears that : being male or female do not have any discriminatory effect ; age constitutes a positive predictor, the 40-49 group having the best chance to be admitted ; being in a couple is a strongly determinant factor, more than being married ; having children also contributes strongly to the model.

Concerning occupational status, one should first note that we do not have the information for 23.5% of the applicants, due to the fact that the variable was not taken into account in 1992 and 1993. It remains that the professional sector is mentioned for the whole period. The logistic regression shows that occupational status do not constitutes a discriminatory variable, except for students and unemployed people, which is due to the exclusion of those categories by the selection criterions. One should only note that being employed in the media, culture or artistic professions constitutes a negative predictor in the model.

We then study motivation letters sent by those volunteers who have finally been included in the network (n= 319). The letters were submitted to a lexical analysis. We used ALCESTE software. The classification and regrouping of responses in terms of proximity between units of lexical context results in a certain number of distinct types of discourse "lexical worlds." Four order of motives to justify volunteering appear.

Class 1 (16.5% of the corpus) characterises itself by the expression of a strong solidarity between the generations. People explain their will to participate by expressing the wish and the hope of a safer future without aids for their own children.

Table 4 shows that the number of women and married people in this class is slightly higher than in the average, and that the number of children increases the chances to belong to that class of motives.

In class 2 (35.65% of the corpus), the motives are mainly expressed in terms of a compelling necessity of commitment, of making gift of oneself. Many of those included in that class are regular blood donors as well as engaged in unpaid helping activities, some of them having already volunteered for other clinical trials. They often oppose their high level of commitment to the simple gift of money, which they consider as to easy a way of having BONNE CONSCIENCE. ?

People employed in the educational sector and employees are over represented in that class. They also have less chance than the average to have any or more than two children (**Table 4**).

In class 3 (22.18% of the corpus), motives are connected with a strong empathy towards PLWA'S. This empathy can be general and linked to the awareness of the danger of the pandemia or it can rely on affective proximity with affected friends or relatives. We find here people who have experienced loss and grief. Priests all belong to this category where teachers and employees are clearly over represented. These people tend to be less married than the average and to have proportionately less kids.

In class 4 : (26.12% of the corpus), the relevant factors for volunteerism can be explained by a professional proximity. Inclusion in a trial is seen as consistent with medical social, or educational sector where these people belong. They also motivate their application by the will to contribute to scientific research and by antecedents to volunteering. Half of them are single and they have less chances to have one or more children.

Figure 1 shows the results of a factor analysis of the dominant vocabulary in the four Alceste's classes. Two axes are structuring the plan. The horizontal axe (55.75% of the inertia) opposes two ways of being concerned with a balancing between the expression of a proximity to HIV and motives defined in terms of solidarity enlarged to all possible sufferings. The vertical axe (44.25% of the inertia) opposes motives expressed on a personal register to motives formulated on a generalised register.
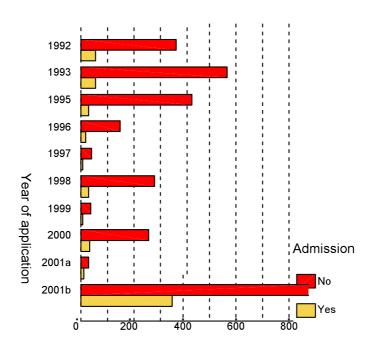
If one look again at the class centers (indicated by the red numbers), one sees that people in **class 1** are motivating their commitment by the fear generated by HIV for them or their offspring (menace, fear, danger, protect) and express that fear on a strong personal register, which explains why closely associated to this group is the vocabulary of family relationships (son, mother, brother, father, child, mother, parent) and links of friendship/love. Motives in **class 3** are also dominantly articulated to a proximity to HIV and are nurtured by the reference to death, loss (hospital, disease, sick, epidemic, body), but motives here are expressed in a generalised register, affective proximity to HIV being systematically linked to broader social and political problems such as the spreading of the epidemic in Africa or the disappearing of a whole generation. **Class 2** characterises itself mainly by motives defined in terms of solidarity enlarged to all possible sufferings. Commitment here is clearly conceived as "giving of oneself". Vocabulary in this group is encapsulated in the lexical universe of sharing, support and meeting. Alongside is a proliferation of pronouns (me/my) which, when one adds to them words expressing pursuit of an experience "for oneself" (wish, desire, experience, want, etc) indicate an involvement experienced in terms of strong personal implication, of a desire to reach out to the other and to thereby gain something mutually enriching. **Class 4**, groups motives that are expressing the most generalised concern, in terms of personal proximity to HIV as well as in terms of individual experience. No surprise then than in that class motives are embedded in a vocabulary referring to medicine, the sphere of work and especially health and caring sector.

Finally, factor analysis seems to indicate that motives to participate have evolved across time, being closer in a first period to a personal register of justification (1992-1995) and turning more after 1995 around motives formulated on a generalised register (1996-2001). That result, if confirmed by further analysis, would be consistent with that movement of **desingularisation** ? that Aids sector has experienced in its history, linked with the changing public perceptions of the disease. In that respect the effect of HAART on motives to volunteering is certainly a dimension to be worked out in the future.

Conclusions :

The results of this preliminary longitudinal study suggest that the changing context of the epidemic has not produced a real rupture in the development of volunteering in preventive HIV vaccine trials, but has in certain respects accelerated a process that has been evident over several years, especially concerning socio-biological characteristics, proximity to the epidemic, or reasons discussed for entry or exit. More generally, the selection procedure proved its efficiency : excellent follow up rates have been observed during the last stages of the selection process and the trials.

TABLE 1 : General overview of the network

Nota bene :   2001a = call for participation old formulae
2001b = call for participation new formulae

TABLE 2 : Cohortal analysis

		1992	1993	1995	1996	1997	1998	1999	2000	2001a	2001b	Total	extrap total
Initial applications		416	608	447	165	47	309	42	290	42	1893	**4259**	**4259**
Sél 1 (application letters)	Drop out at Sél1	(1)	(1)	0	0	0	3	0	1	3	7	**14**	**16**
	rejected	(57)	(130)	297	91	20	184	17	133	3	400	**1145**	**1508**
	select	(102)	(237)	150	74	27	122	25	156	36	1486	**2076**	**2735**
Sél 2 (interviews in Selection centers)	Drop out at Sél2	(3)	(4)	0	26	3	69	19	121	24	637	**899**	**906**
	rejected	(30)	(70)	121	29	15	22	0	0	0	427	**614**	**954**
	select	(28)	(64)	29	19	9	31	6	35	12	422	**563**	**875**
Final sélection	Drop out at SélFin	(5)	(6)	0	2	1	2	0	0	0	0	**5**	**7**
	rejected	(0)	(0)	0	0	0	-2	0	0	0	0	**-2**	**-2**
	select	194	99	29	17	8	31	6	35	12	422	**853**	**853**
Admission in the network	Do not enter	137	42	0	0	0	0	0	0	0	76	*255*	*255*
	enter	*57*	*57*	*29*	*17*	*8*	*31*	*6*	*35*	*12*	*346*	*598*	*598*
	D-out	*6*	*1*	*1*	*1*		*3*		*1*		*7*	*20*	*34*
Inclusion in trials	none	8	9	6	5	2	5	1	16	2	346	**400**	**400**
	At least one	49	48	23	12	6	26	5	19	10	0	**198**	**198**
	Two trials	0	0	0	4	1	13	3	0	0	0	**21**	**21**
State of the network in en 2003		*51*	*107*	*135*	*151*	*159*	*187*	*193*	*227*	*239*	*578*		
Contribution of each cohort to the network 2003		*8,8%*	*9,7%*	*4,8%*	*2,8%*	*1,4%*	*4,8%*	*1,0%*	*5,9%*	*2,1%*	*58,7%*	*100,0%*	*100,0%*

NB1 : Bracketted numbers for 1992 et 1993 are extrapolated figures based on the mean drop outs and rejected for the other eight years