 DOI: 10.1590/S0034-8910.2013047003953

Participants recruitment in ELSA-Brasil (Brazilian Longitudinal Study for Adult Health)

Estela M L Aquino[I]
Maria Jenny Araujo[I]
Maria da Conceição C Almeida[II]
Patrícia Conceição[I]
Célia Regina de Andrade[III]
Nágela Valadão Cade[IV]
Marilia Sá Carvalho[V]
Roberta Carvalho de Figueiredo[VI]
Maria de Jesus M da Fonseca[III]
Luana Giatti[VII]
Greice Maria de Souza Menezes[I]
Maria Angélica Nunes[VIII]
Angelita Gomes de Souza[IX]
Paulo R Vasconcellos-Silva[II,X,XI]
Alvaro Vigo[XII]

I MUSA Programa Integrado em Gênero e Saúde. Instituto de Saúde Coletiva. Universidade Federal da Bahia. Salvador, BA, Brasil

II Centro de Pesquisa Gonçalo Moniz. Fundação Oswaldo Cruz. Salvador, BA, Brasil

III Escola Nacional de Saúde Pública. Fundação Oswaldo Cruz. Rio de Janeiro, RJ, Brasil

IV Departamento de Enfermagem e Programa de Pós-Graduação em Saúde Coletiva. Universidade Federal do Espírito Santo. Vitória, ES, Brasil

V Programa de Computação Científica. Fundação Oswaldo Cruz. Rio de Janeiro, RJ, Brasil

VI Programa de Pós-Graduação em Saúde Pública. Faculdade de Medicina. Universidade Federal de Minas Gerais. Belo Horizonte, MG, Brasil

VII Departamento de Nutrição Clínica e Social. Universidade Federal de Ouro Preto. Ouro Preto, MG, Brasil

VIII Programa de Pós-Graduação em Epidemiologia. Faculdade de Medicina. Universidade Federal do Rio Grande do Sul. Porto Alegre, RS, Brasil

IX Hospital Universitário. Universidade de São Paulo. São Paulo, SP, Brasil

X Pós-Graduação em Ensino em Biociências e Saúde. Instituto Oswaldo Cruz. Fundação Oswaldo Cruz. Rio de Janeiro, RJ, Brasil

XI Departamento de Medicina Especializada. Escola de Medicina e Cirurgia. Universidade Federal do Rio de Janeiro. Rio de Janeiro, RJ, Brasil

XII Departamento de Estatística. Instituto de Matemática. Universidade Federal do Rio Grande do Sul. Porto Alegre, RS, Brasil

Correspondence:
Estela Maria Motta Lima Leão de Aquino
Campus do Canela - UFB
R. Basílio da Gama, s/n 2º andar
40110-040 Salvador, BA, Brasil
E-mail: estela@ufba.br

Received: 11/13/2011
Approved: 7/7/2012

Article available from: www.scielo.br/rsp

ABSTRACT

OBJECTIVE: To present the recruitment and communication strategies of the ELSA-Brasil *(Estudo Longitudinal de Saúde do Adulto* – Brazilian Longitudinal Study for Adult Health)

METHODS: The strategies were directed at dissemination, institutionalization and recruitment. The communication actions intended to promote the strengthening of a positive institutional image for the study, knowledge management and an effective dialogue with its target audience. An official website was created in order to communicate with different audiences, to disseminate scientific knowledge, and to contribute to consolidate the image of the study within society.

RESULTS: We recruited 16,435 men and women, active employees and retirees of six public institutions of education and research, to constitute the cohort of 15,105 participants. The recruitment goals were fully achieved in the six centers, with a slight predominance of women and of younger adults, and slightly fewer employees with lower level of schooling.

CONCLUSIONS: The strategies used were adequate and essential to the successful inclusion and participation of the employees.

DESCRIPTORS: Multicenter Studies as Topic, methods. Cohort Studies. Longitudinal Studies. Research subject recruitment. Communication strategies.

INTRODUCTION

Epidemiological studies with large samples require effective and efficient strategies to recruit participants. In longitudinal studies, the selection and recruitment of adequate population are crucial,[1] as differential losses in the follow-up may compromise the validity of the results.[15,17] Due to this, the strategies for attracting and recruiting should concentrate on the broad adherence of an adequate amount of participants, without losing sight of their permanence over the years.[2] Therefore, the communication strategies should strive to expand the adherence and to mitigate the decrease in participation rates – an issue that is extremely relevant in studies of this type.[12]

In the international literature, barriers and difficulties to reach minority or more resistant groups have been discussed in different contexts,[2,7,10,11,13,14,18] and the importance of adopting a "cultural sensitivity"[14] to achieve broader adherence has been emphasized. The majority of the papers have described procedures, mainly in experimental studies, without evaluating their effectiveness,[10,14,18] but there are evidences that higher participation rates result from the combination of different recruitment strategies.[10,13-15]

In Brazil, although there are ongoing cohort studies, there are no papers describing the challenges to participant recruitment and retention, and the few papers that were identified involve hard-to-reach populations.[5,16]

This paper describes the communication and recruitment strategies in the *Estudo Longitudinal de Saúde do Adulto* (ELSA-Brasil - Brazilian Longitudinal Study for Adult Health) and discusses the results achieved in the constitution of the cohort, as well as aspects that contributed to its effectuation.

METHODS

It is a cohort study of women and men aged 35 to 74 years, civil servants of six teaching and research institutions located in the Northeast, Southeast and South regions of Brazil. In the baseline, data production included interviews, measurements, tests and storage of biological material. Annually, the participants are contacted by telephone and invited every three years to be submitted to new interviews, measurements and tests in face-to-face contacts to follow up their health status and monitor outcomes.[3]

The constitution of the cohort during the baseline study occurred at two moments: Stage 1 – pre-enrollment – it included the recruitment (confirmation of interest in participating, of the person's eligibility and of the identification data), the signature of the *Termo de Consentimento Livre e Esclarecido* (TCLE – Informed Consent Document) and the first part of the interview, at workplaces or at the headquarters of the Investigation Center (IC); Stage 2 – enrollment – it involved the second part of the interview, measurements and tests, always at the IC. In some centers (Bahia, Rio de Janeiro and São Paulo), image tests were complemented in a third or even fourth visit.

The exclusion criteria were: the intention of leaving the institution, being pregnant or having been pregnant less than four months before, having severe cognitive or communication difficulty and, if retired, living outside the corresponding metropolitan region. A category of temporary ineligibility was created due to possible changes in eligibility during recruitment – concerning minimum age or the status of pregnancy – or due to licenses for sabbaticals or medium-duration academic trips. The sample is constituted of volunteers and people who were actively recruited from lists of employees provided by the institutions. Sample size was calculated at approximately 6,400 participants, based on estimations of incidence of type 2 diabetes and myocardial infarction for the Brazilian population.[3] To compensate for gender differences and possible losses in the follow-up, the size of the sample was increased to 15 thousand participants, distributed across the six centers, proportionally to the respective population of eligible employees. For a better distribution, recruitment goals were defined by sex (50% each), age (15% aged 35-44, 30% aged 45-54, 40% aged 55-64 and 15% aged 65-74 years) and occupational category (35% of support level, with incomplete elementary school; 35% with high school and 30% with higher education/teaching level).

The participants recruitment included general strategies – for standardization across centers – and local strategies – to meet the specificities of the institutional contexts and of the population of each center. They were grouped into seven items, in a typology that was adapted from other authors.[15]

Awareness-raising and involvement of the academic community

Fieldwork was preceded by institutional contacts, with visits to teaching units and other units, which aimed to raise the managers' awareness of the study, with initial distribution of promotional material. Information on the functioning and structure of the unit was collected, as well as facilitating and limiting aspects to fieldwork and indication of people to support the operational team.

For the recognition of the study's cultural universe, focal groups were conducted with potentially eligible employees to map meanings and practices in relation to health and the motivation to participate in the study at two centers.

Countless meetings were held with leaders and employees in institutional spaces. Other awareness-raising strategies included billboards, banners and posters at the campuses; inclusion of articles in local informative leaflets, departments' bulletins, and in newspapers of institutions, university hospitals, associations of teachers and of employees; news and reports on the radio and TV; inclusion of virtual banners in the intranet of units and of news in institutional and associations portals.

Creation of the study's visual identity

The study's visual identity was constructed, with the design of an easy-to-remember figurative logo that expressed fundamental concepts associated with the ELSA-Brasil. The following elements were prioritized: health (and not illness), represented by moving bodies; ethnic, age and gender diversity; the longitudinal nature of the research; process, temporality.

The logo, which represents people who are visually differentiated walking in the same direction, was applied to all the promotional materials, including stationery, stickers, envelopes and leaflets, as well as to the material used by the team (clothes, bags and backpacks) and by participants during the tests. Thus, the aim was to grant unity to the initiatives, contributing to the team's feeling of belonging and fixing a positive image of the study among eligible people, participants and the public in general.

Dissemination of information about the study

Since the beginning, efforts were invested in communication actions and strategies, especially by the Ethics, Recruitment and Social Communication Committee, under the coordination of the IC of the State of Bahia (Northeastern Brazil), where the Communication Center was organized for specialized support and education in scientific journalism.

The official website of the ELSA-Brasil[a] was created with the purpose of dialoging with different audiences, functioning as a scientific disseminator and contributing to the formation and consolidation of the study's image within society. Based on the division in sections – General Interest, Participants and Researchers –, the website has enabled the dissemination of information about the study and of scientific knowledge to the population.

The institutional means and spaces were mapped for transmission of information about the study and promotional products were developed.

The poster with the logo summoned people to participate in the study and strengthened potential benefits, like free access to health control tests and the contribution to disease prevention and control in Brazil through the generation of scientific knowledge.

The awareness-raising folder was the main printed material that was used and it included information on the ELSA-Brasil and its importance, participation criteria and enrollment instructions. In a detachable form, the volunteers registered data that enabled to locate them for recruitment. Two pullouts included in this folder were targeted at health professionals, who have specialized knowledge about the object of the study; and at the retirees, due to their age and employment situation.

The reading of the TCLE before the Stage 1 interview enabled the volunteer to understand his/her rights and commitments when entering the study. Many pre-tests were carried out with outsourced employees whose profile was similar to that of the eligible employees, until the comprehension problems were overcome.

After performing the first part of the interview, the person received the Guide for Participation in the ELSA-Brasil, with instructions to perform tests and to the visit to the IC, when he/she could solve doubts and complement information.

All the centers, at distinct moments, conducted personalized dissemination, or dissemination for specific groups, like teachers and retirees, by sending folders or invitation letters attached to paychecks, placed in personal pigeonholes, sent by mail or electronic message.

A folder for international dissemination contains information about the study in Portuguese, Spanish and English.

Study's team

The selection of the team to perform the recruitment focused on relevant skills to obtain the participants' adherence, such as communication capacity, assertive and reliable attitude, responsibility, persistence and flexibility. The training for the recruitment lasted 12 hours within a broader program of interviewers' qualification. In the specific module, forms, materials and promotional means were presented, as well as general and local recruitment strategies, such as approaching eligible people at the workplace and dealing with situations of limited availability of time, evasive attitudes and explicit refusals, the interest of ineligible people, the scheduling of the interview, and special situations (people with special needs, pregnant women, retirees).

Supervision mechanisms were defined so as to support the interviewers in order to take maximum advantage of the recruitment opportunities, besides enforcing strict

[a] ELSA-Brasil. [cited Mar 8 2013]. Available from: http://www.elsa.org.br/

quality assurance. These included weekly face-to-face meetings between supervisors and the local team, and the supervisor network, through face-to-face meetings or audio-conference.

Contact and scheduling methods

Since the initial contact, the researchers attempted to ensure that the volunteers learned about all the stages of the study, received correct and reliable information, and that the commitment to the ethical conduction of the study was transmitted to them.

An element that facilitated adherence was the possibility of choosing the time for the Stage 1 interview, even in the evenings, and its performance at workplaces, where spaces with privacy were selected. The Stage 1 interviews also took place at the IC headquarters, in the case of retired interviewees, or when the location of the headquarters facilitated the participant's access or provided greater privacy. Exceptionally at this stage, retirees were interviewed at their own homes.

The subjects were offered the option of scheduling the visit to the IC during recruitment or after the Stage 1 interview, on a date and at a time chosen by the participant according to different flows. A maximum of three re-schedulings was allowed. With antecedence of 24 to 48 hours, the participants received a call from "ELSA calls" to confirm the date and time of the visit to the IC and to revise instructions for measurements and tests.

Characteristics of the interaction for data production

Recruitment included interviewers' visits to the units. They approached employees, distributed promotional material and, if possible, performed the immediate recruitment. Stands were installed at the campuses as bases to support the team and to collect the contact forms that had been filled in. Boxes were also placed at strategic places, like bank branches (which concentrate the employees' payment), medical service, restaurants, employees' unions, and at the assistance center of human resources units.

The contact with active and retired volunteers was made predominantly by telephone. After the eligibility criteria were confirmed, the Stage 1 interview was scheduled and, at some centers, also the visit to the IC. Volunteers who did not confirm the initial interest were no longer contacted, but they were informed that they could participate in the study if they changed their minds.

The recruitment of retirees required special care, as they no longer attend the workplaces and have less access to the information about the research, especially because older generations use electronic communication resources less frequently. Several strategies were used to reach them and to stimulate them to participate, such as telephone contacts, the sending of letters and distribution of posters and folders at bank branches of the campuses, class entities, and at the employee service venues of the human resources unit.

One strategy that proved to be effective was the involvement of participants as multipliers. They distributed folders at their workplaces and indicated colleagues to be invited to participate in the study.

During the participants' permanence at the IC, it was attempted to offer a warm environment, including care for special needs, such as limited mobility or difficulty to tolerate fasting, visual or hearing impairment, diabetes, obesity, food restrictions and use of medicines. The ICs headquarters were constructed or adapted for wheelchair users and the team was trained to receive and deal with people with different types of limitation.

Benefits of the study and non-financial incentives

One of the immediate benefits to the cohort participants is the access to results of measurements and tests, which are useful to clinical assessments. They are informed of incidental diagnoses, with orientations and referral to the most adequate assistance within what is offered by the institutions and by the *Sistema Único de Saúde* (Brazilian Unified Health System), or to another service of their preference.

The participants have received small gifts, such as calendars, mugs, pens, fridge magnets, badges, diaries, containing the logo, so as to consolidate the study's image, maintaining it in the participants' memory and strengthening in them the feeling of belonging to the cohort. With the same purposes, they receive messages on special dates, like the "Day of the Civil Servant", birthday cards and end of the year cards.

Beyond immediate benefits, a strong motivation to the participants' adherence was the opportunity to contribute to the generation of new knowledge about health in Brazil, which had been identified in previous focal groups and was confirmed by the explicit statement after the performance of interviews and tests.

RESULTS

The constitution of the cohort and the baseline study occurred in the period from August 2008 to December 2010.

The results achieved with people who were recruited and interviewed at Stages 1 and 2, and the losses between stages, are shown in Figure 1. The recruitment goals were achieved at the six centers, and this enabled to form a total of 15,105 participants enrolled

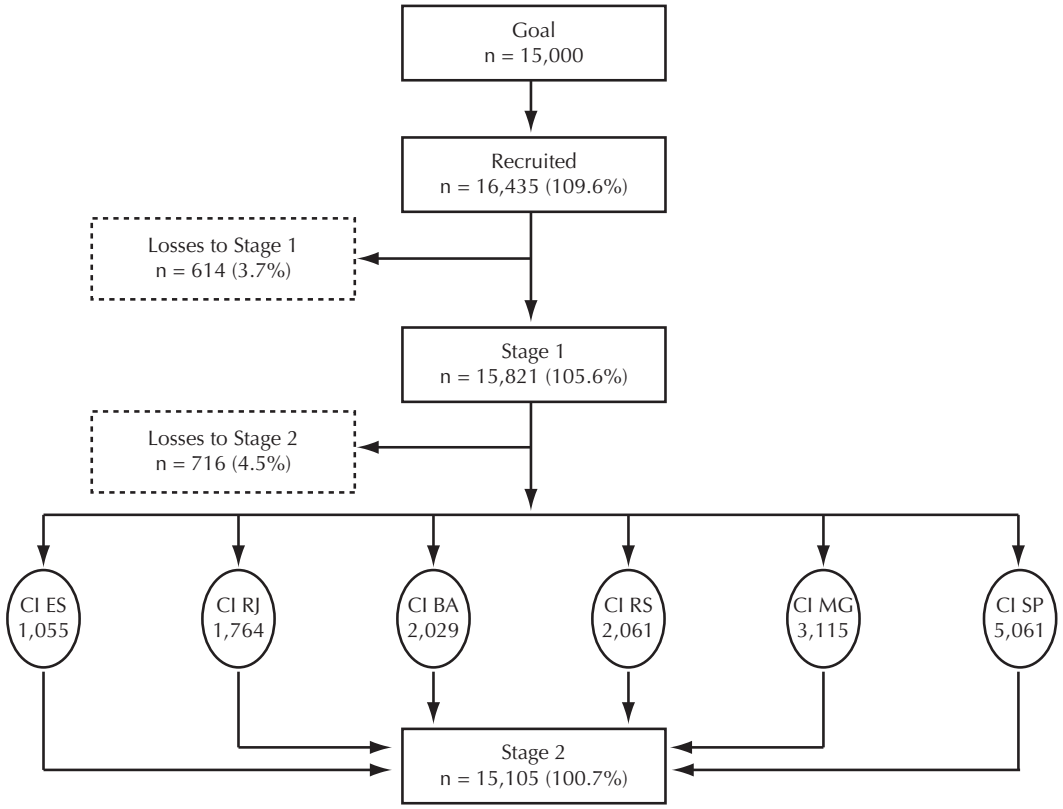


Figure 1. Global goal of recruitment and performance according to the stage of cohort constitution. ELSA-Brasil, 2008–2010.

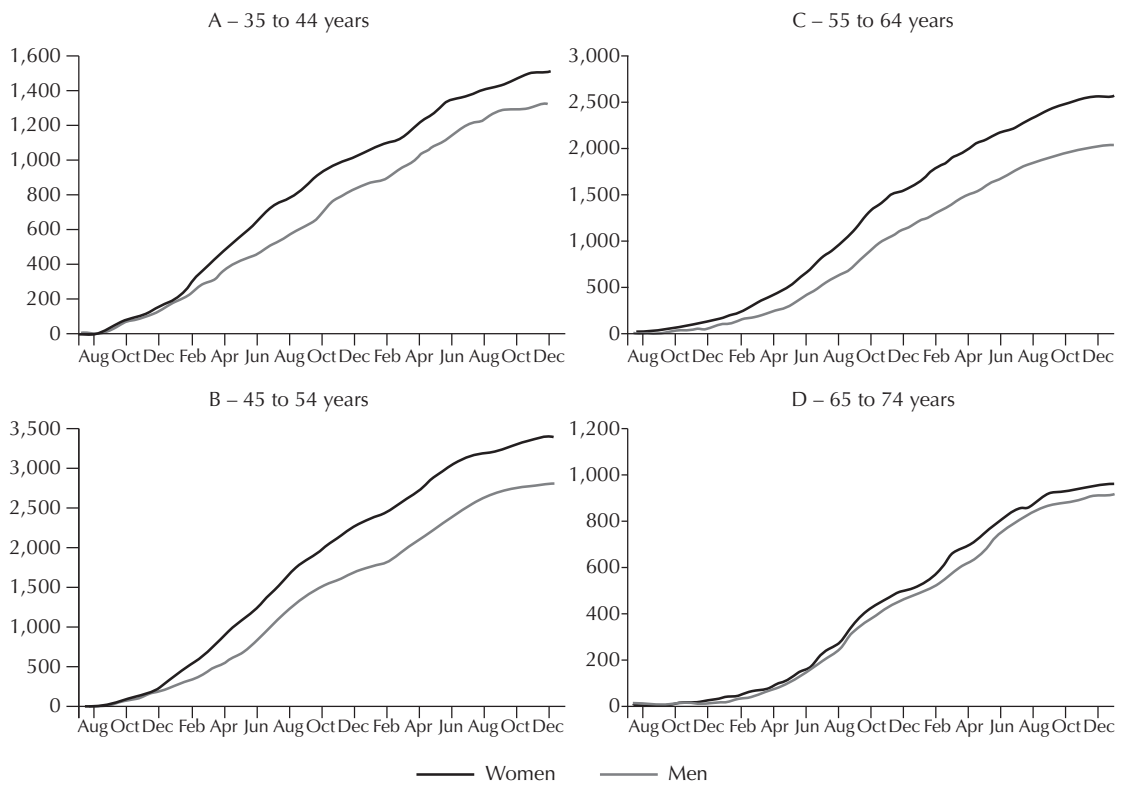


Figure 2. Temporal distribution of participants according to sex and age groups. ELSA-Brasil, 2008–2010.

in the cohort. The losses were of 3.7% between recruitment and Stage 1, and 4.5% between Stage 1 and Stage 2.

The number of women was slightly higher in recruitment and at Stages 1 and 2 (Table). In the cohort, they corresponded to 54.4% of the total.

Analyzing the distribution per age group, occupational group and employment situation at the distinct stages, it is possible to notice that the percentages did not show great variations between women and men, except in the extreme age groups (Table).

Table. Results achieved at each stage of the cohort constitution, according to selected characteristics and sex. ELSA-Brasil, 2008–2010.

Characteristics	Recruitment	Stage 1	Stage 2
Women	% (n = 8,913)	% (n = 8,616)	% (n = 8,211)
Age group			
35 to 44	21.1	21.4	18.0
45 to 54	39.2	39.6	39.7
55 to 64	29.0	28.8	30.7
65 to 74	10.7	10.2	11.6
Level of the employment category			
Support	25.9	25.7	26.1
High School	38.5	38.4	38.4
Higher education/ Professor	35.6	35.9	35.5
Employment Situation			
Active	78.6	79.1	78.6
Retired	21.4	20.9	21.4
Men	% (n = 7,522)	% (n = 7,205)	% (n = 6,894)
Age group			
33 to 44	22.2	22.3	18.7
45 to 54	38.2	39.0	39.2
55 to 64	27.0	26.8	28.9
65 to 74	12.6	11.9	13.2
Level of the employment category			
Support	29.5	30.2	30.8
High School	32.2	32.2	32.5
Higher education/ professor	38.3	37.6	36.8
Employment Situation			
Active	83.4	84.7	84.4
Retired	16.6	15.3	15.6

[a] The employment categories were grouped according to the required level of schooling. "Support" represents the set of occupations to which incomplete elementary education is required. In the absence of a more appropriate name, it was called support level.

The temporal distribution of the constitution of the cohort shows the earlier adherence of the women, except between 65 and 74 years of age (Figure 2) and in the group of support level (Figure 3), where the differences practically disappear.

The ethnic-racial heterogeneity of the cohort is evidenced in Figure 4: while the IC in the State of Bahia – the only one in the Northeast region – has a majority of blacks and browns (78.4%), this proportion is reduced in the centers located in the Southeast, and in the South of the country, in the IC located in the State of Rio Grande do Sul, the composition is inverted, with 75% of its population self-reporting themselves as whites.

DISCUSSION

ELSA-Brasil had a good receptiveness. It reached the recruitment goals with few losses between the distinct stages after the initial recruitment. Several elements may have contributed to facilitate and maintain adherence.

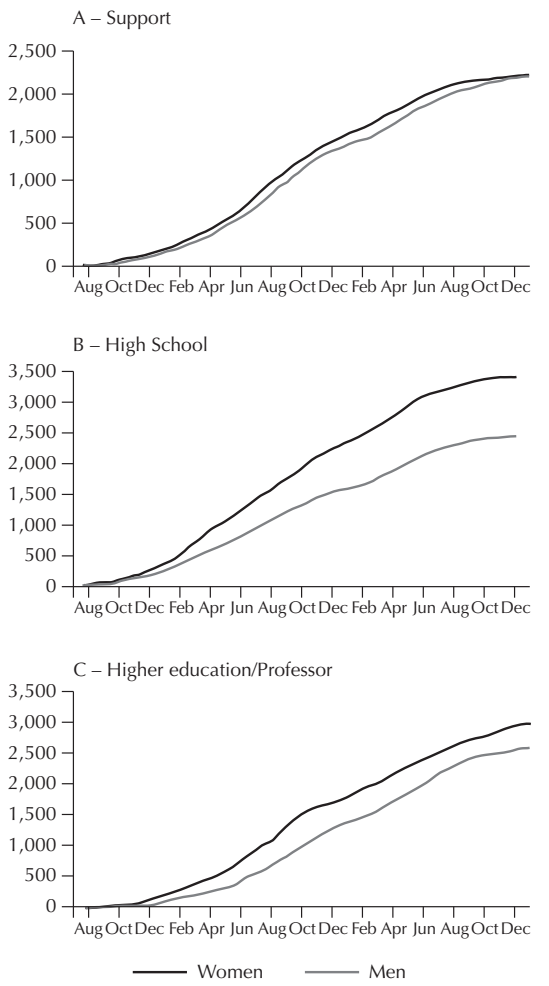
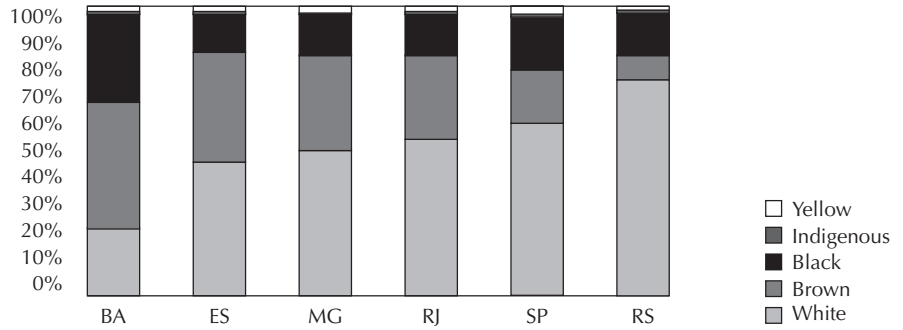


Figure 3. Temporal distribution of participants according to sex and level of the employment category. ELSA-Brasil, 2008–2010.



	BA	ES	MG	RJ	SP	RS
Yellow	1.2%	1.7%	2.3%	2.0%	4.3%	0.7%
Indigenous	1.4%	1.0%	0.6%	0.8%	1.1%	1.4%
Black	33.5%	11.8%	13.0%	13.5%	13.7%	14.0%
Brown	44.9%	41.6%	35.0%	30.9%	21.5%	8.7%
White	19.0%	44.0%	49.1%	52.8%	59.4%	75.3%

Figure 4. Relative distribution of the cohort participants according to self-reported color/race per Investigation Center. ELSA-Brasil, 2008–2010.

The study being of the observational type, with only one minimally invasive procedure (blood collection), and the large experience in research of the institutions that develop the study, contributed to the good results that have been achieved.

The choice of civil servants with stable employment facilitated the access to eligible individuals and will contribute to their follow-up. Although it excludes the participation of less favored social strata and informal workers, the recruited cohort is fairly heterogeneous in socioeconomic and ethnic-racial terms, and it comes from different cultural contexts of Brazil.

There were few exclusion criteria, so as to amplify participation and the possibility of reaching the goals. Temporary ineligibility was an adequate decision, as it enabled even more to reach the goals, and also consolidated the study's inclusive image.

The operationalization of the baseline in two stages was a great challenge, with long interviews and multiple tests and measurements until the enrollment was concluded.

The broad age range and the relative heterogeneity of the cohort demanded "cultural sensitivity"[14] in approaching potential volunteers, with careful recognition of the research contexts before beginning to conduct the study. The effort targeted at cultural adaptation was present in the training of the team, in the production of specific messages for subgroups – like health professionals, retirees and elderly individuals –, in the care with the language of the communication products, and in the incorporation of participants as multipliers, as it has been described in other studies.[14]

The community's preparation for the study, by means of multiple awareness-raising strategies, resulted in a good acceptance of the project in all the centers. The information was transmitted with clear messages and many resources were systematically used to maintain the study in the memory of potential participants at all the stages until recruitment was concluded.

Two strategies that contributed to maintain adherence between stages were the flexibility of times in scheduling contacts[15] and the service "ELSA calls", which recalled the scheduled date and time and the procedures that should be carried out before the tests.

The literature emphasizes that multiple strategies and actions obtain higher participation rates, especially if they take into account specificities of subgroups.[10,13-15]

Retirees, especially the older ones, had greater difficulty in mobility and in the access to information about the study, as it has been described in the literature.[14] Unlike what we might suppose, they have little available time, as many of them continue working, and mainly the women are busy performing domestic chores, taking care of children and of ill people.[4] In these cases, flexible scheduling favored greater participation.

As they are outside the institutional spaces, except at specific moments and places, the retirees required differentiated means of communication. Many of them do not have the habit of using the internet, which makes the sending of electronic messages and the dissemination via website become little effective strategies. However, they responded positively to personalized telephone contacts, which were interpreted as a way to value the retired employees, and this was reflected on the increase in the adherence to the study. Due to

their age, this segment has more physical and cognitive limitations and lower concentration capacity, which increased the duration of the interviews.[14] To overcome these difficulties, care with accessibility at the ICs and the training of the team were important, like what has been observed in other contexts.[13,14]

The group belonging to the employment category of support, with lower level of schooling and income, has less autonomy to get away from work, which demanded negotiations to obtain their bosses' authorization. Lower participation rates and higher resistance to adhering to longitudinal studies have been described by other authors, who have emphasized the importance of multiple approaches to reach larger representation of less favored strata.[10,13,18]

The women responded more promptly to the recruitment actions, confirming other studies[10] and their greater engagement in health care. The male resistance was remarkable, especially in the State of Bahia, which required specific communication strategies until the end of the baseline. In traditional gender relations, the role of provider is given to men, who focus on work, are "strong" and resistant to health care, especially to preventive measures,[6,8,9] which probably explains the greater difficulty in incorporating them.

The experience described here is a contribution that has been scarce in Brazil, and although it refers to the specific population of civil servants, it may be useful to be reproduced in similar studies.

As it has been emphasized in the international literature,[10,14,18] more than describing recruitment strategies, in new studies it is necessary to evaluate the relation between the cost and effectiveness of the actions, mainly when we are dealing with research funded by public resources.

However, the main challenge from now onwards is the retention of the cohort, in order to produce results that subsidize public policies to improve the health and wellbeing conditions of the Brazilian population.

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The Brazilian Longitudinal Study for Adult Health (ELSA-Brasil) was financed by the Ministry of Health (DECIT – Departamento de Ciência e Tecnologia – Science and Technology Department) and by the Ministry of Science and Technology (FINEP – Studies and Projects Finance Organization and CNPq – Conselho Nacional de Desenvolvimento Científico e Tecnológico (National Council for Scientific and Technological Development) (Processes N. 01 06 0010.00 RS, 01 06 0212.00 BA, 01 06 0300.00 ES, 01 06 0278.00 MG, 01 06 0115.00 SP, 01 06 0071.00 RJ).
The authors declare that there are no conflicts of interest.
This manuscript was submitted for publication and underwent a peer review process as any other manuscripts submitted to this publication, and anonymity was guaranteed for authors and reviewers. Editors and reviewers declare no conflicts of interest that may affect the peer-review process.