

Original paper

Determinants of follow-up participation in the Internet-based European influenza surveillance platform Influenzanet

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Abstract

Background

InfluenzaNet is a network of Internet-based platforms aimed at collecting real-time data for influenza surveillance in several European countries. More than 30000 European volunteers participate every year in the study, representing one of the largest existing Internet-based multicentre cohorts. Each week during the influenza season, participants are asked to report their symptoms (if any) along with a set of follow-up questions.

Objective

Focusing on the first influenza season of 2011-12 when the InfluenzaNet system was completely harmonized within a common framework among Sweden, United Kingdom, the Netherlands, Belgium, France, Italy and Portugal, we investigated the propensity of users to regularly come back to the platform to provide information about their health status. Our purpose is to investigate demographic and behavioural factors associated with participation in follow-up.

Methods

By means of a multilevel analysis, we have evaluated the association between the participation in the follow-up during the season and some socio-demographic and behavioural features extracted by a background questionnaire proposed to participants.

Results

We found that lower participation in follow-up was associated with lower educational status (Odds Ratios [OR] = 0.80, 95% Confidence Interval [CI] = 0.75-0.85), smoking (OR = 0.64, 95% CI = 0.59-0.70), younger age (OR ranging from 0.30, 95% CI = 0.26-0.33 to 0.70, 95% CI = 0.64-0.77), not being vaccinated against seasonal influenza (OR = 0.77, 95% CI = 0.72-0.84) and living in a household with children (OR = 0.69, 95% CI = 0.65-0.74). Most of these results hold when single countries are analysed separately.

Conclusions

Given the opportunistic enrolment of self-selected volunteers in the InfluenzaNet study, we have investigated how socio-demographic and behavioural characteristics may be associated with follow-up participation in the InfluenzaNet cohort. The study described in this paper shows that overall, the most important determinants of participation are related to education and lifestyle: smoking, lower education level, younger age, people living with children and people who have not been vaccinated against seasonal influenza tend to have a lower participation in follow-up. Despite the cross-country variation, the main findings are similar in the different cohorts, and indeed the results are found to be valid also when performing a single-country analysis. Differences between countries do not seem to play a crucial role in determining the factors associated to the participation in follow-up. This suggests that the self-selection of volunteers through an Internet-based system does not introduce different motivations or determinants for follow-up participation in a study with respect to traditional non-Internet based epidemiological studies.

Keywords

Influenza, surveillance, Internet, participation, digital epidemiology

Introduction

The Internet is becoming an increasingly used tool in epidemiological data collection, especially for recruitment and follow-up of large cohorts. Successful examples of this approach include the Millennium Cohort Study [1], the Nurses and Midwives e-Cohort Study [2], the Internet-based Pregnancy Planning Study —‘SnartGravid’ [3], the participatory nutritional study Nutrinet [4] and the new born cohort NINFEA [5]. Some studies have systematically examined the advantages of the Internet-based approach [6,7], mostly in terms of the reduction of costs and time required for the data collection. Moreover, an unknown proportion of individuals with symptoms do not attend health care, and this proportion may vary with age, sex or other social groups. Healthcare-seeking behaviour also varies between countries and may change over the course of an epidemic. There is currently no method for systematically assessing healthcare usage. The use of the Internet can help to overcome this issue. Here we focus on Internet-based community surveillance of influenza-like-illness (ILI) as a means of gathering epidemiological data from the general population in a participatory fashion. In particular, we will study how the characteristics of individuals who register for the surveillance system affect their involvement over the course of a surveillance season.

Influenza-like illness in Europe is monitored by means of nationwide networks of sentinel General Practitioners (GPs) detecting only medically attended ILI cases. Internet-based community surveillance of influenza can help to determine the disease burden [8], time trends and seasonality, and to characterise health seeking treatment behaviour [9] and patterns of absenteeism [10]. Internet-based systems can thus enhance traditional GP-based surveillance and support the interpretation of recorded data, both for pandemic and seasonal influenza [8,9].

Collection of data related to influenza-like symptoms using an Internet platform is on going in some European countries: since 2003 in the Netherlands and Belgium [11], since 2005 in Portugal [12], 2008 in Italy and 2009 in UK [8,9]. Starting during the influenza season 2011-2012, for the first time, a network of Internet-based surveillance systems, called Influenzanet [13] has been active in seven European countries (the Netherlands, Belgium, Portugal, Italy, United Kingdom, Sweden, France), each using the same platform with the aim of gathering data across different countries in a standardized way, to monitor in real-time ILI in the community, track vaccine effectiveness [10,14], and to estimate risk factors for ILI.

In the seven countries, epidemiological data are collected with the participation of a self-selected cohort followed over the influenza season. The success of the data collection strongly depends on the participation extent of the volunteers involved in the projects. Here, we investigate the determinants of participation in follow-up of volunteers enrolled in the Influenzanet platforms during the influenza season 2011-2012.

Materials and Methods

Any resident of a country where Influenzanet is implemented can be involved in the influenza data collection by

registering through the national web page [15-20]. In the various countries, identical questionnaires are implemented with questions about respiratory symptoms, access and utilisation of care and self-medication, uptake of vaccines, attitudes to influenza vaccines, and absenteeism. For sake of clarity, in the following the term “users” will indicate all the individuals who have registered with the platform and possess a username and a password, regardless of their subsequent activity during the influenza season.

Upon registration, users are invited to fill in a background questionnaire (BQ) containing various socio-demographic, medical, geographic and behavioural questions. In particular, the background questionnaire covers age, gender, household size and composition, location of home and workplace, education level, occupation, vaccination status for the previous and present influenza season, the presence of a chronic disease, a possible pregnancy and other issues (see the complete list of questions in Media Appendix 1). Users are reminded weekly, via an email newsletter, to report their health status through a brief symptoms questionnaire (SQ), whether or not they experienced any symptoms since last time they visited the platform. Users who report the presence of symptoms are asked some follow-up questions about the symptoms onset date, about their healthcare seeking behaviour, medications taken for that particular episode of illness and time off work/school. The weekly newsletter contains also a summary of the latest influenza facts and news to maintain users’ interest in the questionnaire. Users can also create accounts on behalf of other members of their family/household, thus enabling, for instance, parents to record data for their children.

To study the determinants of participation in follow up, we analysed the behaviour of users over the course of an influenza season focusing on their propensity to return to the platform and provide information about their health status. The background questionnaire proposed when participants register with the InfluenzaNet system allows to study how the socio-demographic characteristics of the participants are related to participation in follow-up. The study sample here consists of all the InfluenzaNet volunteers in the seven European countries who contributed with at least one symptoms questionnaire during the 2011-2012 influenza season and who inserted their own data. In fact, since users can also create accounts on behalf of other people of their family/household, we discarded users whose information was reported to have been provided by someone else (e.g. a husband whose questionnaires are filled in by his wife). Likewise, we did not consider subjects aged less than 15 or more than 70 years old, on the assumption that a different participant may have managed their account. In fact, more than 400 children aged less than 15 years old and more than 200 individuals aged more than 70 years have their own account, i.e. their own username and password to access the platform. This is due to the fact that in the previous years, some of the platforms had the requirement that each individual had to have his/her own account even if it was managed by a relative. Therefore we do impose the additional constraint on the volunteers' age considering a stricter age brackets.

From the study sample, we consider as “enrolled participants”, i.e. participants eligible to be included in the analysis presented here, those who completed their first symptoms questionnaire at least 60 days before the end of the monitoring season, and filled at least one additional symptoms questionnaire within 15 days of the first symptoms questionnaire. From enrolled participants, we considered as ‘participants in follow-up’ or

‘respondent participants’ (either terms will be used in the following) those individuals who filled in at least two symptoms questionnaires during the time window of 30 to 60 days after their first symptoms questionnaire. Otherwise, the enrolled participants were considered not involved in the follow-up (see Figure 1).

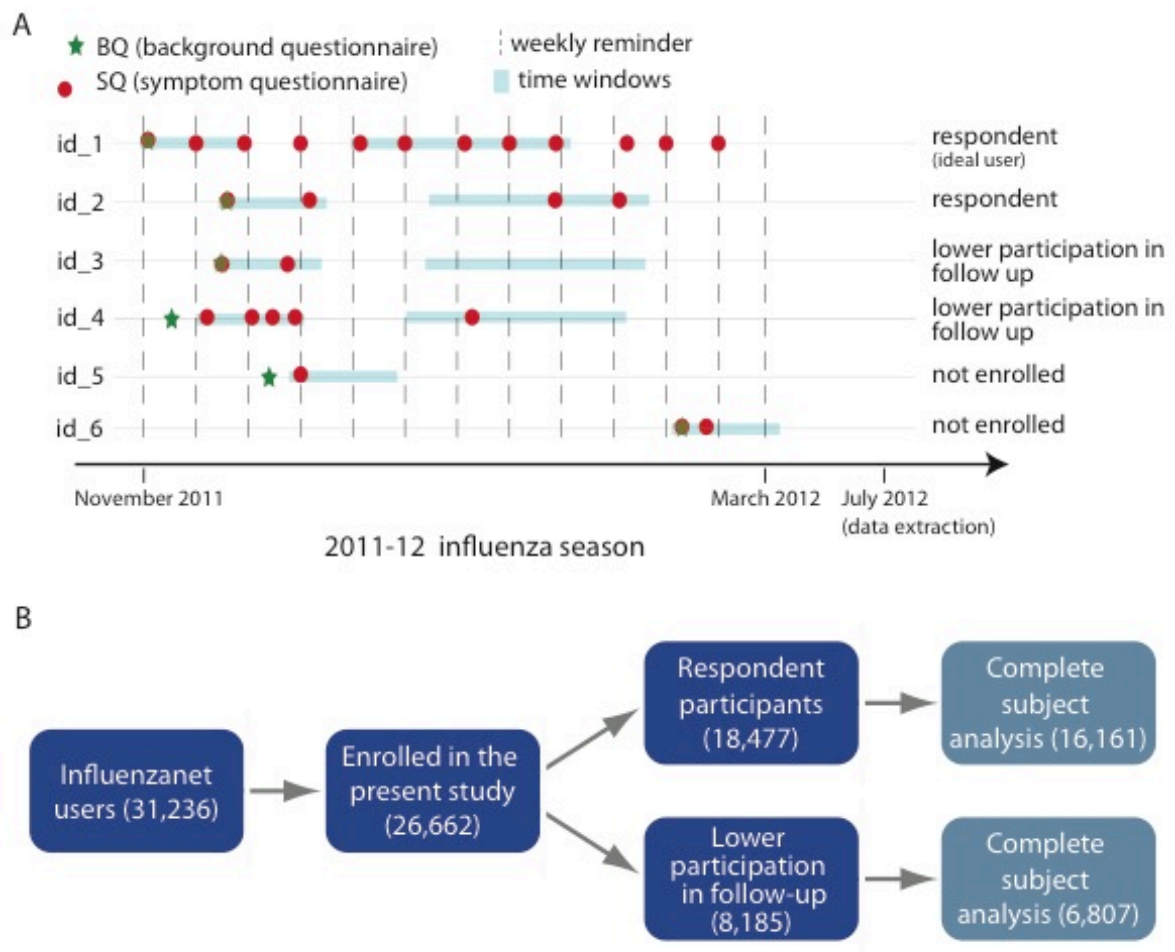


Figure 1: Illustration of the study baseline definitions for enrolment and follow-up participation. Baseline definition for enrolment: first symptoms questionnaire (SQ) at least 60 days before end of the monitoring season and at least one more SQ within 15 days from the first SQ; follow-up participation: at least two SQs during the time window of 30 to 60 days after the first SQ.

In order to properly follow the unfolding of the seasonal epidemic and collect data that can be compared with the sentinel based surveillance (which aggregates data on a weekly basis), we propose weekly follow-up questionnaires to the users. Indeed, although completing the symptoms questionnaire only took a couple of minutes each week, there are numerous missing reports. Nevertheless, many individuals who missed a week did not drop out of the study; instead, they updated their health status more rarely but they continued to provide useful information. On the other hand, some individuals registered on the website just to explore the website and its functionalities and never updated their health status; these individuals are not considered to be enrolled in the study. The definition for enrolled participants and participants involved in the follow-up are indeed arbitrary but they were chosen to capture the data insertion behavior that would guarantee a flow of useful information throughout the season.

By means of a multilevel analysis, we have evaluated the association between the participation in the follow-up during the season and some socio-demographic and behavioural features extracted by the BQ. The multilevel analysis in general is used when the set of values of a categorical predictor variable are seen not as the complete set but rather as a random sample of all values, in order to allow inferences over a wider population than is possible with regression or other general linear model methods. In this case, we considered the follow-up participation as a dichotomous outcome, the socio-demographic and behavioural characteristics as independent variables and the country variability as a random effect. We used as independent variables gender, age, education level, household composition, smoking, presence of a chronic condition, vaccination status. For each variable, we used the following levels:

- gender: male, female;
- age (years old): 15-30, 31 – 40, 41 – 50, 51 – 60, 61 – 70 ;
- smoking: yes (smoking occasionally or daily), no (never smoked or quit smoking);
- education level: no formal qualification (final stage of compulsory education not completed), secondary/high school education (highest level completed was the final stage of compulsory education or the high school diploma), university degree (Bachelor's or a higher degree), still in education (this was not a mutually exclusive category per se, as users were asked, if still in education, to select also the highest level of education achieved; we thus performed a sensitivity analysis considering this category as a missing value and obtaining very similar results);
- presence of a chronic condition/disease: yes (regularly taking medications for asthma, diabetes, lung disorder, heart disorder, kidney disorder or an immune-compromising condition), no;
- vaccination against seasonal influenza for 2011/12 season: yes, no;
- household with children (≤ 18 years old): yes, no;

In the multilevel analysis, each variable was adjusted against all the others as potential confounders for the outcome. Since some subject records for the various independent variables were missing, we have used a complete-subject analysis to deal with such missing records, thus the multilevel regression was performed only on those enrolled individuals who provided information for all the considered variables. The education level was asked only to participants above 15 years old, and therefore those with 15 years old are excluded from the multivariate analysis. The reference age group was chosen to be the one with more participants in the total population (51-60 years old) in order to reduce the estimates of confidence intervals. Given the relatively small number of clusters (i.e. countries), we verified that a logistic regression where the countries are considered as dummy variables led to results comparable with those obtained with the multilevel regression in terms of strength of association (i.e. odds ratios) and significance (*P value*). Data were analyzed using Stata software, version 11.0.

In The United Kingdom, the Flusurvey study was approved by the London School of Hygiene and Tropical Medicine Ethics Committee (Application number 5530). In Sweden, the Influenzakoll study was approved by the Stockholm Regional Ethical Review Board (Dnr. 2011/387-31/4). In France, the GrippeNet study has been approved by the Comité consultatif sur le traitement de l'information en matière de recherche (CCTIRS, Advisory committee on information processing for research, authorization 11.565) and by the Commission Nationale de l'Informatique et des Libertés (CNIL, French Data Protection Authority, authorization DR-2012-024).

In all the participating countries, the study was conducted in agreement with national regulations on privacy and data collection and treatment. Informed consent has been obtained from individuals who participated in the study described in this article that the information collected through their data may be used for scientific purposes and published.

Results

Overall, 31,236 individuals registered and filled at least one symptoms questionnaire during the influenza season 2011-2012, of which 28644 were aged ≥ 15 and ≤ 70 years old, thereby comprising the sample in this study. Among these, there was a total of 26,662 enrolled participants, according to the definition above. The socio-demographic characteristics of enrolled participants are shown in Figure 2: gender, age, education level, household composition, smoking, presence of a chronic condition and vaccination status.

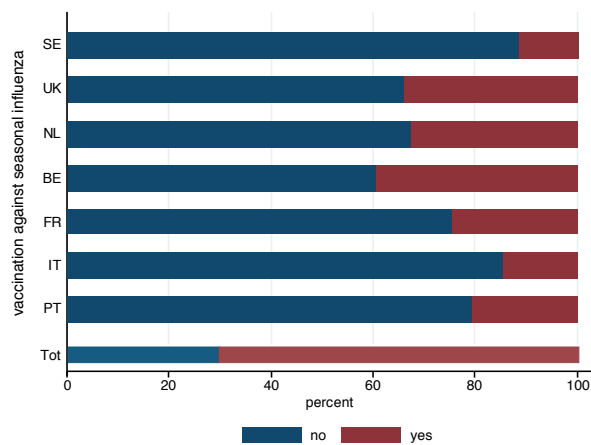
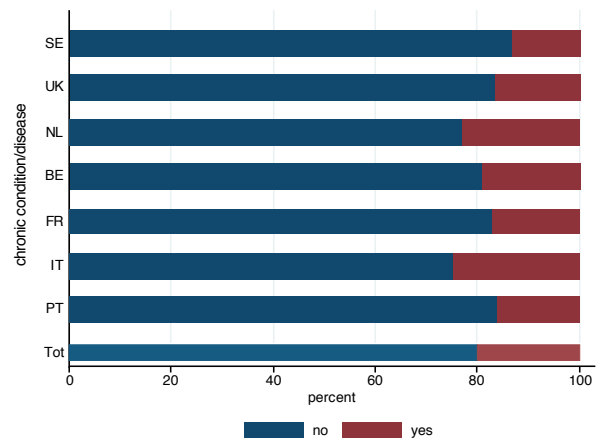
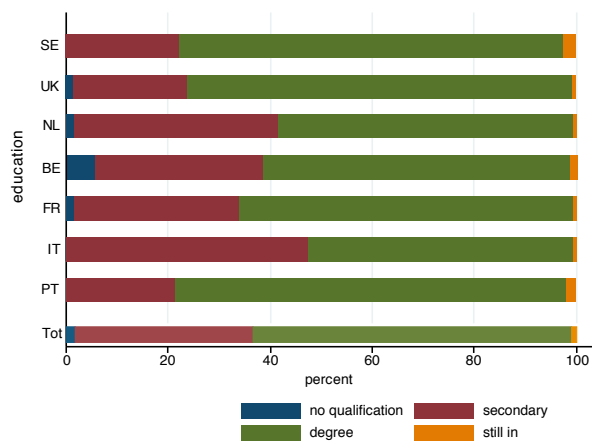
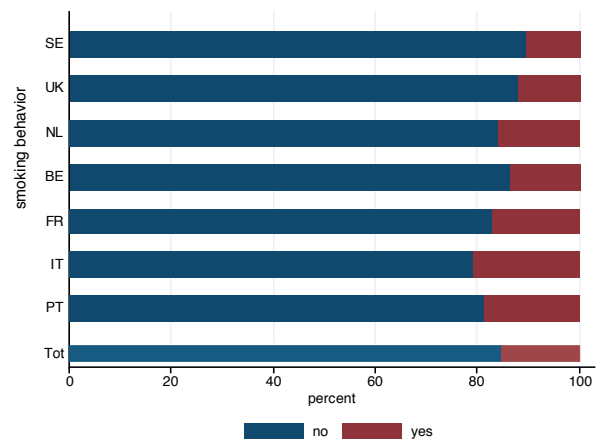
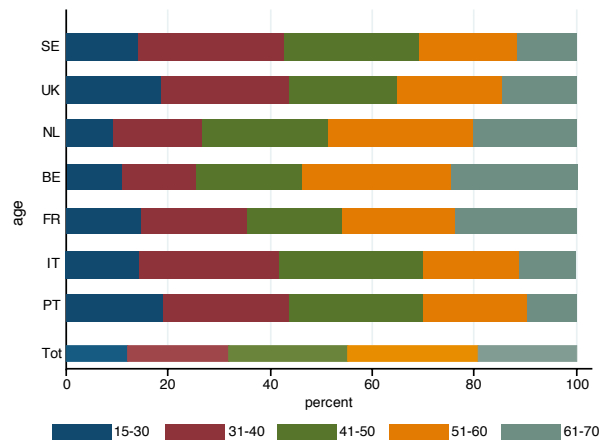
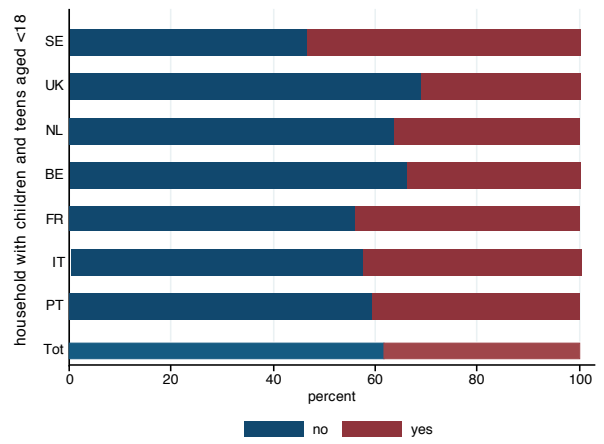
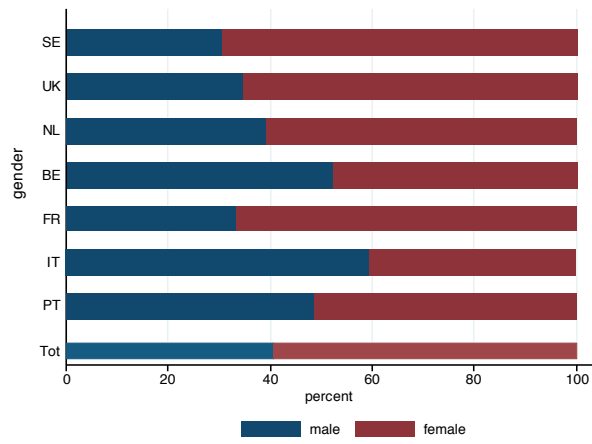


Figure 2: Country-specific distribution of the independent variables of enrolled participants: gender, age, education level, household composition, smoking habits, presence of a chronic condition and vaccination status.

For each country, the numbers of enrolled participants and follow-up respondents are shown in Table 1. After the complete-subject exclusion of individuals with missing records, the final sample on which the multilevel regression has been performed was of 22,968 enrolled individuals who provided information for all the variables (86% of all enrolled participants).

Table 1: Cohort size and participation proportion in the seven countries considering two different enrolment definitions [Odds Ratios are abbreviated as OR, Confidence Interval is abbreviated as CI]

Country	Baseline Criterion		
	Enrolled participants	Respondent participants (%)	Participants not involved in follow up (%)
Sweden	2,097	904 (43)	1,193 (57)
United Kingdom	2,171	1,180 (54)	991 (46)
Netherlands	12,524	9,679 (77)	2,835 (23)
Belgium	3,834	3,042 (79)	792 (21)
France	3,540	2,227 (63)	1,313 (37)
Italy	1,354	657 (49)	697 (51)
Portugal	1,152	788 (68)	364 (32)
Total	26,662	18,477 (69)	8,185 (31)

The proportion of follow-up participation varies between 43% and 79% across the national platforms for the baseline definition and between 52% and 83% when a stricter definition is used. The Dutch cohort represents almost half of the entire Influenzanet cohort, while the sample sizes of the others studies range between 1,152 and 3,834 individuals.

For comparison, we report in Table 2 the information regarding Internet access in each country, i.e. the fraction of internet users with respect to the general population.

Table 2: General population and fraction of Internet users for each country in the cohort.

Country	Population (2012 Ets.)	Internet users (30 June 2013)	Penetration (% population)
Sweden	9,103,788	8,441,718	92.7 %
United Kingdom	63,047,162	52,731,209	83.6 %
Netherlands	16,730,632	15,549,787	92.9 %
Belgium	10,438,353	8,489,901	81.3 %

France	65,630,692	52,228,905	79.6 %
Italy	61,261,254	35,800,000	58.4 %
Portugal	10,781,459	5,950,449	55.2 %

The results of the multilevel analysis are shown in Table 3. A *P value*<0.001 associated with the likelihood-ratio test allows us to reject the null hypothesis that the between cluster (i.e. between countries) variance is zero, thus confirming that a multilevel analysis is required.

Table 3: Random effect multilevel logistic regression performed on the set of enrolled individuals (Odds Ratios are abbreviated as OR, Confidence Interval is abbreviated as CI)

Variable	Reference group	Adjusted OR	95% CI	<i>P value</i>
Gender				
Female	Male	1.01	0.95-1.08	0.775
Age				
15 - 30	51-60	0.30	0.26-0.33	<0.001
31-40	51-60	0.47	0.43-0.52	<0.001
41-50	51-60	0.70	0.64-0.77	< 0.001
61 -70	51-60	1.42	1.28-1.59	< 0.001
Smoking				
Yes	No	0.64	0.59-0.7	< 0.001
Education				
No formal qualification	University degree	0.70	0.55-0.88	0.002
Secondary/high school education	University degree	0.80	0.75-0.85	< 0.001
Still in education	University degree	0.71	0.53-0.95	0.023
Chronic condition/disease				
Yes	No	0.80	0.74-0.87	< 0.001
Vaccination against seasonal influenza for 2011/12				
Yes	No	0.77	0.72-0.84	< 0.001
Household with children				
Yes	No	0.69	0.65-0.74	< 0.001

The multilevel results show that men and women do not differ significantly in terms of follow-up participation. Holding a university degree, a non-smoking behaviour and an increasing age are associated with a higher participation in follow-up. On the other hand, even though the majority of enrolled participants composing the sample had not been vaccinated against seasonal influenza, those who were vaccinated are more likely to participate in follow-up. Moreover, enrolled participants who lived in a household without children are also more likely to be participating in follow up. The diagnosis of chronic disorder/condition does not seem to boost the participation in follow-up, as participants with chronic disorders tend to be less likely to participate in follow-up than healthy individuals.

We performed a separate analysis for each country by calculating both the crude and adjusted odds ratio for being a follow-up participant using the same variables that were used for the random effects multilevel analysis. Results are shown in Figure 3.

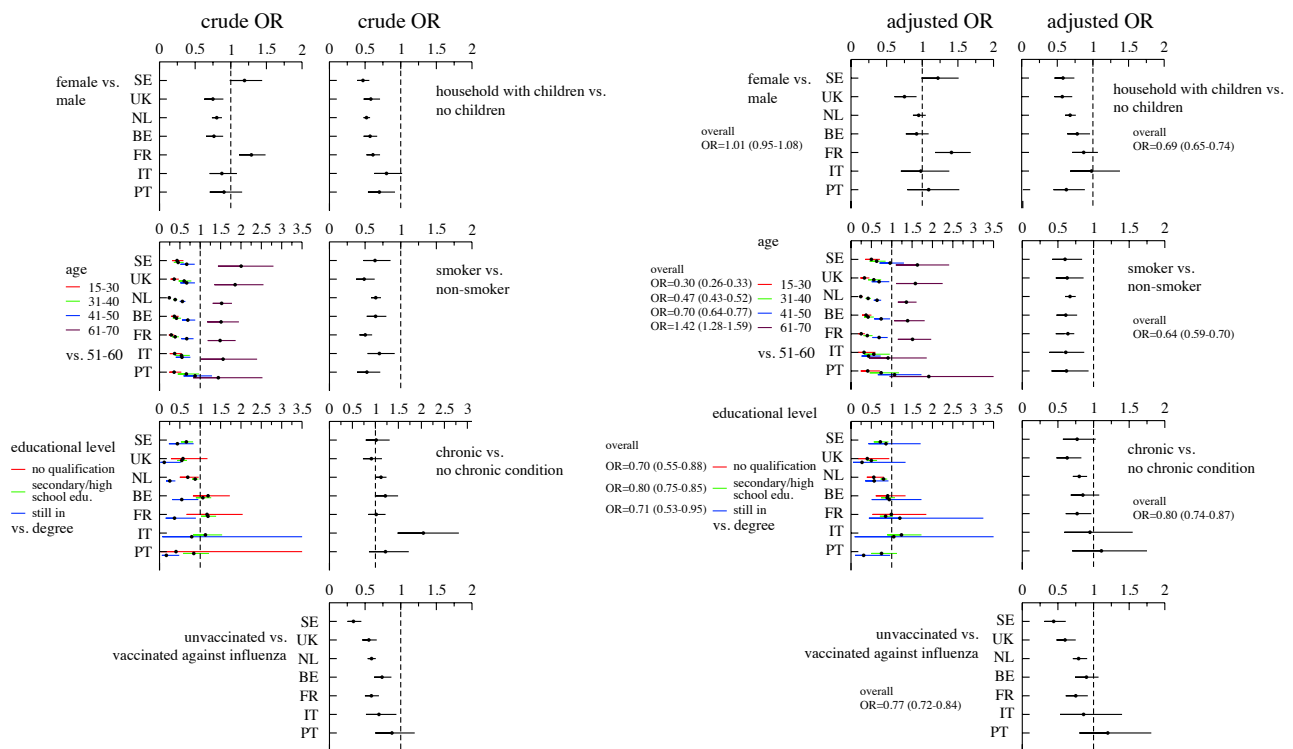


Figure 3: Crude (left panels) and adjusted (right panels) OR by country. An odds ratio greater than one is associated with a higher likelihood of participation in follow-up.

The adjusted results in Figure 3 (and Table 4 in Multimedia Appendix 2) indicate that for all the n countries where a significant association could be obtained, participation at follow-up was positively associated with being: non-smoker ($n=7$ countries), older than 60 years ($n=5$), vaccinated against seasonal influenza ($n=4$), not having a chronic condition ($n=3$), having a university degree (vs. secondary/high school, $n=3$; or vs. having no formal education, $n=2$), and being female in the United Kingdom, while being male in France.

To assess the suitability of our definitions of enrollment and participation in follow-up, and to test the possible sensitivity of the results to the details of the definitions, we tested a slightly stricter definition for enrollment and follow-up participation, requiring one additional symptoms questionnaire for “enrollment”, and shifting the time window for “follow-up participation” to 45 to 75 days (instead of 30 to 60 days) after the first symptoms questionnaire. Similar conclusions were obtained for the determinants of follow-up participation when using the stricter definition for enrollment and follow-up participation (results not shown).

Discussion

The first year of Influenzanet data collection took place in seven European countries and saw the participation of several thousands of individuals among the general population. Given the opportunistic enrolment of self-selected volunteers in the Influenzanet study, it is important to investigate how socio-demographic and behavioural characteristics may be associated with follow-up participation in the Influenzanet cohort. The study described in this paper shows that overall, the most important determinants of participation are related to education and lifestyle: smoking (OR=0.64 95%CI=0.59-0.70), lower education level (OR ranging from 0.70 to 0.80 depending on the educational level compared with people holding a university degree) and younger age (OR ranging from 0.30 to 0.70 with an increasing trend in participation with older age) are associated with a lower rate of follow-up participation. People living with children participate in follow-up less than people living alone or in a household consisting only of adults (OR=0.66 95%CI=0.65-0.74); people who have not been vaccinated against seasonal influenza tend to have a lower participation in follow-up with an associated (OR=0.77 95%CI=0.72-0.84). We speculate that even though individuals living with children are at greater risk of being infected with ILI and so might be expected to be more motivated to report their health status, the demands of parental care mean that voluntary participation in follow-up could be affected by lack of time. Regarding the vaccination status, the fact that individuals who chose to be vaccinated are more likely to be respondents could be due to the possibility that individuals who get the vaccine might also be individuals more concerned about their personal health and thus more likely to be participating in follow-up throughout the influenza season. Finally, males and females do not have significantly different follow-up participation behaviour (OR=1.01 95%CI=0.95-1.08).

Despite the cross-country variation, the main findings are similar in the different cohorts, and indeed the results are found to be valid also when performing a single-country analysis. Differences between countries do not seem to play a crucial role in determining the factors associated to the participation in follow-up. The results of the multilevel analysis performed on the Influenzanet cohort as a whole indicates, as expected, that the results regarding the smoking, education, and age are similar to what can be found in the literature for traditional non-Internet based epidemiological studies [21-23], i.e. people who smoke, who are younger and who have a lower educational level are more likely to have a lower participation in follow-up. This suggests that the self-selection of volunteers through an Internet-based system does not introduce different motivations or determinants for follow-up participation in a study with respect to traditional non-Internet based epidemiological studies.

The overall percentage of follow-up responders for the different countries varies between 43% and 79%. The platforms running longer (the Netherlands, Belgium and Portugal) tend to have the higher proportions of follow-up responders suggesting that the participation behaviour of the Influenzanet users may change over the years as they become more likely to become regular respondents the longer they are involved in the project. It is also

worth mentioning that longer standing systems are better able to keep people engaged in a tool, due to lessons learned about what works and what doesn't. In our sample, we did not distinguish between users who registered during the 2011-12 season and users from previous seasons but future work could investigate whether this explains the differences between countries. These differences could be also due to different level of Internet penetration. The large differences in the fraction of internet users among the general population, as shown in Table 3, can be an index of different cultural attitudes in the various countries leading to the variation in the participation attitude. Further analysis might also consider the level of engagement defining the outcome as the proportion of symptoms questionnaire completed out of the maximum possible number of questionnaires that could have been completed since registration, instead of the dichotomous definition of follow-up participation explored in the present analysis. Future work could also investigate if the determinants implied in retention over several seasons are the same as the determinants identified in the present study.

Previous works compared the self-selected sample of Influenzanet users in a single country with the general population [8,11] and it has been found that individuals recruited by the platforms are neither demographically nor geographically representative [8]. In this work we have focused on the cohort of enrolled participants from the seven countries during the season 2011-12 as a whole but we have not attempted to make comparisons with the general population. Rather, this is one of the first attempts to describe the determinants of follow-up participation in an Internet-based multi-country cohort study assessing the impact of the demographic and behavioural characteristics on follow-up participation.

This work has thus provided information that will help investigators to improve the planning of studies for future Internet-based surveillance and to guide enrolment and retention strategies aimed not only at enlarging the samples with motivated participants but also to enhance the control over potential biases introduced by differences among the participants.

Our findings can additionally be used to inform the design of engaging campaigns strategically targeted at the less self-motivated people, to promote their participation and thereby further enhance these surveillance systems by minimize the selection bias.

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Conflicts of Interests

The authors declare they have no conflict of interests

Authors' contributions

All the authors were involved in the management, design and editing of the Influenzanet national websites. Paolo Bajardi and Daniela Paolotti conceived the study, analysed the data and prepared the manuscript. Ken Eames,

Clément Turbelin, Marion Debin, Vittoria Colizza, Ana Franco, Annasara Carnahan and Moa Rehn also contributed to improve previous versions of the manuscript. All authors read and approved the final manuscript.

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