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Living & learning with allergy: a European perception study on respiratory allergic disorders

J. de Monchy[a], P.S. Andersen[b], K.-C. Bergmann[c], T. Chivato[d], A. Holm-Hansen[e], R. Jarisch[f], E.F. Mohácsi[g], S. Rak[h], S. Slørdal[i], V. Spicak[j], E. Valovirta[k], R. Dahl[l,*]

[a]*State University Hospital, Groningen, The Netherlands*
[b]*ALK-Abelló A/S, Bøge Alle 6–8, Hørsholm, Denmark*
[c]*Allergie und Asthma Klinik, An der Martinusquelle 10, Bad Lippspringe, Germany*
[d]*Department of Allergology, Hospital Aire, C/Arturo Soria 82, Madrid, Spain*
[e]*Lungemedicinsk Afdeling, Århus Kommunehospital, Århus, Denmark*
[f]*Astma-Allergi Forbundet, Hovedvejen 9c, Glostrup, Denmark*
[g]*I. Univ. Hautklinik, Franz-Jonas Platz 8, Vienna, Austria*
[h]*Szent János Kórház-Allergológia, Pethényi kõz 1, Budapest, Hungary*
[i]*Allergidivisionen, Sahlgrenska Sjukhuset, Göteborg, Sweden*
[j]*Barneklinikken, Regionssykehuset, Trondheim, Norway*
[k]*Faculty Hospital Bulovka, Budinova 2, Prague, Czech Republic*
[l]*European Federation of Asthma and Allergy Associations and Turku Allergy Center, Kotkaukatu 2, Turku, Finland*

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Summary *Background*: Knowledge of allergy patients' perception of own disease is inadequate, and understanding of the impact of local environment, including family and health-care system, on patients' management of disease is insufficient. We examined the potential of telephone-based survey techniques for establishing this knowledge in 10 European countries.

Methods: A two-phased questionnaire developed by use of focus groups in seven countries was translated into 10 languages. To ensure that the true values of the populations were restored in randomly selected populations, 75 343 telephone numbers selected for screening represented balanced national distributions of households.

Results: Eight thousand two hundred and sixty-eight respiratory allergy sufferers were identified by the telephone screening process. 85.4% accepted to participate in the survey and 89.6% completed both phases comprising 34 questions and rating of 49 statements. Data for each country were weighted in terms of age, sex and the recorded allergy prevalence within age intervals.

Conclusions: The telephone survey technique allowed for establishment of random representative samples, and application of mathematical weighting procedures assured that the true national values were restored in the data set. As all interviews were performed in a standardised manner we conclude that the telephone-based survey methodology enables national representative data set to be established and compared.

*Corresponding author. Lungemedicinsk Afdeling, Århus Kommunehospital, DK 8000 Århus C, Denmark.

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Introduction

Research within allergy is intense and studies addressing aspects of immunology,[1–3] symptoms[4,5] and treatment[6–8] are reported continually. Despite this, the knowledge of the allergy patient's perception of own disease and of its consequences is scarce. Moreover, the understanding of the impact of local environment, including family and national health-care systems, on the patient's management of own disease is insufficient.

In this paper, we describe a study on the European allergy patients' own perception of allergy and of life with a derived respiratory disease. It is the first time that allergic people have been addressed directly and cross-nationally with the objective of obtaining information about their perception of allergy and their life with this disease.

The aims of this study called "Allergy—Living & Learning" were to (1) evaluate the prevalence of respiratory allergic diseases in the population of 10 European countries by national screening of random and representative populations, (2) identify which factors are important to the allergic patient's perception and management of own respiratory disease and influence on social life, (3) investigate the potential consequences of specific diagnosis and treatment for the patient and (4) make comparisons between the 10 European countries included. Consequently, the study included both patients with an objective medical diagnosis and those without.

This paper describes the method applied and its feasibility, especially the selection of study population and the development and validation of the questionnaire used in the investigation.

In principle, the Allergy—Living & Learning study consisted of three phases, a qualitative study, a pre-testing phase, and a quantitative study. In the qualitative phase, a specific instrument was developed, i.e. a questionnaire, by means of interviews of allergy patient focus groups. Phase two embraced pre-testing, translations into 10 European languages and linguistic validation. In the quantitative phase, 7000 patients with asthma and hay fever were identified from 10 European countries, i.e. Austria, Denmark, Finland, Germany, Italy, the Netherlands, Norway, Spain, Sweden and the United Kingdom.

Materials and methods

The European Advisory Board (EAB)

The study was initiated, co-ordinated and supervised by an international advisory board, the EAB, consisting of physicians, scientists and representatives from European patient organisations including the European Federation of Asthma and Allergy (EFA). The EAB was responsible for the development of the questionnaire and the study protocol, for the conduct of the study, for the data analyses and for the reporting. No EAB member was involved in the study, neither as investigator nor as participant.

Study design

The Allergy—Living & Learning project consisted of three phases, as outlined in Fig. 1.

In phase one, the EAB developed guidelines for the focus group interviews in co-operation with psychologists experienced in conducting group interviews and handling focus groups. These guidelines aimed at identifying issues to be included in the quantitative phase and exploring their relevance at a European level. Focus group interviews were held in seven countries, each group consisting of 7 to 11 allergic patients. Based on these results, the EAB developed a questionnaire and a procedure for telephone interviewing, including the issues identified as important to the allergic patient.

The interviews were divided into three steps: a telephone interview, a self-completion of a questionnaire, and a second telephone interview to collect the answers from the self-completed questionnaires. The first telephone call aimed at collecting the factual information; whereas the postal questionnaire contained complex statements to be rated.

Phase two comprised a pilot test of the questionnaire, followed by revisions, translation into 10 European languages, and linguistic validation. In phase three, the quantitative phase, 7004 interviews were carried out in 10 European countries.

Ethical standards

The focus group interviews, the pilot test interviews and the quantitative pan-European study were conducted in accordance with the Code of Conduct of the European Standards of Market Analysis and Research (ESOMAR, Amsterdam, the Netherlands). This code of conduct guarantees the full anonymity and integrity of the respondents.

Interviews

The focus group interviews, the pilot testing and the quantitative interviewing were performed by a global market survey institute with local representations in the countries in question (ACNielsen AIM, Copenhagen, Denmark).

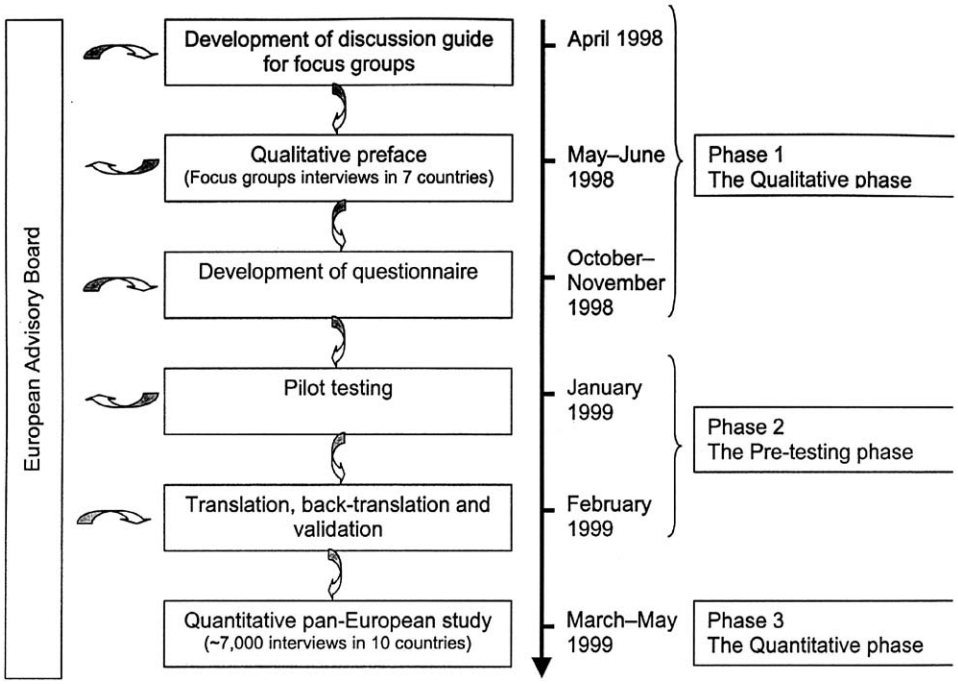

Figure 1 The Allergy—Living & Learning study design.

The population

The target population aged 16–60 years was identified by telephone screening of random, national, representative samples of telephone numbers. The study inclusion criteria were a positive reporting of respiratory allergy to pollen (i.e. trees, grasses or weeds), house dust mites, moulds, dog, cat or other animals and, concomitantly, a description of appropriate symptoms, see Fig. 2. In order to be eligible for participation, though asked, the respondent should not necessarily be able to report the medical diagnosis as, e.g. rhinitis or hay fever. Consequently, the full population included in the Allergy—Living & Learning study reported to be suffering from a respiratory allergy, irrespective of the degree of symptoms.

The study did not include children to avoid the bias when parents answer on behalf of their children. People older than 60 years of age were not included as they often have non-allergic respiratory conditions that mimic allergic respiratory disorders.

In order to minimise bias and to obtain a truly random sample, the interviewer first asked to talk to the person in the household whose birthday was next to come around. In case this person was unavailable, up to six more calls were made in order to establish contact. The respondent was not informed about purpose and scope of the interview when completing the screening phase. If the initial respondent did not fulfil the inclusion criteria in the screening phase, another person in the household could be requested to complete the screening phase.

The qualitative phase

Study set-up

The focus groups consisted of 7 to 11 allergic patients aged 18–60 years. People participating in focus groups must be at least 18 years of age according to legal restrictions and the ESOMAR guidelines. Focus group participants were identified as described above and they gave written consent prior to the interview. They were brought together in a major town in Denmark, England, Germany, Italy, the Netherlands, Spain or Sweden. A psychologist from the individual country conducted the group interview in accordance with the master discussion guide. A leading psychologist supervised all interviews and briefed the local moderators thoroughly prior to each of the interviews. Additionally, each session was videotaped. Immediately after the sessions, participants were debriefed by the psychologist and could watch the videotape.

Analysis

The team of psychologists interpreted the results represented by focus group participants' state-

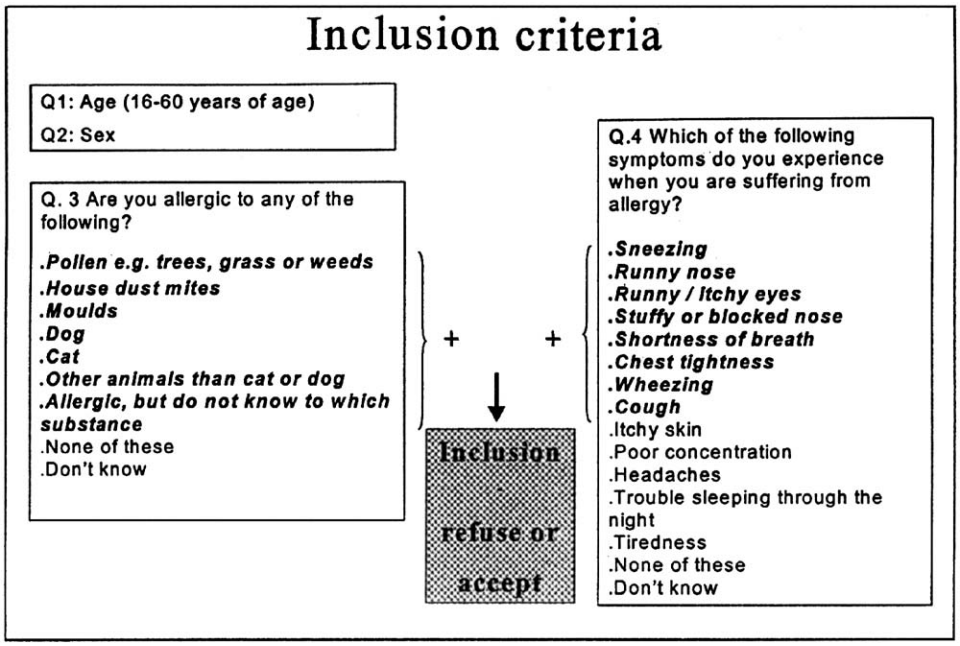

Figure 2 Study inclusion criteria were the positive reporting of respiratory allergy to pollen (e.g. trees, grasses or weeds), house dust mites, moulds, dog, cat or other animal, and, concomitantly, a description of appropriate symptoms.

ments and reactions and reported the findings in national reports, written in English. The main findings were gathered in a trans-national report.

Focus group results

Sixty-eight respiratory allergics participated in seven focus groups. The focus group results disclosed that the perceived restrictions on and problems of persons with allergy are very similar irrespective of nationality, the specific allergy and the allergic disease. Subsequently, the results indicated that the issues of relevance to the allergic population were shared in all participating countries.

In general, focus group participants reported that allergy was neither accepted as a real disease by general physicians nor by friends and family. Additionally, all focus groups reported that self-medication was standard as the professional advice was perceived to be of little or even no value. Furthermore, a critical need for more information about allergy and allergic diseases was present but unmet by health-care systems and patient organisations.

Moreover, all focus group participants said that the presence of social and psychological problems was caused by lack of acceptance of their disease by family and friends, a feeling of being unattractive when experiencing symptoms and a feeling of isolation both at work and socially.

Based on the focus group results, the EAB prepared an instrument, i.e. a questionnaire, for the quantitative phase addressing the aspects identified as important. This questionnaire comprised three parts: eight categorising questions about, e.g. income and level of education, 32 multiple-choice questions addressing perception of allergy, allergy triggers, specific diagnoses, symptoms, disease management and knowledge of own disease as well as the rating of 54 statements concerning symptoms, restrictions and social functioning. The first two parts of the questionnaire were to be answered immediately during the first telephone contact, whereas the third part containing the rating of statements was to be forwarded in writing by post, and the answers were subsequently collected by a second telephone call.

The pre-testing phase

Study set-up

Phase two embraced pilot testing of the questionnaire, translation into 10 European languages and linguistic validation.

In January 1999, the questionnaire was tested in 50 telephone interviews in Denmark. In this pilot test, only the person in the household whose birthday was next to come around was screened.

Upon completion of the questionnaire, the respondents were asked to comment both specifically and freely on the questions.

Based on the results of the pilot test and the comments, the questionnaire underwent modifications and the EAB signed off on an English master questionnaire. In each country, a professional, native translator translated the master into the nine other European languages of relevance and had the interpreted questionnaire verified by a local specialist familiar with allergy terminology. The local questionnaires were then collected and professionally translated back into English by a translation agency (Communicare, London, England). These translations were then compared with the master questionnaire, and the local translator and the local EAB member corrected any discrepancy before final acceptance.

Pre-testing results

The telephone statistics of the pilot test are shown in Table 1. A total of 268 telephone calls were made in a telephone screening of a random, representative sample of Danish telephone numbers in order to identify 50 positively screened allergics who accepted to complete the questionnaire. An estimate of the Danish prevalence of perceived respiratory allergy was 18.7%. Ninety per cent of those accepting to answer the questionnaire completed the full questionnaire indicating that the telephone–postal–telephone procedure worked well. Based on an evaluation of non-response items, direct correlation between questions, the time for completion of the full interview and of comments/input from respondents, the questionnaire was modified slightly by the EAB. Upon revision, the questionnaire was reduced to comprise six categorising questions, 28 multiple-choice questions, and the rating of 49 statements. Lastly, the database into which the responses were entered worked well as free cross-tabulations could be made and any sub-population could be constructed and characterised.

Table 1 Telephone statistics from the pilot study

Number of calls (N)	268
Number of positive screenings, $(\sum 1\text{st})$	50
Number completing 1st interview	50
Number completing 2nd interview, $(\sum 2\text{nd})$	45
Prevalence estimate $(\sum 1\text{st}/N)$	$\frac{50}{268} = 18.7\%$
Completion estimate $(\sum 2\text{nd}/\sum 1\text{st})$	$\frac{45}{50} = 90.0\%$

Sample size and statistical methods

Sample sizes were determined based on an expected minimum prevalence of respiratory allergic diseases of 10% and a Gaussian distribution of the population. Thus, the 95% confidence interval around any such estimate is given by $\pm 1.96\sqrt{p(100-p)/N}$.

It was assumed that 80% of the respondents completing the first part of the interview would finish the full questionnaire. The national samples were chosen accordingly to contain a minimum of 500 respondents in order to obtain appropriate statistical power of all questions. In Finland, Sweden, Norway, Denmark, Austria and the Netherlands the national samples were 500. As a large population and extent geography may constitute sources of variation, national samples of Germany, the United Kingdom, Italy and Spain were 1000.

The quantitative phase

Study set-up

In each country, the local survey institute chose a person responsible for the survey and a group of four to six native speaking and experienced interviewers. They were all briefed thoroughly in relation to allergy and related local terminology. Additionally, each interviewer was accustomed to the use of the questionnaire prior to performing the real interviews. In order to maintain standards and a uniform approach, the person responsible for the survey covertly listened in on the interviews and corrected during the data collection, if necessary.

The interviewers read the questions to the respondent from a computer monitor, and the answers were computerised online as the interviewer immediately entered each answer into the database. All multiple-choice options were randomised by the computer when presented to the respondent. Technically, it was made impossible to provide answers with built-in contradictions, e.g. did the respondent inform the interviewer that s/he did not take medicine, s/he could not claim use of nasal sprays without changing the first input. Classification questions about income, education and geographical region were country specific and varied in accordance with national standards.

The average duration of the first telephone interview including screening was approximately 15 min. Collection of responses to the self-completion questionnaire (second telephone interview) took approximately 6 min; however, the amount of time each respondent spent on the self-completion questionnaire is unknown.

The screening and the performance of the first interview were distributed evenly during 3 months, starting on 1 March 1999. Each interview–postal–interview procedure should not exceed 2 weeks, and consequently the total data collection was completed by 15 June 1999.

Data management, weighting and analysis

The data were entered into a database nationally as the responses were collected. The entry of the data was checked both locally and centrally by re-coding data to eliminate inconsistent responses.

In order to ensure that the values of the true population were restored in the randomly selected population, the telephone numbers selected for screening represented a geographical balanced national distribution of households. The official records of age and sex distributions of each country were accessed and national weighting matrices were set up for the three age intervals, and for the sex distribution of each interval. Then, the data for each country were weighted in terms of age, sex and the recorded allergy prevalence within three age intervals of 16–29, 30–49 and 50–60 years.

Results

The telephone statistics of the quantitative study are shown in Table 2. A total of 75 343 different telephone numbers were identified from random selected national representative samples from which 8268 perceived respiratory allergy sufferers were identified. 7065 accepted the invitation to participate in the study and 1204 declined representing an initial refusal rate of 14.6%. Sixty-one entries were deleted due to inconsistent responses after completion of the interviewing.

The allergics' initial refusal rate varied significantly among countries from 0.6% in Germany to 30.8% in Norway. Upon completion of the interview in the first telephone interviews and after receipt of the written questionnaire, 733 of the participants declined to participate in the second telephone interview representing a secondary refusal rate of 10.4% varying between 19.0% in Austria and 1.0% in Germany. The number of respondents completing both parts of the Allergy—Living & Learning questionnaire was 6331 of the 7004 entering the study.

Relatively, Spain and Austria were the countries in which most calls were needed to obtain the required number of respondents. In Spain, it was a general problem to reach people by phone when comparing with other countries, and in Austria, the population is less inclined to participate in surveys.

The allergics' initial refusal rates in Italy and Norway were 27.5% and 30.8%, respectively, and significantly higher than that of any other country included. In general, the relative surplus of refusers in Italy and Norway was recorded when the potential participants were informed that they were to receive a written questionnaire and therefore should provide information about name and address. Though emphasising that there would be kept no record of personal information including name, address and telephone number, experience shows that the employment of written contact increases the refusal rate dramatically in these two countries.

Table 2 Telephone statistics from the quantitative study in 10 European countries

	Number sample	Negative*	Net sample	Allergic refusers	Allergic refusers (%)	1st interview	Refuse 2nd interview	2nd interview	2nd/1st interview (%)
Denmark	4573	4033	540	39	7.2	502	32	470	93.6
UK	9329	8291	1038	44	4.2	994	159	835	84.0
Sweden	2359	1760	599	100	16.7	499	51	448	89.8
Norway	4575	3842	733	226	30.8	507	74	433	85.4
Finland	5484	4893	591	83	14.0	508	47	461	90.7
Germany	7169	6162	1007	6	0.6	1001	10	991	99.0
Austria	14 182	13 596	586	90	15.4	496	94	402	81.0
The Netherlands	5909	5305	604	56	9.3	548	42	506	92.3
Italy	6380	4989	1391	383	27.5	1008	123	885	87.8
Spain	15 383	14 204	1179	177	15.0	1002	101	901	89.9
Total	75 343	67 075	8268	1204	14.6	7065[†]	733	6332	89.6

*Includes: no contact, refuse at contact or no positive screenings.
[†]61 entries were deleted after the interview was complete.

Table 3 The distributions of unweighted and weighted entries by country

	Total		DK	SF	D	I	NL	N	E	S	GB
Number	7004	496	502	508	1001	1008	548	507	1002	499	994
Unweighted data											
Female (%)	63	56	58	71	62	64	69	52	65	53	66
Male (%)	37	44	42	29	38	36	31	48	35	47	34
16–29 years (%)	34	34	30	28	27	36	28	26	53	32	29
30–49 years (%)	50	52	49	44	52	46	57	56	38	56	59
50–60 years (%)	16	15	21	28	21	18	14	17	9	12	11
Weighted data											
Female (%)	53	50	53	58	44	51	51	53	54	47	53
Male (%)	47	50	47	42	56	49	49	47	46	53	48
16–29 years (%)	38	39	33	33	30	36	41	36	50	35	39
30–49 years (%)	46	46	46	49	48	46	48	47	39	42	47
50–60 years (%)	17	15	21	18	22	18	12	17	12	23	14

Weighting was done in relation to sex age, and relative weight of respiratory allergics.

The highest rate of secondary refusal was recorded in Austria where a high tendency to refuse participation in surveys in generally is present.

Distributions of data according to age and sex are shown in Table 3, including the distributions after mathematical weighting in respect to each country's true distribution of age, gender and the relative weight of respiratory allergy measured in the three age intervals. Men and younger people were underrepresented in the population, as the refusal rate generally was higher among men, and younger people were more difficult to contact at home. This is in accordance with the common picture seen in telephone-based surveys. Additionally, respiratory allergy prevalence was higher among young people.

Discussion

The study addressed patient perception only and did not imply any objective disease parameter accordingly as, e.g. positive skin prick testing or the detection of allergen specific IgE. It was therefore possible to use telephone-based survey techniques and exploit a number of advantages linked hereto.

The telephone statistics of this study demonstrate that it is possible to obtain disease-specific information by telephone interviewing techniques, developed for and normally implied in election polls or market surveys. In the case of respiratory allergy, the sufferers were readily prepared to give information over the phone as 85.4% of the positively screened accepted to participate in the 25 min long and two-phased study, when asked. Additionally, as nearly 90% of the identified perceived respiratory allergic respondents entering the study completed both the 50-item questionnaire and the two-phased interviewing procedure, it implied that the large set-up worked well.

For many years, the telephone survey techniques have been standardised and refined in order to be capable of obtaining information concerning the perceptions and opinions of the general population or specific sub-populations.[9–11] Subsequently, the techniques of today are sophisticated and much scientific information is available about response rates, reliability, cross-national comparisons and mathematical data weighting. As telephone survey techniques secure a low random sampling error, the use of such techniques allows for identification of truly random, national test populations, representative of sex, age and geographical distributions in each country.

Alternative survey techniques do not possess the same power in terms of selecting randomised and national representative populations as they often involve direct human contact, and subsequently become restricted in relation to randomisation of one or more parameters.

In general, it is difficult to assure representative sampling, i.e. low random sampling error, as all methods cause some limitation to the accessibility of one or more sub-groups. In telephone surveys, men and younger people are usually underrepre-

sented. The reasons for this are that the refusal rate is commonly higher among men and that younger people are more difficult to contact at home. This picture was also seen in this study. However, it was possible by means of a validated mathematical weighting procedure to correct imbalances and achieve the ideal distribution of each country in terms of age and sex (Table 3).

The focus groups reported that family, physicians and the society underestimate and neglect the consequences of atopic respiratory diseases. This could mask an appropriate assessment of the extent of allergy-related problems, and subsequently hamper appropriate action as the allergic patient may be less inclined to stand out. Many different effects could derive from such attitude and include patient denial and resultant delay in consulting a physician, wrongful or lack of specific allergy diagnosis, self-administration of OTC symptomatic drugs, and subsequent underestimation or ignorance of disease progression and consequences.

This study examined the use of and the consequence for the allergic patient of diagnostic testing, medical diagnosis and the prevalence of patient perceived respiratory allergy at a European level. Consequently, it was neither a criterion to have had a medical diagnosis nor to have had a specific allergy test. The Allergy—Living & Learning populations established consisted of people who reported that they were allergic to one or more specific substances and who declared to be suffering from specific symptoms related to allergic respiratory diseases. The inclusion was based on the respondents' reporting only, and hypochondriacs or subjects with a non-allergic disease could potentially go through both the screening and the interviewing phases. Nonetheless, questions elucidating seasonal and diurnal variations in symptoms, respiratory allergic substances, the use of medication and more, allowed an indirect verification of the respiratory allergy by means of cross-tabulation. These checkpoints minimised the bias potentially introduced however, whenever in doubt, about a specific respondent's status, the respondent was included.

For respiratory allergy, especially asthma, more epidemiological studies have been and are being conducted.[12–14] Upon identification of a potential participant, all implied methodologies include more objective diagnostic tests such as SPT and specific IgE test, and/or medical examination verifying the diagnosis prior to inclusion. Such thorough inclusion procedures ensure the status of the individual included and are necessary when purely medical problems are to be addressed. Nonetheless, as in some European countries both allergy specialist and allergy centres are very few, the involvement of medical expertise may either cause restrictions of the geographical representative status or prevent data collection.

In Europe, the allergy health-care systems vary significantly between countries as do both the definition of the allergic diseases and previously reported national prevalence.[13,15] Such differences restrain comparisons between countries and potentially cross-national optimisation of allergy care and treatment. The methodology applied in this study was standardised and worked well in the 10 European countries involved, and consequently a homogenous data set was established for each country making cross-national comparisons possible.

The telephone-based interviews were conducted in accordance with the ethical standards set out for the market survey industry, ESOMAR, assuring respondents' anonymity. Specifically, the respondents were in contact with the interviewer by telephone only. Anonymity is normal in scientific research and clinical studies but may be perceived differently by the participant when there is a physical contact. Demanding a physical contact may not just be limiting to the composition of the population due to logistics, timing and trouble involved but also due to the patient's perception of loosing anonymity and subsequently integrity. For various reasons, some people may deny contact to physicians and a medical diagnosis and subsequently only feel comfortable with an interviewing procedure that is considered non-personal.

In conclusion, the telephone survey technique implied enabled the simultaneous establishment of national representative data sets from 10 European countries. A questionnaire comprising approximately 50 question units and a two-phased interviewing procedure worked satisfactorily. The data have been collected in a database in which cross-tabulations are unrestricted and any sub-group that is identifiable by the questionnaire may be characterised in detail.

Further analysis of data will focus on the consequences of medical diagnosis and specific testing to patient comprehension and management of disease and on the potential cross-national variation in allergy prevalence, perceived allergy knowledge and the patient's perceived need for information.

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