

ORIGINAL ARTICLE

EPIDEMIOLOGY AND GENETICS

Spatiotemporal monitoring of allergic rhinitis symptoms in the Netherlands using citizen science

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Abstract

Background: Airborne pollen is a major symptom trigger in allergic rhinitis patients, but the impact of pollen differs among patients and regions and is influenced by environmental factors. To study these complex relationships, there is a need for data on the severity of symptoms in space and time. 'Citizen science' is increasingly recognized as an effective tool to monitor changes in our environment. The aim of this study was to investigate the feasibility of a citizen science-based survey to monitor spatiotemporal variation in allergic rhinitis symptoms.

Methods: Participants were recruited through the Web site Allergieradar.nl. After registering by completing an extensive questionnaire, they entered (preferably daily) their symptoms of eyes, nose, and lungs on a scale from 1 to 10, as well as their geographic location.

Results: The registration questionnaire revealed that the majority of the participants (77%) had physician-diagnosed hay fever and 65% of the participants had been tested positively for their allergy. This study shows that the symptom scores of the participants are related to (i) pollen concentrations in the air, (ii) the self-reported sensitivity profile, and (iii) the sales of prescription antihistamines in the Netherlands.

Conclusion: Our data indicate that the collection of allergic rhinitis symptom data by 'citizen science' is feasible and has an added value in studies on the impact of pollen.

Symptoms of allergic rhinitis include sneezing, nasal obstruction, nasal itching, rhinorrhea (1), and often ocular symptoms (2). A major trigger for the symptoms of allergic rhinitis is the presence of pollen in the air. However, the impact of pollen on the severity of symptoms is influenced by (i) the type of the pollen (e.g., grass) (3), (ii) the allergen threshold of the sensitized individuals (4), (iii) ethnic group (5), (iv) the time during the pollen season (6), (v) allergen content of the pollen (7, 8), and (vi) environmental factors like air pollution levels (9, 10).

To study the complex relationship between pollen, environmental factors, and symptom severity in patients, data on when and where which patients suffer from allergic rhinitis symptoms are required. Collection of patient symptoms, an important outcome parameter in clinical trials (11), is costly and is

often scheduled during a limited period in a small region. In order to learn more about the severity and the spatiotemporal distribution of allergic rhinitis symptoms in the Netherlands, we started an innovative approach based on citizen science. Using a public Web site www.allergieradar.nl (in Dutch), the allergic rhinitis symptoms of participants were collected. Because allergic rhinitis due to pollen is better known among the public as hay fever, we used this term on our Web site.

The drawback of the 'citizen science' approach is that the individuals that score their symptoms do not necessarily have physician-diagnosed allergic rhinitis/hay fever. The aim of this study was to investigate whether this 'citizen science' approach is feasible and whether it results in the collection of symptom scores that are related to pollen and that can be used for scientific studies.

Methods

Description of the Allergieradar Web site and the recruitment of participants

In May 2009, the public Web site Allergieradar.nl was launched. The launch of the Web site received substantial attention in the media. Patients were recruited through the media (e.g., radio, television, newspapers) throughout the study period. In order to register, participants completed an extensive questionnaire (see Appendix S1). The aim of the questionnaire, developed in collaboration with a team of medical professionals (allergists, pharmacists, ENT specialists, general practitioners), was to characterize the clinical condition of the participants. Participants were also requested to provide information on medication use to prevent or control their hay fever symptoms. Following registration, participants were instructed to use the Web site to report (preferably daily) the severity of their nose, eye, and lung symptoms on a scale from 1 to 10, which medication they used that day, and their whereabouts on the map of the Netherlands. Only symptoms of the reporting date or the day before could be reported to prevent recall bias. These reported symptoms were immediately translated into colored dots on the map (Fig. 1). Registered participants could generate graphs of their symptoms in combination with the pollen counts on a password-protected part of the Web site and show these to their physician. During registration, partici-



Figure 1 Screenshot of the 'Allergieradar' map of April 25, 2011, showing the individual symptom scores of participants of the last 24 h, illustrating the current severity of allergic rhinitis symptoms. Colored dots indicate no symptoms (yellow) to very severe symptoms (dark red).

pants gave their consent to use their information for research anonymously. All information is stored in an anonymous way in the database, and therefore, no ethical issues were applicable to this study.

Pollen counts

Pollen counts were determined (6) in Leiden, which is located approximately 25 km from the west coast (52°23'N; 4°29'E). Before generating graphs, daily pollen counts were square-root-transformed. The flowering season of a pollen type was calculated as the period beginning with 1% and ending with 95% of the annual sum of that pollen type.

Data analysis

The data from May 20, 2009, until December 31, 2012, were analyzed. Data from participants less than 7 years of age were excluded, and 1.8% of the participants were between 7 and 12 years of age. Most of these children reported symptoms related to grass pollen exposure. Reported medication was divided into the following groups: 1. oral medication, 2. nasal sprays, 3. inhalers, 4. eye drops. For each day, the mean maximum symptom score (=meanMSS) was determined by selecting the maximum score of either nose, eye, or lung symptoms and subsequently calculating the daily means of these maximum scores (6). Participants indicating during registration that they were positively tested for only grass pollen (mono-grass) or only positive for tree pollen (mono-tree) were analyzed separately. Mean maximum symptom scores were calculated on days with 4 or more entries from either of these two participant subgroups.

The sales of prescription antihistamines (ATCcode R06A) in the Netherlands were provided as monthly sales figures for 2009–2012 by Farminform (www.farminform.nl). For the comparative analysis of these monthly sales, the monthly meanMSSs were calculated. To study the relationship between two parameters, the Pearson correlation coefficient was calculated. Statistical analyses were performed using the software package Intercooled STATA 11.0 (StataCorp, College Station, TX, USA).

Results

Characterization of the participant group and entry of symptom scores

Based on the registration questionnaire, 77% of the participants had a physician-diagnosed hay fever and 65% had been tested for sensitivity to aeroallergens (Table 1). Self-reported positive testing was similar for grass (71%) and tree pollen (72%). The majority of the participants used oral medication (85%) and/or nasal sprays (67%). Most participants live in the highly populated, coastal area of the Netherlands (Table 1). Around 7000 entries of symptom scores per year were submitted by approximately 500 participants (Table 2). The highest daily number of entries (144) was obtained during the week after the launch of the Web

Table 1 Characterization of the participant group based on information from the registration questionnaire

	2009–2012
Age range	7–84
Median age	39
Percentage of total participants	
Men/women	47/53
Visited physician because of hay fever symptoms	85
Physician-diagnosed hay fever	77
Screening for sensitization for allergens	65
Positive test for grass*	71
Positive test for tree pollen*	72
Positive test for weed pollen*	25
Symptoms of nose	88
Eyes	91
Lungs	51
Medication use	79
Oral medication (tablets, syrups)†	85
Nasal spray (antihistamine, corticosteroids, others)†	67
Inhalers†	26
Eye drops†	10
Distribution over the Netherlands	
Coastal area (western part)	40
Northeast	13
Mid-east	29
Southeast	18

*Percentage of participants that claim to have been tested.

†Percentage of the participants that use any medication.

site, due to much attention in the media. In other years, the maximum number of entries occurred during the tree pollen season (Fig. 2A). Most participants entered their scores not more than five times, while only 1–4% of the participants submitted scores more than 100 times a year (Table 2). Participants suffered most from nose and eye symptoms and

Table 2 Analysis of the entries of symptom scores in the 4 years. Since the Web site was launched on May 20, 2009, data from that year are incomplete

	2009 from May 20	2010	2011	2012
Total entries/year	6521	7089	6516	6905
Maximum number of entries per day	144	54	73	58
Number of participants that submitted scores	512	486	513	512
Percentage of participants submitting their scores				
1–5 times/year	80	77	82	81
6–10 times/year	9	7	6	5
11–20 times/year	4	5	3	5
21–100 times/year	6	8	5	5
More than 100 times/year	1	4	4	4

to a lesser extent from lung symptoms (Table 2). Only 0.7% of the participants indicated to suffer exclusively from lung symptoms.

Analysis of the daily scores for symptoms

The daily means for nose and eye symptoms were always higher than the daily means for lung symptoms. In 89% of the individual scores, the daily scores for nose and eye symptoms were higher than the scores for lung symptoms.

The meanMSS followed in large the course of the pollen counts (Fig. 2B). In the beginning of each year, the appearance of hazel and alder pollen was accompanied by an increase in symptoms. In early January 2010 and 2011 and December 2012 small peaks of alder pollen from the early flowering alder species (12) coincided with small peaks in symptoms (Fig. 2B). During days with high concentrations of alder pollen (>600 pollen/m³ in 2010 and 2012) meanMSSs increase even further. One of the main peaks in the symptom scores occurred in the birch pollen season (meanMSS = 6.1 and 6.9 in 2010 and 2011, respectively), except for 2012; in that year, the birch pollen counts were historically low due to frost damage of the catkins in February and allergic patients reported clearly less symptoms (highest meanMSS = 5.1). Interestingly, this low birch pollen season did not overlap with the poplar and ash pollen season which it usually does. The symptoms showed an increase when both poplar pollen and ash pollen were present in high quantities (data not shown) and were reduced during the exceptionally low birch pollen season (Fig. 2B). A second main peak in the meanMSS occurred during the grass pollen season. High grass pollen counts were often accompanied by high symptom scores (6).

Because the symptoms followed in large the pollen counts, we studied the correlation between the meanMSS of the participants and the major allergenic pollen types, alder, birch, and grass pollen during their respective flowering seasons. The grass pollen counts show a good correlation coefficient in all 3 years varying from 0.57 (2012) to 0.66 (2010), which is in a similar range as found in a clinically well-defined grass pollen-allergic patient group (6). Alder pollen showed a good correlation in 2010 (0.68) and 2011 (0.59), but a weak one in 2012 (0.18). Birch pollen showed a low correlation with symptom scores and in 2011 (−0.08) and 2012 (−0.23) even negative correlation coefficients. The correlations for birch pollen were only slightly improved by using exclusively the symptom scores of participants living in the region close to the pollen trap (data not shown).

Analysis of the symptom scores of participants that claim to be either mono-grass pollen or mono-tree pollen sensitized revealed that the latter sent in scores almost exclusively during the tree pollen season and these scores corresponded to the peaks in the tree pollen counts (Fig. 3). The participants claiming to be mono-grass pollen sensitized sent in their scores mostly during the grass pollen season, and their scores corresponded to the grass pollen concentrations. Some of the latter participants also sent in their scores during the tree pollen season, but these scores were often low.

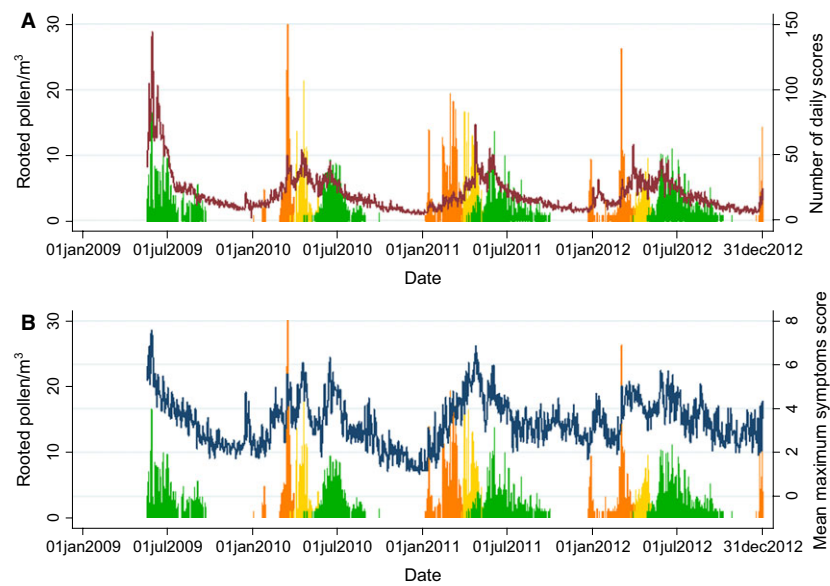


Figure 2 Number of daily scores from May 20, 2009, until December 31, 2012 (A, red line), mean maximum symptom scores of the

participants (B, blue line), and the square-rooted pollen counts of alder (orange bars), birch (yellow bars), and grass (green bars).

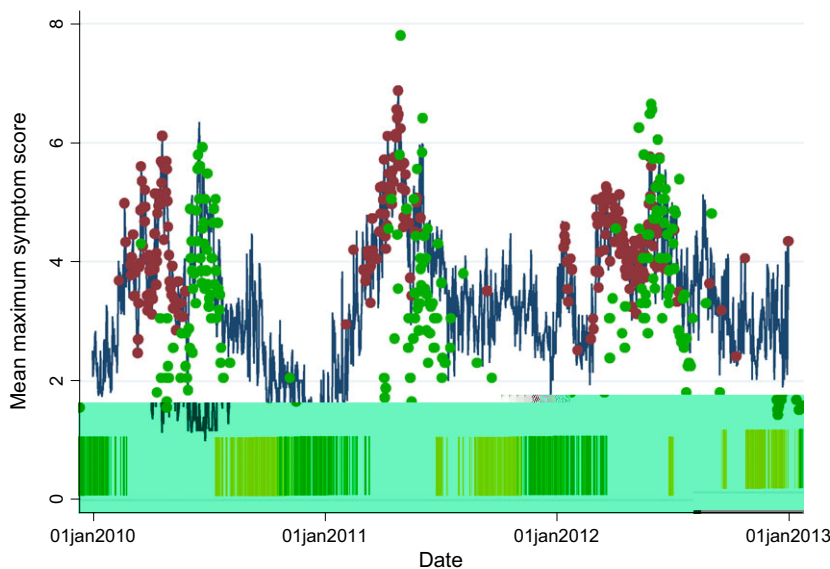


Figure 3 Mean maximum symptom score of the participants (blue line) and of the participants claiming to be mono-tree pollen allergic (red dots) or mono-grass pollen allergic (green dots). At the bottom of the figure, yellow blocks indicate the presence of tree pollen

(alder, hazel, or birch) and green blocks indicate the presence of grass pollen in the air. Because the data from 2009 are not complete, this year is not shown in this analysis.

Prescription antihistamines

The numbers of monthly sales of prescription antihistamines for systemic use in the Netherlands appeared to correlate very well with the monthly meanMSS of the participants of Allergieradar.nl (correlation coefficient = 0.88). Each year the sales as well as the symptoms started to increase with the presence of alder pollen, both increasing even further with the presence

of birch pollen (Fig. 4), except for 2012: After an increase during the first 3 months of that year, both sales and symptoms decreased in April when historically low birch pollen was counted. During the grass pollen season, sales, symptoms, and grass pollen peaked in June. Interestingly in 2010, when the birch pollen season and the grass pollen season were not overlapping (unlike in 2011 and 2012), the monthly meanMMS and the sales both showed distinct peaks.



Figure 4 Monthly mean of the symptom scores entered in Allergiaradar.nl (dashed line) and the monthly sales of prescription antihistamines ($\times 10^4$) in the Netherlands (continuous line). Bars indicate the monthly total counts for alder (orange), birch (yellow), and grass

pollen (green). In this analysis, May 2009 was omitted because the registration of the symptom scores in this month was not complete.

Discussion

This study shows that it is feasible to use citizen science as a tool to monitor temporal variation in symptom severity of allergic rhinitis and it may have an added value in studies on allergic rhinitis symptoms. Our analysis shows that the symptom scores of the participants are associated with (i) the pollen (e.g., grass and alder) concentrations in the air, (ii) the sensitivity profile that the participants claim to have, and (iii) the sales of prescription antihistamines in the Netherlands. However, the relationship between symptoms and birch pollen counts appeared to be weak. The questionnaire completed during registration showed that the large majority of the participants had a physician-diagnosed hay fever and had been tested for their allergy. Furthermore, during registration, the vast majority of the participants (99.3%) indicated to suffer from nose and/or eye symptoms. These results suggest that the majority of the symptoms reported by the participants are related to allergic rhinitis, including eye symptoms. Citizen science has increasingly proven to be an effective tool in monitoring environmental changes [e.g., (13, 14)]. Changes in the pollen concentration in the air are a relevant trigger for symptom development in pollen-allergic patients (15). The advantage of a citizen science approach for collecting hay fever symptoms is that numerous participants spread over a large area can enter their symptom scores during the whole year. However, a drawback of this approach is that allergic rhinitis is potentially not physician diagnosed, and therefore, it is not sure that all the symptoms reported by the participants are caused by an allergic disorder. To overcome this problem, we asked the participants at their registration to fill in an extensive questionnaire on their symptoms. Analysis of

this questionnaire showed that the majority of the participants group is most likely suffering from hay fever. The participants suffered mostly from both nose and eye symptoms and less from symptoms of the lungs. Their self-reports indicate that the majority have been tested positively for grass (71%) and/or birch pollen (72), which is in line with results from a multicenter French study (16). The most frequently used medication is oral medication followed by nasal spray. These observations are in line with studies in clinically well-defined patient groups (6, 16–18). The questionnaire also enabled us to discriminate participants that were mono-tree sensitized or mono-grass sensitized (according to self-reporting) and they reported high symptom scores mainly during the grass and tree pollen season, respectively, showing that the information on sensitization provided by the participants in the questionnaire correlates well with their response to the pollen.

Most clinical studies focus on one particular pollen season, for example birch or grass pollen. Using citizen science as a tool, we collected symptoms through all seasons and we could show that, besides grass and birch pollen, alder pollen is a relevant allergenic pollen, which is associated with increased symptoms as early as end of December/January. The symptom scores of 2012 suggest that also ash and/or poplar pollen may be relevant allergenic pollen as the symptom scores increased during a period when these two pollen types were dominantly present.

The highest symptom scores were observed during the birch and the grass pollen season. For grass, the severity of the symptoms showed a good correlation with the pollen counts. Among the tree pollen, alder also showed a good correlation in two of the 3 years, while birch pollen showed

little, and sometimes even a negative, correlation. It needs to be noted that the pollen counts are performed in one place, whereas the symptoms come from all over the Netherlands. Pollen counts from Leiden most likely are indicative for a large part of the Netherlands. Timing of the flowering season of several relevant pollen types is largely comparable with the other pollen counting station in the southeast part of the Netherlands in Helmond (L. A. de Weger, unpublished data). Of course, local variation in vegetation and weather will result in different exposures, and limited differences in timing of the flowering season may occur between the northern and the eastern part of the Netherlands. We considered the possibility that this regional difference explained the poor correlation with birch pollen, but when using only the symptoms of the participants from the region around Leiden, the correlation coefficients with birch pollen only slightly improved. Other explanations for this weak correlation may be that (i) birch pollen can differ in their allergen content from day to day (7) and (ii) participants were not well characterized and thus may respond to pollen of other trees like ash (19), which is often present in high quantities in the air at the same time as birch pollen. These observations indicate that for birch pollen the correlation with the symptoms of this participant group may be more complicated [see also (20)] and thus limits the use of these data. The symptom scores were highly correlated with the sales of prescription antihistamines. Interestingly, these sales numbers and symptom scores in 2010 and 2011 were highest during the birch pollen season, while in 2012 these sales numbers and the symptom scores were clearly reduced due to the low amounts of birch pollen produced in that year.

Almost simultaneously with Allergieradar, another web-based symptom survey, 'Patient's Hay-fever Diary' (PHD), was launched in several European countries (20–23). This initiative was also successful in generating an interesting symptom database which is expected to be useful for personalized symptoms forecasts (20, 21, 23). Differences with our approach are that whereas there are more participants in PHD, it lacks a registration questionnaire and the time span over which previous symptoms can be entered goes back to 1 week compared to 1 day back in our approach, which may introduce a recall bias in PHD.

Since the start of Allergieradar.nl, 2023 participants sent in 27 031 symptom scores, but the majority of the participants sent in their symptoms less than six times per year. The number of daily entries was related to the pollen counts, indicating that the participants are more motivated to send in their symptom scores when they suffer from their symptoms.

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Similar results have also been observed in the PHD study (22). This is a clear limitation of a citizen science-based system such as Allergieradar. It needs to be noted that because our participants had to complete an extensive questionnaire before entering their daily scores, we expect that even the participants with a low number of entries will submit reliable scores. Nevertheless, days with low numbers of entries, such as the days outside the pollen season with less than 10 entries per day, offer less detailed and reliable information. Next to increasing the number of participants, it is one of our concerns to improve the compliance of the participants. Therefore, we recently introduced a smartphone App to facilitate the entry of symptom scores.

The current approach may contribute to improved self-management in the control of pollen-related allergy. Personal graphs of symptoms and pollen that can be generated are likely to increase awareness of which pollen type(s) is/are the causative agent(s) of the symptoms. Although it is important to keep in mind that the participants are not doctor diagnosed, this study shows that allergic rhinitis symptoms collected by citizen science are relevant, and may contribute to studies on hay fever forecasts or on, for example, the interaction between pollen and air pollution exposures.

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Author contributions

EodB, AvV, LdW, and PSH designed the study; EodB, AvV, and LdW designed the Allergieradar Web site; LdW and AvV analyzed the data; LdW wrote the manuscript; AvV and PSH contributed in writing and editing the manuscript. All authors approved the final version of the manuscript.

Conflicts of interest

The authors declare no conflicts of interest.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Questionnaire.

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Registration questionnaire Allergieradar (translated from Dutch):

1a. Do you ever suffer from nose symptoms that persist for at least 10 days? Symptoms may include sneezing, nasal drip, itching nose, or blocked nose. Note: this does not apply to nose symptoms that are accompanied by green mucus (snot) or by fever (temperatures higher than 38°C).

☐ yes (*question 1b and 1c appear*)

☐ no (*question 2 appears*)

1b. In which period(s) do you experience nose symptoms (more answers are possible)?

☐ throughout the whole year

☐ in spring (February until April)

☐ in summer (May until July)

☐ in autumn (August until October)

☐ in winter (November until January)

1c. What do you think is the trigger of your nose symptoms?

☐ pollen

☐ animals (*question 1d appears after checking this box*)

☐ house dust mite

☐ irritants (e.g. cigarette smoke, perfumes, baking /roasting air, temperature changes)

☐ do not know

1d. How often are you in contact with the animals for which you are allergic?

☐ daily

☐ a few times per week

☐ a few times per month

☐ a few times per year

☐ hardly

2a. Do you ever suffer from eye symptoms, like tears, itching, red and swollen eyes, without having a fever (temperatures higher than 38°C)?

☐ yes (*question 2b and 2c appear*)

☐ no (*question 3 appears*)

2b. In which period(s) do you have eye symptoms (more answers are possible)?

☐ throughout the whole year

☐ in spring (February until April)

☐ in summer (May until July)

☐ in autumn (August until October)

☐ in winter (November until January)

2c What do you think is the trigger of your eye symptoms?

- ☐ pollen
- ☐ animals (*question 2d appears after checking this box*)
- ☐ house dust mite
- ☐ irritants (e.g. cigarette smoke, perfumes, baking /roasting air, temperature changes)
- ☐ do not know

2d. How often are you in contact with the animals for which you are allergic?

- ☐ daily
- ☐ a few times per week
- ☐ a few times per month
- ☐ a few times per year
- ☐ hardly

3a. Do you have regular lung symptoms such as coughing, wheezing and/or shortness of breath?

- ☐ yes (*question 3b and 3c appear*)
- ☐ no

3b. In which period(s) do you have lung symptoms (more answers are possible)?

- ☐ throughout the whole year
- ☐ in spring (February until April)
- ☐ in summer (May until July)
- ☐ in autumn (August until October)
- ☐ in winter (November until January)

3c What do you think is the trigger of your lung symptoms?

- ☐ pollen
- ☐ animals (*question 3d appears after checking this box*)
- ☐ house dust mite
- ☐ irritants (e.g. cigarette smoke, perfumes, baking /roasting air, temperature changes)
- ☐ do not know

3.d. How often are you in contact with the animals for which you are allergic?

- ☐ daily
- ☐ a few times per week
- ☐ a few times per month
- ☐ a few times per year
- ☐ hardly

If “no” is the answer to questions 1, 2, and 3, a message appears saying that since the participant claims to have no symptoms at all, it is very unlikely that he/she suffers from allergies or asthma, and that, therefore, there is no need to complete this questionnaire.

1 If one or more of the above mentioned questions are answered by 'yes' , the participant
2 can proceed to the next question.

3
4 4a. Have you ever seen a general practitioner or a specialist for the above mentioned
5 symptoms?

6 ☐ yes (*question 4b appears*)

7 ☐ no (*question 4e appears*)

8
9 4b. Did the general practitioner or a specialist ever diagnose you with "hay
10 fever"?

11 ☐ yes

12 ☐ no

13
14 4c. Have you ever been tested for your allergy (by a skin prick test or blood test)?

15 ☐ yes (*question 4d appears*)

16 ☐ no (*question 4e appears*)

17
18 4d. For which allergens was the test positive (you may check more than
19 one item)?

20 ☐ tree pollen

21 ☐ hazel

22 ☐ alder

23 ☐ birch

24 ☐ other, namely.....

25 ☐ unknown

26 ☐ grass pollen

27 ☐ weed pollen (like mugwort)

28 ☐ mugwort

29 ☐ plane

30 ☐ sorrel

31 ☐ ragweed

32 ☐ other, namely.....

33 ☐ unknown

34 ☐ cat

35 ☐ dog

36 ☐ horse

37 ☐ rodents

38 ☐ house dust mite

39 ☐ food

40 ☐ unknown

41
42 4e. For which allergens do you *think* you are allergic (you may check
43 more than one)?

44 ☐ tree pollen

45 ☐ hazel

46 ☐ alder

- 1 o birch
- 2 o another namely.....
- 3 o unknown
- 4 ☐ grass pollen
- 5 ☐ weed pollen (like mugwort)
- 6 o mugwort
- 7 o plane
- 8 o sorrel
- 9 o ragweed
- 10 o another, namely.....
- 11 o unknown
- 12 ☐ cat
- 13 ☐ dog
- 14 ☐ horse
- 15 ☐ rodents
- 16 ☐ house dust mite
- 17 ☐ food
- 18 ☐ unknown

19

20 5. Do you smoke?

- 21 ☐ yes
- 22 ☐ no

23

24 6a. Do you use medication for the above mentioned nose, eye and/or lung

25 symptoms?

- 26 ☐ yes (*question 6 b appears*)
- 27 ☐ no

28

29 6b. Which medication do you use (you may check more than one)

30 (An extensive list with brand names appears).

31

32 7. What is your year of birth?

- 33
- 34 8. Are you:
- 35 ☐ male
- 36 ☐ female

37

38 9. What are the first 4 digits of your postal code?

39

40

41

42