

Capturing qualitative olfactory dysfunction with PARPHAIT: the parosmia, phantosmia, and anosmia test*

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Abstract

Background: The assessment of qualitative olfactory symptoms is characterised by heterogeneous and unstandardised tools. To improve the means of capturing symptoms and subsequent treatment and care, this study aimed to develop a novel questionnaire, the parosmia, phantosmia, and anosmia test (PARPHAIT).

Methods: PARPHAIT was distributed to 165 participants with qualitative olfactory symptoms mainly due to COVID-19. The content was evaluated in participants with olfactory dysfunction, and an exploratory factor analysis (EFA) and internal consistency assessment was performed to assess underlying constructs and their reliability.

Results: PARPHAIT was scored as suitable, although suggestions for improvement were made. The EFA suggested a four-factor model with 34 items, all having factor loadings over 0.63. The factors had good to excellent reliability.

Conclusions: This study aimed to develop a novel questionnaire, PARPHAIT, and evaluate its content and factor structure. The content and format were satisfactory, but had potential for improvement. EFA resulted in a four-factor, 34-item model with good to excellent internal consistency. PARPHAIT is only just developed and will need to be validated in different populations and confirmed with respect to its factor structure. However, PARPHAIT bears potential of being a robust, comprehensive - yet symptom-specific -, and standardised tool of capturing olfactory dysfunction.

Key words: anosmia, parosmia, phantosmia, psychometrics

Introduction

The awareness of olfactory dysfunction has increased following the COVID-19 pandemic, acknowledged as central symptoms of the disease^(1,2). In this study, we aimed to address specific symptoms. Oftentimes, symptoms are measured and reported in general terms (e. g. "olfactory dysfunction"), making it difficult to know just what phenomena are being addressed. Thus, we have provided descriptions of relevant symptoms in Table 1. In a previous systematic review⁽³⁾ the means of measuring qualitative symptoms due to COVID-19 were assessed. An unmet need for symptom-specific, standardised, and validated tools (i.e. questionnaires and objective tests) was identified, making the measurement, understanding, diagnosis, and treatment of

qualitative olfactory dysfunction a challenge. These issues led to developing a standardised and validated tool that captures both quantitative and qualitative symptoms. Since symptoms are not exclusive to COVID-19, we also included other aetiologies in the study.

Qualitative symptoms of olfactory dysfunction are challenging to measure objectively and reliably. A few objective tests have recently been developed and assessed with regards to validity, including the SCENTinel 1.1⁽⁴⁾ and the Sniffin' Sticks Parosmia Test (SSParoT)⁽⁵⁾. The SCENTinel 1.1 measures odour detection accuracy, intensity, identification, and hedonic score, and the overall test score distinguishes those with qualitative disorders both from normal sense of smell and quantitative symptoms.

Table 1. Olfactory dysfunction: definitions and examples.

Type	Definition (example)
Quantitative olfactory dysfunction	Loss of the ability to detect, discriminate, and/or identify odours
Hyposmia	Partial loss (able to smell fruity odours, but not flowery odours)
Anosmia	Total loss (unable to smell any odours)
Qualitative olfactory dysfunction	Change in the perception of odours' character and/or valence
Parosmia	Change in the character and/or valence of an odour present
Cacosmia	Negative change (coffee smells like detergent)
Euosmia	Positive change («bathroom odours» smell less unpleasant)
Phantosmia	Odour perception in the absence of an odour source (one can smell cigarette smoke when no one is smoking)

The SSParoT measures the difference in ratings and the general perception of pleasant and unpleasant odours. Only the difference in ratings distinguished parosmia from healthy participants with a sensitivity of 29% but did not differentiate parosmia from other types of olfactory dysfunction⁽⁶⁾. Moreover, none of the studies included phantosmia in the analyses, and a limited understanding of this phenomenon persists.

Most research on qualitative symptoms, and especially phantosmia, has relied largely on participants' self-reports. Some of the tools identified in the aforementioned review included both parosmia and phantosmia, but mainly assessed the mere presence of symptoms, and few accounted for other aspects like duration, intensity, and potential triggers. The majority of tools consisted mainly of items assessing general problems with smell or focused on the loss of the ability, leaving room for only a few questions about qualitative symptoms^(7,8). When qualitative symptoms have been addressed⁽⁹⁻¹¹⁾, tools' validity and reliability were not assessed, or results are unclear or not reported. For instance, the widely used Questionnaire of Olfactory Disorders (QoD)⁽¹²⁾ has been tested with regards to internal consistency. QoD measures general symptoms (negative statements), coping ability, parosmic symptoms, and whether or not responses are honest. However, authors did not clarify to what items the analysis applied. Sub-scales of a shorter version were analysed in a later study⁽¹³⁾, revealing a relatively modest split-half reliability of 0.60 and Chronbach's alpha of 0.63 for parosmic statements. These items were adapted from Landis and colleagues' Parosmia questionnaire⁽¹⁴⁾, who performed sensitivity and specificity analyses. Here, the one item assessing phantosmia had a relatively poor ability (area under the curve= 0.68) of capturing the symptom.

The tools identified in the systematic review⁽³⁾ were also highly heterogeneous regarding the content and format. Some questionnaires measure the symptomatology only⁽¹⁵⁾, while others focus on quality-of-life consequences⁽¹²⁾. While these aspects are closely and naturally related, they are not interchangeable. As such, symptoms may affect patients' different roles and daily activities, but this may not reflect the type, nature, or degree of symptoms experienced. While some tools were extensive and covered numerous factors of interest^(10,16), others assessed

the mere presence of qualitative issues using only one or two questions^(17,18). Moreover, most studies were biased towards unpleasant symptoms, except for one study⁽¹⁰⁾ where pleasant changes in odour perception (i.e. euosmia) were addressed. No study specifically assessed the presence of pleasant phantom smells. The response design varied across tools, and some scored responses^(9,19). However, one may ask to what extent different scoring procedures help in determining adequate and consistent diagnoses. While data collected remain clinically important, a standardised tool could improve practices.

To advance our understanding of qualitative symptoms, different aspects could be beneficial to explore further and incorporate in the measurement of symptoms. Such aspects include symptom duration, frequency, intensity, valence, sensory modality (i.e. orthonasal or retronasal perception), and different triggers. Triggers may be environmental factors like changes in the weather^(20,21), visual stimuli⁽²²⁾, negative emotions and memories⁽²³⁾, and types of food^(10,24). Some of the questionnaires did account for some of these factors, but none were standardised or validated.

The aim of this study was to improve the diagnostic methods for olfactory dysfunction, with focus on qualitative symptoms. The objective was to develop a novel, valid, and reliable questionnaire that measures the loss (i.e. anosmia) and change of smell (i.e. parosmia and phantosmia) in separate sub-scales. This will allow for capturing overall olfactory dysfunction and capturing the specific symptoms (e.g. parosmia). This could improve our knowledge about olfactory dysfunction, leading to better treatment and care according to the patient's needs.

Methods

Study design

We named the questionnaire the Parosmia, phantosmia, and anosmia test, abbreviated and hereupon referred to as PARPHAIT. Items were developed based on findings of a systematic review⁽³⁾, followed by having participants with olfactory symptoms completing this first version of PARPHAIT. In addition, we asked them to evaluate the content and format. Alterations were done according to their feedback, and an exploratory factor analysis (EFA) and reliability testing was performed to explore

Table 2. Response rates and demographics.

	Mean	SD	Missing
Age (range 21-84)	55.41	12.63	7
	Frequency	Percentage	
Invited	309		
Complete responses	165	53	
Sex			
Female	143	86.7	
Male	21	12.7	
Prefer not to say	1	0.6	
Years of education			2
Elementary/middle school	3	1.8	
High school	53	32.1	
Bachelor's degree	68	41.2	
Master's degree	33	20	
Doctorate degree	6	3.6	
COVID-19 related OD			1
Yes	120	72.7	
No	44	26.7	
Duration of OD			2
Less than two weeks	1	0.6	
~ 1 month			
~ 2 months	1	0.6	
2-6 months			
6-12 months	1	0.6	
More than a year	160	97	

OD: Olfactory dysfunction, SD: Standard deviation.

the factor structure of the questionnaire. All statistical analyses were done using IBM SPSS (released 2021, version 28).

Participants

Participants were recruited in collaboration with AbScent, a UK-based charity for people with olfactory dysfunction⁽²⁵⁾. Participation is not restricted to UK residency, however, as long as participants understand English. Participants' e-mail addresses were provided by AbScent, to which they received a link to the questionnaire.

All participants (n=165) were adults with olfactory symptoms. Most were caused by COVID-19 (n=120, 72.7%). COVID-19 diagnosis did not require verification since all items in the questionnaire, including whether the olfactory dysfunction occurred after COVID-19, were self-reported by respondents. The study was approved by the Regional Committee for Medical and Health Research Ethics in Norway (Ref. 350517), and participants had provided their informed consent.

Questionnaire development

PARPHAIT was built on an established tool, the Self-MOQ⁽²⁶⁾ and was further developed based on the findings from the aforementioned review⁽³⁾, from which we extracted the following data: number of items, formulations, response options, and scoring protocols. Items were sorted into categories: presence

of symptoms, location (e.g. left nostril), sensory modality (i.e. when breathing through the nose or while eating), duration and frequency, intensity, and triggers related to emotional, auditory, environmental, tactile, food, and memory-related stimuli. We researched potential variables outside the scope of the review to include other relevant aspects: weather⁽²⁰⁾, autobiographical memories and mood⁽²³⁾, visual stimuli⁽²²⁾, temperature changes, and fatigue⁽²¹⁾.

To assess whether items were representative for the constructs assessed, the initial questionnaire was evaluated by the core research group (AE, KKB, KVMH, and DAL), considering the relevance, clarity, formulations, response design, scoring, and possible important information not yet included. Through discussion some items were removed, changed, or added, resulting in a pool of 93 items (Appendix A), including the 14 Self-MOQ items, four additional quantitative items, 31 items covering phantasmia, and 44 assessing parosmia. The Self-MOQ exists in a shorter version⁽¹³⁾, however, we decided to include all 14 items due to our changes to some of these. For the other items, we removed example cues to avoid bias, location (e.g. left nostril), as this seemed irrelevant⁽²⁷⁾, and food triggers for the phantasmia items. We included the emotions disgust and surprise, and added chocolate, lemon, and melon as food triggers for parosmia⁽²⁴⁾.

Content evaluation

To assess the content and format of PARPHAIT it was distributed digitally to participants using Nettskjema⁽²⁸⁾. Data were collected between the 4th and 25th of July 2023, and participants who had yet to complete the questionnaire received a reminder (three times in total). Participants were asked to evaluate the relevance, clarity, length, duration, number of items, and response design on a scale from 1 (not suitable) to 5 (highly suitable). A free-text entry allowed for further comments. The survey can be found in Appendix B.

Item analysis

An item analysis consisted of evaluating the sample size and inter-item correlations. Kaiser-Meyer-Olkin test for sampling adequacy (KMO) was applied to assess items' suitability for factor analysis, and Bartlett's test for sphericity (BTS) assessed whether items were related. Multicollinearity, as indicated by the determinant R, was inspected. Inter-item correlations >0.8 were removed, as suggested by Field⁽²⁹⁾. Communalities (i.e. variance explained by the factors for each variable) <0.2, as cited by Child (2006) in⁽³⁰⁾ were excluded. Average communality should be 0.5-0.6 for a sample size of 100-200⁽³¹⁾.

Exploratory factor analysis

The main analysis consisted of factor extraction, using principal axis factoring (due to latent (i.e. not directly observable) varia-

Table 3. Summary of content evaluation.

	Response rate			
	Total	%	Median	SD
Relevance	164	99.4	4	1.02
Clarity	163	98.8	4	0.92
Length	162	98.2	5	0.85
Number of items	162	98.2	4	1.06
Time to complete	162	98.2	4	1.04
Response design	161	97.5	4	1.09
Other comments	85	51.5		

SD: Standard deviation

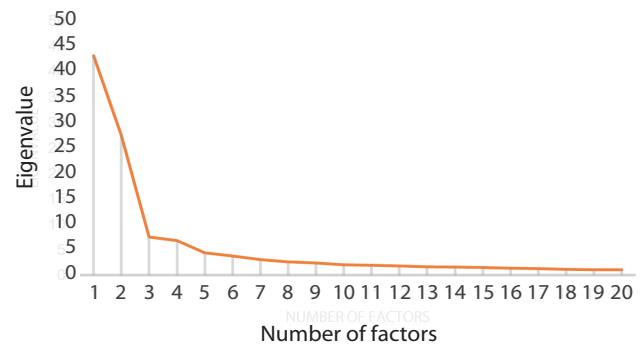


Figure 1. Scree plot of potential factors.

bles and since variance explained includes common and unique variables ⁽³²⁾. We applied oblique rotation (Promax) with Kaiser Normalization. Kaiser’s criterion, eigenvalues, and the scree plot was inspected to determine the number of factors. Items were included based on factor loadings >0.63 (i.e. "very good"; Tabachnick and Fidell, 2007, as cited in ⁽³³⁾). Cross-loadings >0.32 ⁽³⁴⁾ were removed.

Internal consistency

Finally, to assess whether items were reliably measuring the same construct, an internal consistency analysis was performed.

Results

Results are presented in the order of participants’ completion and evaluation of PARPHAIT, followed by statistical assessment of items, factor structure, and reliability. Overall response rates and demographical data are presented in Table 2.

Content evaluation

Response rates, median scores, and standard deviations for the content evaluation (i.e. scoring and giving feedback on PARPHAIT) are presented in Table 3. Participants’ feedback on the different aspects are presented below in the order of relevance, clarity, length, response design, and other comments. Regarding the relevance, some noted that questions were difficult to answer, subjective, or did not apply to them because they had anosmia and suggested including a screening question for the type of olfactory dysfunction. One participant did not see the relevance of temperature, while others found emotional states to be interesting, although they had not previously noticed any relationship between emotions and olfactory symptoms. Five reported that questions were vague or unclear, and suggested having more specific questions (e.g. describing environments in more detail, as opposed to "silent" and "noisy"). Food

trigger questions could have been clearer, and some words were reported not to be commonly used, such as "dog pile" (item 8) and "perfumeries" (item 9). One participant considered the questionnaire to be very long, and two thought items were too many. Two suggestions applied to the response design: Adding "I haven't noticed" to the emotional triggers and having a list of options for describing odour distortions. Other comments concerned variations in symptom onset, duration, and fluctuations (e.g. changing from day to day, and occurring every two months to once a year). Others reported symptoms that resolved a few months ago. Trigger factors not yet included were mentioned: peanut butter, egg whites, other people’s breath, own and others’ body odour, sweat, natural versus "man-made odours", and "bathroom odours". Others confirmed onion, garlic, chicken, meat, chocolate, coffee, and apple as food triggers. One participant reported that phantom smells could be new odours that were hard to identify, while another experienced them to be random and not triggered by anything specific. Others pointed to an evocative effect of elevated stress levels and alcohol consumption, whilst humidity, exercise, and the control of the surroundings reduced symptoms. One participant mentioned that phantom smells were located "...on my skin and in my nose and/or in my head", and others missed questions about the quality of life. One reported having issues mainly with taste, and four had issues due to reasons other than COVID-19.

Item analysis

After assessing the correlation matrix, high inter-item correlations were removed, resulting in keeping 56 items. The KMO was 0.84, indicating that items were suitable for factor analysis. Items were correlated (BTS: $\chi^2 = 7425.16$, $df = 1540$, $p < 0.001$) and the determinant was >0.0001 (=4563.19). There were no missing values. Item 14 had a communality value of 0.18 and was removed.

Table 4. Eigenvalues and variance explained.

Factor	Eigenvalue	% of variance	Cumulative %
1	43,12	30,14	30,14
2	27,45	19,39	49,53
3	7,48	8,72	58,25
4	6,76	4,13	62,39
5	4,37		
6	3,77		
7	3,03		
8	2,61		
9	2,36		
10	2,03		
11	1,93		
12	1,81		
13	1,65		
14	1,57		
15	1,47		
16	1,37		
17	1,26		
18	1,15		
19	1,05		
20	1,04		

The average communality (0.53) was adequate for our sample size of 165.

Exploratory factor analysis

Based on eigenvalues (Table 4) and Kaiser's criterion, 20 factors had values >1. However, when considering eigenvalues >2, ten factors were suggested, while the scree plot suggested four. We tested Direct oblimin and Promax rotation methods, where Promax had the better fit. After successive factor reduction and scree plot inspection (Figure 1), a four-factor model appeared most adequate having minimum three variables per factor. The factor loading cut-off point was set to 0.63, and items lower and/or cross-loading (Appendix C) were removed successively. This resulted in keeping 34 items. Factors were labelled Triggers of parosmia, Presence, valence, frequency, and intensity of phantosmia, Loss of smell, and Frequency of parosmia (Appendix D). These accounted for 62.39% of the variance (Table 4).

Internal consistency

Factors had good to excellent reliability ($\alpha=0.95, 0.95, 0.88,$ and $0.88,$ respectively), and mean corrected item total correlations were all satisfactory (Appendix D).

Discussion

In this study, we developed the novel PARPHAIT and assessed its

content validity and factor structure. Although questionnaires and objective tests for qualitative olfactory dysfunction do exist, these are mostly unstandardised, heterogeneous, and focus on parosmia. For instance, the widely used QoD only contains four questions about qualitative symptoms, where only one addresses phantosmia. PARPHAIT includes three aspects of smell dysfunction: loss of smell, parosmia, and phantosmia. As such, it makes for capturing, understanding, and managing qualitative olfactory symptoms.

Content validity was measured in terms of scoring and providing written feedback on each aspect (e.g. relevance). Participants scored all aspects a median of 4 points, except for length, which was considered "highly suitable" with a median score of 5. The written feedback on relevance revealed that some participants acknowledged aspects they had previously been unaware of, such as the connection to emotional states. Many patients see a clinician due to new symptoms they have no previous experience with, and may not be aware of triggers or intensity, for instance. Such aspects have been addressed in previous research⁽¹⁰⁾ but are not standardised. Thus, we emphasise the importance of including aspects that may provide such insight, that also make patients feel acknowledged and understood. While qualitative sub-scales were reported irrelevant by some (due to anosmia), questions could still be relevant given how self-reported anosmia may not apply objectively⁽³⁶⁾. Moreover, as loss of smell can be partial or odour-specific⁽³⁷⁾ and since phantosmia inherently occurs in the absence of odours, anosmia does not automatically eliminate qualitative symptoms.

Triggers of parosmia varied among participants, and some mentioned peanut butter, egg whites, people's breath, humidity, exercise, and alcohol. While humidity and exercise were reported to reduce symptoms, alcohol could exacerbate the issue (although it is unclear whether this is due to the sensory experience itself or alcohol's effect on the nervous system). Stress triggered phantosmia for some, while others did not see such patterns. Some had problems identifying phantom odours, as the odours were something they had never smelled before. One participant could locate the phantom odours, which is puzzling since phantosmia occurs in the absence of an odour source. As such, one may question if the reported phantom smell was in fact parosmia.

Several suggested including quality of life-related questions. While relevant, PARPHAIT aims to capture symptoms and not necessarily their consequences. Questionnaires that measure such effects, like the Olfactory Disorders Outcomes Rating⁽¹⁷⁾ and the QoD are already available and widely used. Some mentioned the link to taste, and although the two domains are closely related, taste dysfunction may occur in isolation⁽³⁸⁾. As such, causal inferences may be erroneous, and to avoid this, taste was not addressed in PARPHAIT. However, tools for assessing taste⁽³⁹⁾ could be used together with PARPHAIT when relevant. Regar-

ding item formulations and response design, “perfumeries” (item 8) and “dog pile” (item 9) were retained. However, for future validation studies, we suggest using “perfume shop” or “perfume store”, and “dog waste” or “dog droppings”. To reduce bias, we replaced “and” with “or” (item 10), substituted “miss” with “do not perceive” (item 15), and added “partner” (item 19).

We included six response options, one of which was “not applicable”. Compared to other scales (e.g. QoD) an extension of options and inclusion of “not applicable” could improve reliability, as suggested by Zou et al. ⁽¹³⁾.

Symptom fluctuation is one aspect we did not explicitly account for. While this could aid in capturing symptoms, it will be challenging to quantify and standardise, due to great variability ⁽³⁵⁾. Related to this, reporting symptoms relative to the past week was challenging for some because symptoms had recently resolved. We applied this time frame because remembering detailed symptoms gets increasingly difficult as time passes. However, to account for these variations, extending the time frame could be beneficial.

Following the content evaluation, we conducted an EFA to assess factor structure. The EFA suggested four factors, reducing 56 items to 34. Factors were logically labelled, sorted, and presented coherently: Loss of smell, Presence, Valence, Frequency and intensity of phantosmia, Triggers of parosmia, and frequency of parosmia. Although higher α -values suggest a possible item redundancy, we decided not to remove additional items for the sake of content validity.

Zou et al. ⁽²⁶⁾ have previously reduced the 14-item Self-MOQ to five reliable items ($\alpha = 0.84$). In our study, the included items differed and had an improved reliability of 0.88. The differences in items included could be due to the lower sample size in our study but could also have to do with methodological differences. Zou et al. did a principal component analysis, and it is unclear what rotation method they used (reporting both Promax and Varimax). In comparison, we applied Promax and did a principal axis factoring extraction. As such, the importance of adequate and replicable procedures are emphasised.

When it comes to the items addressing character and valence of parosmia, cross-loadings led to removing these from the model. These aspects are important since parosmia involves the change of odour pleasantness and character. However, these items do not seem to capture any additional information. In previous tools ^(12, 14), the distinction between these and the inclusion of both have not been emphasised. No elaboration has been given on why this is, but our finding may be one reason. In a future study it is possible that a larger sample generates more robust factor loadings, and if not, this would corroborate the notion of how these aspects are not crucial in assessing parosmia.

What we found useful, however, was the inclusion of aspects beyond the mere presence of symptoms, such as food triggers. With factor loadings starting at 0.68, the most robust include

nuts, rice, fish, tomato, and chocolate. Meat, lemon, coffee, milk, eggs, melon, and onion were also retained, many of which were confirmed in participants’ comments and in previous research ⁽³⁵⁾.

Research has generally paid less attention to phantosmia, whereas PARPHAIT aims to include qualitative symptoms in a comprehensive and balanced manner. Parosmia and phantosmia are distinguished and addressed in detail, and questions are not limited to “constant” and “unpleasant” symptoms as in other tools (e.g. QoD). Another strength is accounting for changes in both character and pleasantness. Although our results may not suggest this distinction as useful, we suggest future studies investigate this further using a larger sample.

Using PARPHAIT as one standardised tool instead of several heterogeneous scales or subjective interpretation could improve practices. Developing a scoring protocol can also make PARPHAIT easy to use without advanced training. These strengths can improve both the communication between patients and clinicians, and lead to more reliable diagnoses and management of the condition(s).

One limitation to our study is the method for developing and including items. Applying a Delphi method ⁽⁴⁰⁾ could have improved our methods and ensured additional aspects were considered. However, the tools identified in the review are based on expertise and clinical observations, and the two methods may have led to similar results. Nonetheless, in the continuation of developing and strengthening PARPHAIT, we suggest including a larger pool of items.

Another issue concerns the sample size recommended for EFA. Several suggestions have been offered, with regards to factors and their loadings ⁽⁴¹⁾, communalities ⁽³¹⁾, and number of items ⁽⁴²⁾. We refer to a simulation study ⁽⁴³⁾ where the number of factors and items, as well as factor loadings are considered. Results suggest a minimum of 68 participants for a four-factor, 96-item model with factor loadings >0.60 . Considering our initial pool of 93 items and the slightly higher cut-off point (0.63) applied in our study, the sample size is adequate for an EFA.

The initial version of PARPHAIT has only just been developed and will need to be validated in different populations. We chose to focus on COVID-19, and did not account for other causes of olfactory symptoms to reduce the demands of completing the survey. However, symptoms do indeed apply to other conditions, and further development of PARPHAIT should include such relevant populations. Moreover, clinical evaluation of olfactory function would improve methodological quality and should be implemented in future studies. In this study, such procedures were difficult to conduct and monitor due to an international sample and web-based design.

We plan to perform an in-depth quality analysis of PARPHAIT in a group of experts to further validate its content, and suggest future research conduct a confirmatory factor analysis in larger

samples. This is an important step in supporting (or opposing) the number and nature of underlying factors identified in this exploratory study. First, however, suggestions offered from patients and experts should be considered included in PARPHAIT.

Conclusions

In this study, we have developed PARPHAIT, a novel questionnaire for measuring quantitative and qualitative olfactory symptoms. Although considerable efforts remain in ensuring its validity, quality, and applicability, PARPHAIT bears potential as a time-effective and intuitive questionnaire for capturing general and specific olfactory dysfunction. Aiming for a standardised tool, PARPHAIT can improve clinical practice as well as patients' insight of their own condition.

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Authorship contribution

AE: Study design, data collection, statistical analyses, interpretation, drafting and reviewing the manuscript. SW: Reviewing the manuscript. KVMH: Study design and reviewing the manuscript. DAL: Study design, statistical analyses, interpretation, and reviewing the manuscript. KKB: Study design and reviewing the manuscript.

Ethics approval and consent to participate

Not applicable.

Availability of data and materials

Not applicable.

Conflict of interest

There is no conflict of interest to declare.

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SUPPLEMENTARY MATERIAL

Appendix A. Initial pool of items (prior to inspecting correlation matrix and potential factors).

Item no.	Item formulation
8	In perfumeries, I hardly perceive the fragrance
9	It may happen that I do not notice it when I step into a dog pile
10	I do not perceive the smell of coffee or fresh bread
11	I do not perceive when other people smell strongly like garlic
12	I like to look around the flower shop, but I cannot smell anything
13	I do not smell the perspiration of sweaty people
14	My pleasure in eating does not come with a pleasant smell experience
15	I do not perceive the "typical smell" of paint thinner or glue
16	I do not smell the fresh tar at a road construction site
18	Other people know earlier than me when food smells bad
19	I do not smell the body odour of my girlfriend/boyfriend/partner
20	I do not perceive the musty odour in a damp cellar
21	I do not recognise the smell of freshly mowed grass
22	I do not mind the bad smell in some public toilets
23	I cannot perceive any odours at all
24	I find it difficult to detect certain odours
25	It is particularly hard for me to name certain odours
26	Distinguishing one odour from another is challenging for me
28	I perceive phantom smells
29	I perceive pleasant phantom smells
30	I perceive unpleasant phantom smells
31	I perceive neutral phantom smells
32	I perceive phantom smells more often when I eat
33	I perceive phantom smells more often when breathing through my nose
34	I perceive phantom smells all the time
35	I perceive phantom smells about once an hour
36	I perceive phantom smells about once a day
37	I perceive phantom smells about once a week
38	I perceive phantom smells less than once a week
39	I perceive phantom smells only vaguely
40	I perceive phantom smells' strength like other odours
41	I perceive phantom smells intensely
42	I perceive phantom smells more often when I am sad
43	I perceive phantom smells more often when I am happy
45	I perceive phantom smells more often when I am angry
46	I perceive phantom smells more often when I am disgusted
47	I perceive phantom smells more often when I am surprised
48	I perceive phantom smells more often when I am scared
49	I perceive phantom smells more often when I am tired
50	I perceive phantom smells more often when I listen to music

Item no.	Item formulation
51	I perceive phantom smells more often when I am in a noisy environment
52	I perceive phantom smells more often when I am in a silent environment
53	I perceive phantom smells just by seeing something that has a distinct odour
54	I perceive phantom smells when lights or colours are blinking around me
55	I perceive phantom smells more often when I am outdoors
56	I perceive phantom smells more often when temperature changes occur
57	I perceive phantom smells more often when I am indoors
58	I perceive phantom smells more often when I am reminded of happy memories
59	I perceive phantom smells more often when I am reminded of traumatic memories
61	Some odours smell different from what they used to
62	Some odours that previously smelled pleasant, now smell unpleasant
63	Some odours that previously smelled unpleasant, now smell pleasant
64	I perceive odours differently more often when I eat
65	I perceive odours differently more often when breathing through my nose
66	I perceive odours differently all the time
67	I perceive odours differently about once an hour
68	I perceive odours differently about once a day
69	I perceive odours differently about once a week
70	I perceive odours differently less than once a week
71	I perceive changed odours only vaguely
72	I perceive changed odours' strength like other odours
73	I perceive changed odours intensely
74	I perceive odours differently more often when I am sad
76	I perceive odours differently more often when I am happy
77	I perceive odours differently more often when I am angry
78	I perceive odours differently more often when I am disgusted
79	I perceive odours differently more often when I am surprised
80	I perceive odours differently more often when I am scared
81	I perceive odours differently more often when I am tired
82	I perceive odours differently more often when I listen to music
83	I perceive odours differently more often when I am in a noisy environment
84	I perceive odours differently more often when I am in a silent environment
85	I perceive odours differently just by seeing something that has a distinct odour
86	I perceive odours differently when lights or colours are blinking around me
87	I perceive odours differently more often when I am outdoors
88	I perceive odours differently more often when temperature changes occur
89	I perceive odours differently more often when I am indoors
91	I perceive odours differently more often when I eat or prepare meat
92	I perceive odours differently more often when I eat or prepare fish
93	I perceive odours differently more often when I eat or prepare eggs
94	I perceive odours differently more often when I eat or prepare rice
95	I perceive odours differently more often when I eat or prepare nuts
96	I perceive odours differently more often when I drink or prepare milk
97	I perceive odours differently more often when I eat or prepare carrot
98	I perceive odours differently more often when I eat or prepare tomato
99	I perceive odours differently more often when I eat or prepare onion
100	I perceive odours differently more often when I drink or prepare coffee

Item no.	Item formulation
101	I perceive odours differently more often when I eat or prepare chocolate
102	I perceive odours differently more often when I eat or prepare melon
103	I perceive odours differently more often when I eat or prepare lemon
104	I perceive odours differently more often when I eat or prepare apple
105	I perceive odours differently more often when I am reminded of happy memories
106	I perceive odours differently more often when I am reminded of traumatic memories

Appendix B. Nettskjema-survey (containing information letter, demographic and COVID-19 related variables, PARPHAIT, related psychological aspects, and face-validation questions).

Related psychological aspects include depressive symptoms, cognitive status, and sensory sensitivity. To evaluate depressive symptoms, we used the Patient Health Questionnaire 9⁽¹⁾. Cognitive function was assessed by using the Cognitive Failures Questionnaire (CFQ)⁽²⁾, and to investigate sensory sensitivity we included the Highly Sensitive Person Scale (HSP)⁽³⁾. We wanted to include these variables in the study due to how depression

⁽⁴⁾, cognition (specifically the development and presence of neurodegenerative disease⁽⁵⁾), and sensitivity to sensory input are thought to be related to olfactory function. These aspects are interesting in terms of their potential confounding effect, but also because we wanted to investigate how they relate to qualitative symptoms of olfactory dysfunction.

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AbScent Smell dysfunction study

Are you experiencing problems with your sense of smell?

We would like to invite you to participate in our study, where the aim is to develop a new questionnaire that measures problems with smell. Perhaps you find that odours smell weaker now than before? Or perhaps something that previously smelled pleasant now smells foul? Maybe you can even sense odours that only you can smell?

If this sounds familiar, you are welcome to complete our questionnaire.

What does participation involve?

This online questionnaire takes about 20 minutes to complete. We will ask questions about age, sex, education, cause of smell problem and symptoms you may have, cognitive functioning, depressive symptoms, and how sensitive you are to sensory stimuli. The reason we want to ask questions about cognitive functioning, depressive symptoms, and sensitivity is because the sense of smell is thought to relate to these aspects.

Participation is voluntary. Should you wish not to participate or withdraw from the study, you can choose to do so at any time without giving a reason.

How do we store and use your data?

We treat the data collected confidentially and in accordance with the data protection regulations. The data will only be accessed by the research group involved in this project, consisting of a PhD-student, a main supervisor, and two co-supervisors, all affiliated with the University of Stavanger in Norway.

To ensure that data are secured, your e-mail address will be encrypted, meaning that data can only be accessed using a code that is stored separately from the collected data.

It will not be possible to tie published results to your personal data. The data collected will be stored for five years, but will only be used for the purposes of the research project. Provided that you can be identified in the collected data, you are entitled to access your data, have it rectified or deleted, receive a copy of the data, and submit a complaint about the processing of the data. In this regard, you can contact the Data Protection Officer

at personvernombud@uis.no.

Is the project ethically approved?

The Regional Committees for Medical and Health Research Ethics (REC) has ethically approved the processing of personal data for this research project.

Do you have any questions?

Should you have any questions regarding the project, please contact PhD-student Annelin Espetvedt by e-mail: annelin.espetvedt@uis.no or the chief investigator Daniel A. Lungu by e-mail: daniel.a.lungu@uis.no.

If you are using a smartphone to complete the questionnaire, we recommend that you rotate the screen for a more user-friendly experience.

Please fill in the following

Age

Sex

Male

Female

Other

Prefer not to answer

Highest level of education

Elementary and middle school (or equivalent)

High school (or equivalent)

Bachelor's degree

Master's degree

Doctorate degree

Is COVID-19 the underlying cause of your problems with smell?

Yes

No

If you are currently experiencing problems with smell, for how long have they lasted?

Less than two weeks

About 1 month

About 2 months

2-6 months

6-12 months

For more than a year

If you have recovered from the problems with smell, how long did the problems last?

Less than two weeks About 1 month

About 2 months

2-6 months

6-12 months

For more than a year

Below are statements about how you experience your own sense of smell.

On a scale from agree to disagree, how do the following

statements apply to you during the past week?

If the statement does not apply to you, if you are not sure, or if you are unfamiliar with the odours, please select the "not applicable" option.

In perfumeries, I hardly perceive the fragrance.

Not applicable

Agree

Somewhat agree

Neither agree nor disagree

Somewhat disagree

Disagree

It may happen that I do not notice it when I step into a dog pile.

Not applicable

Agree

Somewhat agree

Neither agree nor disagree

Somewhat disagree

Disagree

I do not perceive the smell of coffee or fresh bread.

Not applicable

Agree

Somewhat agree

Neither agree nor disagree

Somewhat disagree

Disagree

I do not perceive when other people smell strongly like garlic.

Not applicable

Agree

Somewhat agree

Neither agree nor disagree

Somewhat disagree

Disagree

I like to look around the flower shop, but I cannot smell anything.

Not applicable

Agree

Somewhat agree

Neither agree nor disagree

Somewhat disagree

Disagree

I do not smell the perspiration of sweaty people.

Not applicable

Agree

Somewhat agree

Neither agree nor disagree

Somewhat disagree

Disagree

My pleasure in eating does not come with a pleasant smell experience.

Not applicable

Agree

Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I do not perceive the "typical smell" of paint thinner or glue.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I do not smell the fresh tar at a road construction site.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
Other people know earlier than me when food smells bad.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I do not smell the body odour of my girlfriend/boyfriend/partner.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I do not perceive the musty odour in a damp cellar.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I do not recognise the smell of freshly mowed grass.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I do not mind the bad smell in some public toilets.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree

Somewhat disagree
 Disagree
I cannot perceive any odours at all.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I find it difficult to detect certain odours.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
It is particularly hard for me to name certain odours.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
Distinguishing one odour from another is challenging for me.
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree

Below are statements about **perceiving odours that other people around you do not experience and that has no apparent odour source.**

In the statements such odours are referred to as "**phantom smells**"

On a scale from agree to disagree, how do the following statements apply to you during the past week?

If the statement does not apply to you, if you are not sure, or if you are unfamiliar with the odours, please select the "not applicable" option.

I perceive phantom smells
 Not applicable
 Agree
 Somewhat agree
 Neither agree nor disagree
 Somewhat disagree
 Disagree
I perceive pleasant phantom smells

Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells about once a week</i>
<i>I perceive unpleasant phantom smells</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells less than once a week</i>
<i>I perceive neutral phantom smells</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells only vaguely</i>
<i>I perceive phantom smells more often when I eat</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells' strength like other odours</i>
<i>I perceive phantom smells more often when breathing through my nose</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells intensely</i>
<i>I perceive phantom smells all the time</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when I am sad</i>
<i>I perceive phantom smells about once an hour</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when I am happy</i>
<i>I perceive phantom smells about once a day</i>	Not applicable
Not applicable	Agree
	Somewhat agree

Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when I am in a silent environment</i>
<i>I perceive phantom smells more often when I am angry</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells just by seeing something that has a distinct odour</i>
<i>I perceive phantom smells more often when I am disgusted</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells when lights or colours are blinking around me</i>
<i>I perceive phantom smells more often when I am surprised</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when I am outdoors</i>
<i>I perceive phantom smells more often when I am scared</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when I am tired</i>
<i>I perceive phantom smells more often when I am tired</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when temperature changes occur</i>
<i>I perceive phantom smells more often when I listen to music</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when I am indoors</i>
<i>I perceive phantom smells more often when I am in a noisy environment</i>	Not applicable
Not applicable	Agree
Agree	Somewhat agree
Somewhat agree	Neither agree nor disagree
Neither agree nor disagree	Somewhat disagree
Somewhat disagree	Disagree
Disagree	<i>I perceive phantom smells more often when I am reminded of happy memories</i>
<i>I perceive phantom smells more often when I am in a noisy environment</i>	Not applicable
Not applicable	
Agree	
Somewhat agree	
Neither agree nor disagree	

- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive phantom smells more often when I am reminded of traumatic memories

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

Below are statements about **perceiving odours differently** from how they usually smell like. By this we mean **a change in the character of an odour and/or the pleasantness of that odour**.

For instance, coffee may now smell like garbage, and smells foul when it perhaps previously smelled pleasant to you. It can also be that something that previously smelled unpleasant now smells more pleasant.

Note that *changed* and *different(ly)* here **does not** include symptoms of a reduced or lost sense of smell.

On a scale from agree to disagree, how do the following statements apply to you during the past week?

If the statement does not apply to you, if you are not sure, or if you are unfamiliar with the odours, please select the "not applicable" option.

Some odours smell different from what they used to

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

Some odours that previously smelled pleasant, now smell unpleasant

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

Some odours that previously smelled unpleasant, now smell pleasant

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree

- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when breathing through my nose

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently all the time

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently about once an hour

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently about once a day

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently about once a week

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently less than once a week

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree

Disagree	Not applicable
<i>I perceive changed odours only vaguely</i>	Agree
Not applicable	Somewhat agree
Agree	Neither agree nor disagree
Somewhat agree	Somewhat disagree
Neither agree nor disagree	Disagree
Somewhat disagree	<i>I perceive odours differently more often when I am scared</i>
Disagree	Not applicable
<i>I perceive changed odours' strength like other odours</i>	Agree
Not applicable	Somewhat agree
Agree	Neither agree nor disagree
Somewhat agree	Somewhat disagree
Neither agree nor disagree	Disagree
Somewhat disagree	<i>I perceive odours differently more often when I am tired</i>
Disagree	Not applicable
<i>I perceive changed odours intensely</i>	Agree
Not applicable	Somewhat agree
Agree	Neither agree nor disagree
Somewhat agree	Somewhat disagree
Neither agree nor disagree	Disagree
Somewhat disagree	<i>I perceive odours differently more often when I listen to music</i>
Disagree	Not applicable
<i>I perceive odours differently more often when I am sad</i>	Agree
Not applicable	Somewhat agree
Agree	Neither agree nor disagree
Somewhat agree	Somewhat disagree
Neither agree nor disagree	Disagree
Somewhat disagree	<i>I perceive odours differently more often when I am in a noisy environment</i>
Disagree	Not applicable
<i>I perceive odours differently more often when I am happy</i>	Agree
Not applicable	Somewhat agree
Agree	Neither agree nor disagree
Somewhat agree	Somewhat disagree
Neither agree nor disagree	Disagree
Somewhat disagree	<i>I perceive odours differently more often when I am in a silent environment</i>
Disagree	Not applicable
<i>I perceive odours differently more often when I am angry</i>	Agree
Not applicable	Somewhat agree
Agree	Neither agree nor disagree
Somewhat agree	Somewhat disagree
Neither agree nor disagree	Disagree
Somewhat disagree	<i>I perceive odours differently more often when I am disgusted</i>
Disagree	Not applicable
<i>I perceive odours differently more often when I am surprised</i>	Agree
Not applicable	Somewhat agree
Agree	Neither agree nor disagree
Somewhat agree	Somewhat disagree
Neither agree nor disagree	Disagree
Somewhat disagree	<i>I perceive odours differently just by seeing something that has a distinct odour</i>
Disagree	Not applicable
	Agree
	Somewhat agree
	Neither agree nor disagree
	Somewhat disagree
	Disagree

I perceive odours differently when lights or colours are blinking around me

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I am outdoors

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when temperature changes occur

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I am indoors

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare meat

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare fish

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare eggs

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare rice

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare nuts

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I drink or prepare milk

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare carrot

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare tomato

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare onion

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I drink or prepare coffee

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare chocolate

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare melon

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare lemon

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I eat or prepare apple

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I am reminded of happy memories

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

I perceive odours differently more often when I am reminded of traumatic memories

- Not applicable
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree

During the past two weeks, how often have you been bothered by any of the following problems?

Little interest or pleasure in doing things

- Not at all
- Several days

More than half the days

Nearly every day

Feeling down, depressed, or hopeless

Not at all

Several days

More than half the days

Nearly every day

Trouble falling or staying asleep, or sleeping too much

Not at all

Several days

More than half the days

Nearly every day

Feeling tired or having little energy

Not at all

Several days

More than half the days

Nearly every day

Poor appetite or overeating

Not at all

Several days

More than half the days

Nearly every day

Feeling bad about yourself - or that you are a failure or have let yourself or your family down

Not at all

Several days

More than half the days

Nearly every day

Trouble concentrating on things, such as reading the newspaper or watching television

Not at all

Several days

More than half the days

Nearly every day

Moving or speaking so slowly that other people could have noticed - or the opposite - being to fidgety or restless that you have been moving around a lot more than usual

Not at all

Several days

More than half the days

Nearly every day

Thoughts that you would be better off dead or of hurting yourself in some way

Not at all

Several days

More than half the days

Nearly every day

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all

Somewhat difficult
Very difficult
Extremely difficult

Below are some statements about how you experience sensory information and how you feel about it.

On a scale from 1 (not at all) to 7 (extremely), how do the following statements apply to you?

Are you easily overwhelmed by strong sensory input?

1 Not at all
2
3
4
5
6
7 Extremely

Do you seem to be aware of subtleties in your environment?

1 Not at all
2
3
4
5
6
7 Extremely

Do other people's moods affect you?

1 Not at all
2
3
4
5
6
7 Extremely

Do you tend to be more sensitive to pain?

1 Not at all
2
3
4
5
6
7 Extremely

Do you find yourself needing to withdraw during busy days, into bed or into a darkened room or any place where you can have some privacy and relief from stimulation?

1 Not at all
2
3
4
5
6
7 Extremely

Are you easily overwhelmed by things like bright lights, strong

smells, coarse fabrics, or sirens close by?

1 Not at all
2
3
4
5
6
7 Extremely

Do you have a rich, complex inner life?

1 Not at all
2
3
4
5
6
7 Extremely

Are you made uncomfortable by loud noises?

1 Not at all
2
3
4
5
6
7 Extremely

Are you deeply moved by the arts or music?

1 Not at all
2
3
4
5
6
7 Extremely

Does your nervous system sometimes feel so frazzled that you just have to go off by yourself?

1 Not at all
2
3
4
5
6
7 Extremely

Are you conscientious?

1 Not at all
2
3
4
5
6
7 Extremely

Do you startle easily?

1 Not at all

2
3
4
5
6
7 Extremely

Do you get rattled when you have a lot to do in a short amount of time?

1 Not at all
2
3
4
5
6
7 Extremely

When people are uncomfortable in a physical environment do you tend to know what needs to be done to make it more comfortable (like changing the lighting or the seating)?

1 Not at all
2
3
4
5
6
7 Extremely

Are you annoyed when people try to get you to do too many things at once?

1 Not at all
2
3
4
5
6
7 Extremely

Do you try hard to avoid making mistakes or forgetting things?

1 Not at all
2
3
4
5
6
7 Extremely

Do you make a point to avoid violent movies and TV shows?

1 Not at all
2
3
4
5
6
7 Extremely

Do you become unpleasantly aroused when a lot is going on

around you?

1 Not at all
2
3
4
5
6
7 Extremely

Does being very hungry create a strong reaction in you, disrupting your concentration or mood?

1 Not at all
2
3
4
5
6
7 Extremely

Do changes in your life shake you up?

1 Not at all
2
3
4
5
6
7 Extremely

Do you notice and enjoy delicate or fine scents, tastes, sounds, works of art?

1 Not at all
2
3
4
5
6
7 Extremely

Do you find it unpleasant to have a lot going on at once?

1 Not at all
2
3
4
5
6
7 Extremely

Do you make it a high priority to arrange your life to avoid upsetting or overwhelming situations?

1 Not at all
2
3
4
5
6
7 Extremely

Are you bothered by intense stimuli, like loud noises or chaotic scenes?

- 1 Not at all
- 2
- 3
- 4
- 5
- 6
- 7 Extremely

When you must compete or be observed while performing a task, do you become so nervous or shaky that you do much worse than you would otherwise?

- 1 Not at all
- 2
- 3
- 4
- 5
- 6
- 7 Extremely

When you were a child, did parents or teachers seem to see you as sensitive or shy?

- 1 Not at all
- 2
- 3
- 4
- 5
- 6
- 7 Extremely

The following questions are about minor mistakes which everyone makes from time to time, but some of which happen more often than others.

On a scale from very often to never, how often have you experienced the following during the past six months?

Do you read something and find you haven't been thinking about it and must read it again?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you forget why you went from one part of the house to the other?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you fail to notice signposts on the road?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you confuse right and left when giving directions?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you bump into people?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you forget whether you've turned off a light or a fire or locked the door?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you fail to listen to people's names when you are meeting them?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you say something and realize afterwards that it might be taken as insulting?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you fail to hear people speaking to you when you are doing something else?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you lose your temper and regret it?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you leave important letters unanswered for days?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you forget which way to turn on a road you know well but rarely use?

Very often Quite often Occasionally Very rarely Rarely Never

On a scale from very often to never, how often have you experienced the following during the past six months?

Do you fail to see what you want in a supermarket (although it's there)?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find yourself suddenly wondering whether you've used a word correctly?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you have trouble making up your mind?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you forget appointments?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you forget where you put something like a newspaper or a

book?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you accidentally throw away the thing you want and keep what you meant to throw away – as in the example of throwing away the matchbox and putting the used match in your pocket?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you daydream when you ought to be listening to something?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you forget people's names?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you start doing one thing at home and get distracted into doing something else (unintentionally)?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you can't quite remember something although it's "on the tip of your tongue"?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you forget what you came to the shops to buy?

- Very often
- Quite often
- Occasionally

- Very rarely
- Rarely
- Never

Do you drop things?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

Do you find you can't think of anything to say?

- Very often
- Quite often
- Occasionally
- Very rarely
- Rarely
- Never

We would very much appreciate your feedback on how you experienced completing the questionnaire.

On a scale from 1 to 5, where 1 is not suitable and 5 is highly suitable, how would you rate the following:

The relevance of the questions



The clarity of questions



The length of questions (in words)



The number of questions



The time it took to complete the questionnaire



The response options



Is there anything we did not ask you that you think would be important to include in the questionnaire? Do you have any other comments?

Appendix C. Items removed (and reasons why) during exploratory factor analysis.

Low communality	
Item no.	Communality
14	.18
Low factor- and cross loadings	
Item no.	Factor loading
8	.62
10	.61
11	.63*
14	.31
15	.51
16	.62
18	.55
19	.60
23	.55
24	.54
25	.42
28	.60
61	.40
62	.42**
63	.50
64	.45**
65	.42**
66	.42**
71	.39
72	.41**
73	.39**
77	.56

*Factor loadings are rounded up when the third decimal is 5 or higher.

For item 11, the factor loading was borderline with a value of .625.

**Items cross-loaded (with >.32) onto more than one factor.

Appendix D. Four-factor model (as presented in logical order).

Item no.	Item formulation	Factor				α	CI-TC	Mean CI-TC
		1 Loss of smell	2 Presence valence, frequency, and intensity of phantosmia	3 Triggers of parosmia	4 Frequency of parosmia			
12	I like to look around the flower shop, but I cannot smell anything	.82					.77	
22	I do not mind the bad smell in some public toilets	.79					.71	
21	I do not recognise the smell of freshly mowed grass	.76					.71	
9	It may happen that I do not notice it when I step into a dog pile	.74					.68	
20	I do not perceive the musty odour in a damp cellar	.66					.61	
13	I do not smell the perspiration of sweaty people	.66				.88	.66	.69
32	I perceive phantom smells more often when I eat		.85				.83	
46	I perceive phantom smells more often when I am disgusted		.83				.81	
36	I perceive phantom smells about once a day		.82				.76	
41	I perceive phantom smells intensely		.80				.78	
33	I perceive phantom smells more often when breathing through my nose		.79				.77	
40	I perceive phantom smells' strength like other odours		.78				.76	
37	I perceive phantom smells about once a week		.77				.74	
57	I perceive phantom smells more often when I am indoors		.77				.76	
29	I perceive pleasant phantom smells		.77				.73	
31	I perceive neutral phantom smells		.71				.69	
38	I perceive phantom smells less than once a week		.70				.72	
30	I perceive unpleasant phantom smells		.70				.67	
39	I perceive phantom smells only vaguely		.67			.95	.67	.74
95	I perceive odours differently more often when I eat or prepare nuts			.92			.85	
94	I perceive odours differently more often when I eat or prepare rice			.88			.85	
92	I perceive odours differently more often when I eat or prepare fish			.86			.75	
98	I perceive odours differently more often when I eat or prepare tomato			.83			.81	
101	I perceive odours differently more often when I eat or prepare chocolate			.80			.79	
91	I perceive odours differently more often when I eat or prepare meat			.79			.76	
103	I perceive odours differently more often when I eat or prepare lemon			.78			.80	
100	I perceive odours differently more often when I drink or prepare coffee			.77			.74	
96	I perceive odours differently more often when I drink or prepare milk			.75			.77	
93	I perceive odours differently more often when I eat or prepare eggs			.74			.77	

Item no.	Item formulation	Factor				α	CI-TC	Mean CI-TC
		1 Loss of smell	2 Presence valence, frequency, and intensity of phantosmia	3 Triggers of parosmia	4 Frequency of parosmia			
102	I perceive odours differently more often when I eat or prepare melon			.73		.77		
99	I perceive odours differently more often when I eat or prepare onion			.68	.95	.70	.78	
68	I perceive odours differently about once a day					.82		
69	I perceive odours differently about once a week					.78		
67	I perceive odours differently about once an hour				.88	.73	.78	

In the initial EFA factor model, factors were suggested in the order of factor 1: Triggers of parosmia, factor 2: Presence, valence, frequency, and intensity of phantosmia, factor 3: Loss of smell, and factor 4: Frequency of parosmia. For the model presented above, we have structured factors in a more logical order, as could be presented in a clinical setting.