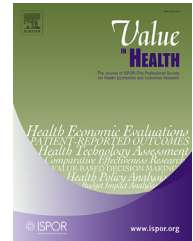


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Patient-Reported Outcomes

Patient-Centered Item Selection for a New Preference-Based Generic Health Status Instrument: CS-Base

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ABSTRACT

Objectives: To develop patient-centered health content for a novel generic instrument (Château Santé Base [CS-Base]) that is suitable to generate values for health status. **Methods:** Candidate items were drawn from existing health frameworks of generic health status instruments and placed in a diagram (HealthFAN™, Zeist, the Netherlands). Through an online survey, patients with a wide range of diseases were asked to select the 9 items that were most important to them. The importance of the items for the whole study group was determined by means of frequency distributions. **Results:** After handling duplicates and overlap, the remaining set of 47 items was placed in the HealthFAN. Among the 2256 Dutch patients who started the survey, the most common diagnoses were neck and back pain, diabetes, and asthma/chronic obstructive pulmonary disease. The 5 health items mentioned most frequently as most important were

pain, personal relationships, fatigue, memory, and vision. Hearing and vision, anxiety and depression, and independence and self-esteem seemed highly intertwined, so we chose to pair these items. **Conclusions:** A total of 12 health items were included in CS-Base. Its content is largely based on patient input and enables classification of patients' health status. CS-Base can be administered by means of an app on a mobile phone, which makes it a convenient and attractive tool for patients and researchers.

Keywords: classification, health status, patient-centered, values

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Introduction

Nowadays, patient involvement and patient advocacy are guiding principles at many levels of healthcare. In addition, patients' views of their symptoms, functional status, and health-related quality of life (HRQOL) are being taken more seriously by policy makers and others.¹ This trend has sparked interest in developing patient-reported outcome measures (PROMs)—any report coming directly from patients about how they function or feel, without interpretation or filtering by physicians or others. These types of outcome measures are also and perhaps better met with measures of *patient-centered* outcomes, because these are of particular concern to the patient. So far, when developing health outcome instruments, the content has largely been based on consensus and expert opinion instead of patients' input.²

The conventional health status construct is often extended to encompass psychological and even social factors. The use of these HRQOL measures has proliferated ever since the World Health

Organization (WHO) published its definition of “health” in 1946. Health outcome measures such as perceived health status, HRQOL, and quality of life are necessary outcomes, because ultimately the goal of all health interventions is to improve or sustain the patient's perceived health condition.³

For a measure of health status to be useful, it has to assess not only the frequency or severity of the complaints, as do most profile measures (eg, Short Form-36 health survey and European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire [Core, 30 items]), but also the impact of these. We need to measure the way in which patients perceive or experience their own health status.^{4–8} Problems that are frequently mentioned by them and therefore presumed by researchers to be important are not necessarily of much concern to a particular person. Yet these same individuals may care a great deal about certain problems that do not rank as important in the analysis because these complaints are mentioned rarely or, when reported, assigned a modest level of severity. It is therefore

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imperative to solicit and incorporate patients' value judgments and preferences into an assessment of their health condition. To do this properly requires special measurement methods that are constructed in a preference-based framework.⁹ In particular, health items must be weighted to reflect the relative importance that patients place on each, thereby producing measures (values) that express the quality of a health state in a single metric number. Such health values can be put to various uses: to indicate change over time in the health of a group of patients, to identify differences in the health of distinct populations, to assess the extent to which the objectives of a health intervention program are being achieved, to assess the cost effectiveness of certain interventions, and to support clinical decision making.

One of the most challenging development tasks is to determine which suite of health items—variously also known as attributes, domains, dimensions, or indicators—should be incorporated to capture the full range of health. To develop a robust health status outcome instrument, a careful selection of health items is paramount. Face and content validity are crucial to the development of a health status instrument, yet these are seldom evaluated. Instead, most of the currently applied health status instruments, and certainly the preference-based health status instruments, have been developed with a top-down approach. That is, their content has either been derived from existing instruments and health surveys or has been generated in consultation with experts.^{8,10} Sometimes a combination of these 2 sources is used. Patient or public involvement in the development of health status instruments, if any, has typically occurred at a later stage. When the developer imposes predefined health items that could result in either omitting health items that have a high relevance to patients or accentuate irrelevant ones. Therefore, a better strategy is to select items on the basis of patient input, as is increasingly recognized.^{8,10–13}

This study describes the first stage in the process of developing patient-centered health content for a novel generic health status instrument that is suitable to generate values for health status.

Methods

In its constitution, WHO defined *health* as a “state of complete physical, mental, and social well-being.” Although physical and mental well-being are distinct concepts, they are also interrelated; the state of one often affects the state of the other. The notion of social well-being extends the concept of health beyond the individual to include the quantity and quality of social contacts and social resources. Nevertheless, Ware et al¹⁴ objected to the inclusion of social well-being, citing evidence that “supports restriction of the definition of personal health status to its physical and mental components, rather than including social circumstances as well.” Although concurring with this argument, we will adhere to the WHO definition and the prevailing opinion in the field. A later version used in WHO's surveys subdivided the concept into 6 domains that are direct indicators of health: mobility, pain and discomfort, cognition, vision, sleep and energy, and affect. In addition, WHO uses some health-related domains that are indirect indicators of well-being: self-care and interpersonal activities.¹⁵

Measurement Framework

To derive health values, the patients have to perform 2 distinct tasks. The first task amounts to taking a “snapshot” of the current health condition: to describe it and rate (classify) it in terms of seriousness. The second task is to assign a value (quantify) to the health state description by means of an appropriate measurement procedure.¹⁶ A new way to rate and value health states was

recently introduced, the multiattribute preference response (MAPR) model, which is based on the Rasch model (an item-response theory model).^{17,18} The MAPR model more or less mimics the situation of a patient with a certain health condition lying in a wardroom where the other occupants have related complaints and symptoms. This patient is asked to compare his own health state to those of his roommates by indicating whether his own state is better or worse. This method operates with the data collection technology HealthSnApp™ (Zeist, the Netherlands) (a mobile app in combination with a central server; www.healthsnapp.info), an innovation in the field of health outcome measurement that combines a newly developed measurement model with interactive software routines that are generic and flexible.^{17,18}

Users of HealthSnApp (ie, patients) are asked to rate their health by ticking boxes until the descriptions in all the boxes best describe their current health. The specific combination of responses (different levels of the health items) constitutes the overall health state (Fig. 1, left). In the second task, their health state, as described in task 1, is compared with those of hypothetical patients with slightly different health states (Fig. 1, right). Patients are then asked to choose whether the hypothetical state is better or worse than their own state. This procedure is essentially in a preference-based measurement in which individuals are asked to indicate their preferences for various health states.^{9,16}

There is a cognitive constraint on the number of items that may be included in a description of a health state. A typical feature of preference-based measurement is that all relevant characteristics of the object of study have to be evaluated together. For our purposes, this means evaluating all relevant health items in combination. The need to evaluate whole sets of items forms a major impediment to preference-based measurement, because it may make the tasks more difficult. As demonstrated by Miller,¹⁹ the span of immediate memory puts severe limitations on the amount of information that people are able to receive, process, and remember. In general, people can discriminate 7 (± 2) pieces of information at a time, and so most preference-based studies usually present no more than 9 items.¹⁹ That is probably the maximum amount of information people can process simultaneously. In task 1 of our measurement procedure, the number of items is not a serious issue. In task 2, where respondents have to compare multiple health state descriptions with their own health state, the amount of information should be kept within manageable limits. An important element of the HealthSnApp procedure is that only 2 of the items may vary in the comparison performed in task 2 (Fig. 1). This constraint reduces the complexity of the assessment substantially, because the respondent no longer has to consider all items in detail. On the basis of the information-capacity argument and the practical fact that more than 9 full bars are unfeasible on a mobile phone screen, the instrument was initially designed to present 9 items.

Selection of Health Items

Step 1: Collection of candidate items

Ideally, the health instrument that we are developing should be sufficiently sensitive and specific to evaluate healthcare provision for the most common patient groups older than 18 years. The candidate items were drawn from existing health frameworks^{20–23} and from existing generic health status instruments,^{24–29} as identified by a literature search. Items that are associated with specific target populations such as psychiatric patients, young children, and cognitively impaired patients (eg, with dementia) were excluded at this stage. For example, psychiatric items (eg, mental state, abnormal perceptions, or thoughts) are not

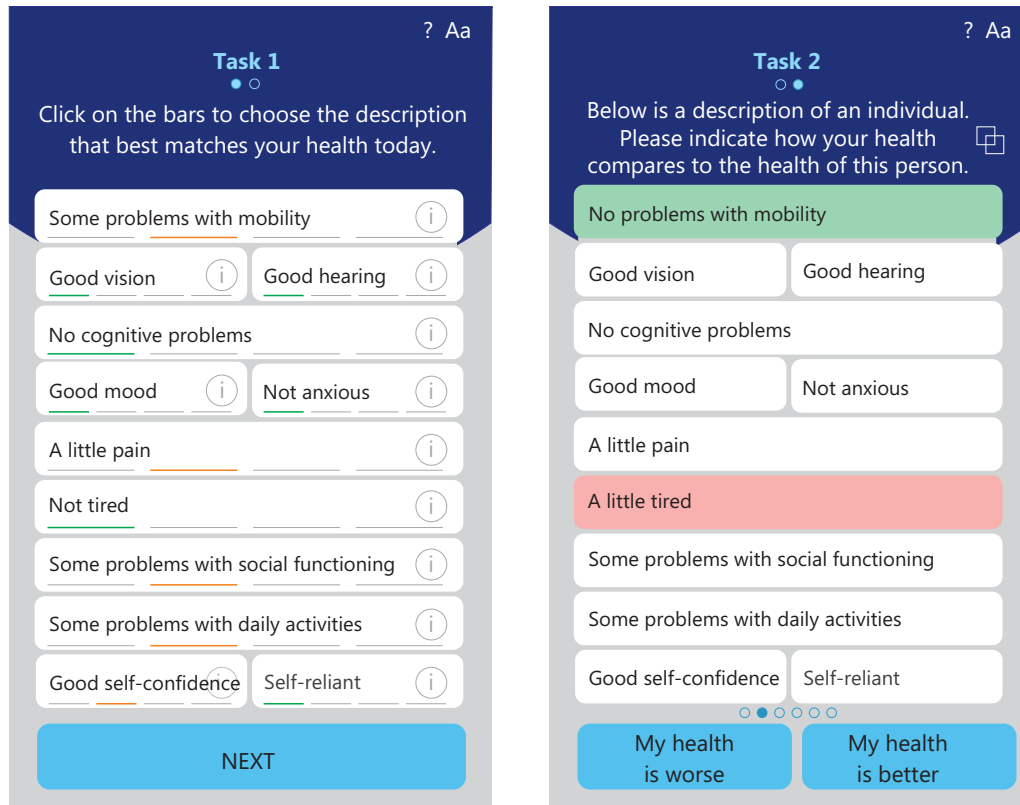


Fig. 1 – The generic health status instrument CS-Base as used in the measurement routine of the HealthSnApp® mobile application (prototype). The mobile app consists of 2 tasks. In task 1, a descriptive task, all health items are listed in interactive boxes presented in table format on a single screen (left). By clicking on the interactive box for a specific item, the box changes to display the response options. For instance, when clicking on the box labeled “mobility,” the box changes and displays the response options “no problems with mobility,” “some problems with mobility,” “moderate problems with mobility,” and “severe problems with mobility.” Information collected in task 1 is used to determine the comparator states in the second task (patent pending). In task 2, respondents compare their own health state from task 1 with other states. Task 2 is intended to derive preferences that are subsequently used to estimate weights for the levels of each item. CS-Base indicates Château Santé Base.

considered, but eudemonic conditions (eg, dignity and autonomy) are included.

Apart from these theoretical considerations, practical concerns were also taken into account, particularly when defining and phrasing the items. First, items need to be described in neutral terms that are factually accurate and sufficiently complete. The level of wording should be compatible with that of most of the population. Moreover, medical terminology or jargon should be avoided. Finally, the terms should not be difficult to translate or have a strong cultural connotation.

Step 2: Selection of the most important health items

A relatively simple task was designed whereby a patient selects the health items he or she considers the most important by choosing items from a diagram: the HealthFAN™ (Zeist, the Netherlands). The HealthFAN systematizes various health items that are associated with broader health domains and subdomains. An online survey introduced the topic at hand and familiarized the respondents with the type of questions to expect. Then they were asked to select the 9 items (the planned number of items to be included in the instrument under development) from the diagram (Fig. 2) that were most important to them. For some of the items an additional explanation appeared on the screen when hovering over an item. The basis of the patient exercise can be

seen as a simplified procedure of Q methodology, which highlights specific relationships and clusters of important items.³⁰

The target group for this task was a large sample of patients with a wide range of diagnosed diseases. The Medical Ethics Review Committee at the University Medical Center of Groningen issued a waiver for this study, indicating that the pertinent Dutch Legislation (the Medical Research Involving Human Subjects Act) did not apply for this noninterventional study (METc 2014.181).

Analysis

The importance of the items was determined by constructing a frequency distribution. Data were analyzed using IBM SPSS Statistics for Windows, version 22.0 (IBM Corp, Armonk, NY).

Results

Candidate Health Items

A huge list of candidate items was expected, but a substantial overlap between them was observed. In fact, on the basis of the formulated criteria, a modest set consisting of 47 items was obtained. All the adopted items were arranged in a HealthFAN diagram to create a clear overview (Fig. 2). They were classified under

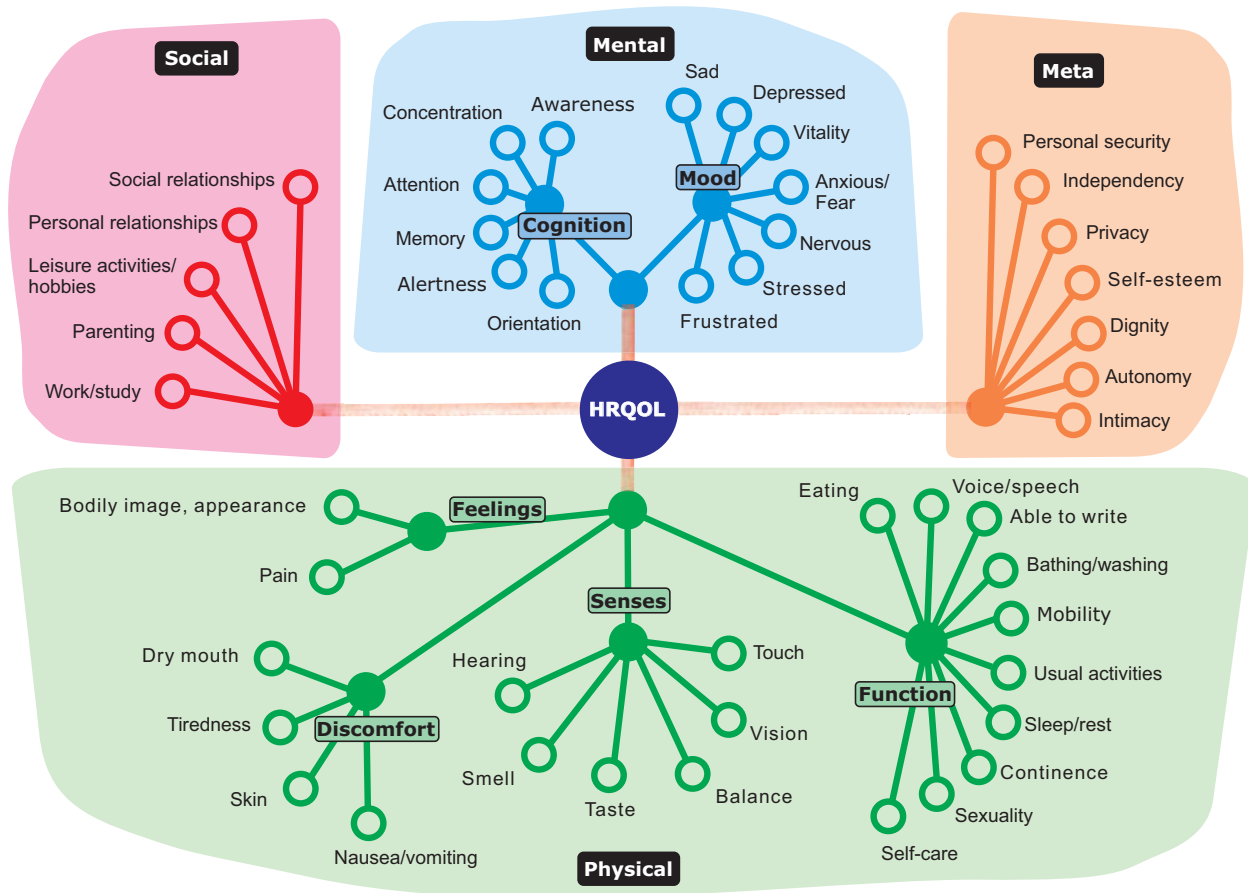


Fig. 2 – Health items depicted in a diagram (HealthFAN) reflecting different domains (social, mental, physical, and meta) and subdomains (discomfort, function, senses, feelings, cognition, and mood). HRQOL indicates health-related quality of life.

the higher order domains: physical, mental, social, and meta. The class of physical items was subdivided into feelings, discomfort, senses, and function. The class of mental items was subdivided into cognition and mood.

Sample

To select patients for the HealthFAN exercise, we contacted a general Dutch sample of 2256 patients registered by a market research company (Survey Sampling, Inc, Rotterdam, The Netherlands). Patients who fully completed the survey received a small financial compensation from Survey Sampling, Inc. The rewards were defined by the company's internal agreements with the groups of respondents. Data were collected from July 2015 till January 2016. The patient sample consisted of 1239 females and 1017 males, with an average age of 47.8 years (Table 1). The HealthFAN exercise was the last task in a series of other tasks (discrete choices about health interventions). As a consequence, 881 patients did not complete the HealthFAN task. The background characteristics have been collected separately at the time of registration for the survey at the sample collection stage, and therefore they are not presented for the completers. The registered sample consisted of patients with a wide range of diagnoses: diabetes, neck and back pain, heart diseases, hearing or vision loss, asthma/chronic obstructive pulmonary disease, eczema, mental health problems, stroke, rheumatism, cancer, epilepsy, lung disease, and gastric intestinal diseases. Patients were asked to self-report their diagnosis. We defined patients as individuals with actual diseases or serious complaints. Therefore, we did not

consider individuals with past experience of a disease. Some patients had been diagnosed with more than one problem, and the most common diagnoses were neck and back pain, diabetes, and asthma/chronic obstructive pulmonary disease.

Selected Important Items

We calculated the proportions of respondents indicating that the item in question was important for their health (Fig. 3). The 5 health items most frequently judged as the most important ones were pain (21%), personal relationships, fatigue, memory, and vision (14%). More than half the items (24 of 47) were considered important by less than 5% of the respondents. In light of the frequency distribution, some of the domains had to be adjusted and were no longer the same as on the HealthFAN. The meta domain was changed to meta/care, and a new domain, tiredness, was added including some items (sleeping/rest, tiredness/fatigue, vitality/energy/liveliness) previously covered by the domains mood, discomfort, and function. Given this redefinition, all the domains, except for the discomfort domain, contained at least 1 item with a frequency of importance of more than 5%.

It should be noted that it was a deliberate choice to mainly include patients with somatic diseases in the sample. For that reason, we think the importance of anxiety and depression might be underestimated in the analysis of the responses to the online survey. Also, in light of other evidence, we feel that this item should not be excluded from a generic instrument. Therefore, items from the mood domain were also considered for their relevance, even though the level of reporting was modest.

Table 1 – Characteristics of the patient sample.

Characteristic	Patients overall registered (N = 2256)
Female, n (%)	1239 (55)
Age (y), mean ± SD	47.8 ± 14.0
Age group (y), n (%)	
18-24	244 (11)
25-34	223 (10)
35-44	281 (12)
45-54	580 (26)
>55	928 (41)
Diagnosed with,* n (%)	
Neck and back pain	995 (44)
Diabetes	736 (33)
Asthma/chronic obstructive pulmonary disease	418 (19)
Mental health problems	383 (17)
Hearing or vision loss	370 (16)
Eczema	352 (16)
Rheumatism	335 (15)
Heart disease	302 (13)
Gastrointestinal disease	168 (7)
Cancer	153 (7)
Lung disease	86 (4)
Stroke	80 (4)
Epilepsy	53 (2)

SD indicates standard deviation.
 * The total frequencies exceed 2256 because some patients were diagnosed with more than 1 disease.

Originally, the plan was to define a maximum of 9 items for inclusion in the instrument and thus in the descriptive system (classification). Nevertheless, we had serious difficulty choosing between pairs of items that seemed highly intertwined or strongly related. These were the items hearing and vision, anxiety and depression, and independence and self-esteem. We have chosen to chunk these 3 pairs of health items. Therefore, the descriptive system asks patients to categorize their own health condition on 12 items (Fig. 1). Each item expresses a single aspect (no double-barreled terms such as pain/discomfort, as used in the EuroQol 5-dimensional questionnaire). Nevertheless, some items were rephrased to better address the issue we are interested in. The item depression as presented in the HealthFAN was rephrased to mood in the final version of the instrument (mood is more general and captures depression), independence was rephrased to self-reliance (independence suggests an attitude where a person does not need or accept help or advice, whereas self-reliance means handling practical situations on one's own), and self-esteem was rephrased to self-confidence (self-esteem is a component of temperament and is embedded in personality, whereas self-confidence is performance-related and situational). To ensure that the response categories would be clear and unambiguous, each item had only 4 levels (Table 2).

Discussion

After collecting relevant items on the basis of a literature search, selecting the most important ones, and subsequently surveying a population of patients with various diagnoses, a total of 12 health items were included in this new instrument. These are mobility, vision, hearing, cognition, mood, anxiety, pain, fatigue, social functioning, daily activities, self-confidence, and self-reliance.

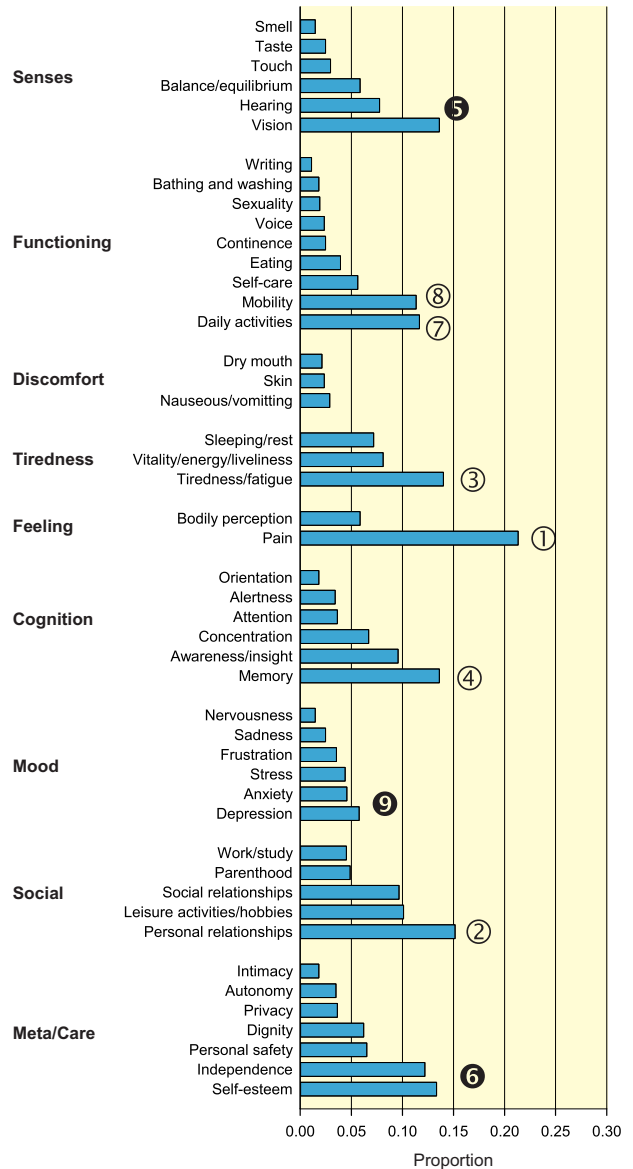


Fig. 3 – Proportion of respondents reporting the item in question to be important for their health. The numbers indicate the 9 most important items; the numbers in the black circles represent a paired set of items.

Combining some of the items left 9 main health characteristics for the final version.

The generic instrument presented here, Château Santé Base (CS-Base; www.chateau-sante.info), differs from existing instruments in many ways. The procedure for selecting its content consists largely of patient input. CS-Base generates a single value for a patient's health status from 12 distinct health items. Moreover, CS-Base is grounded in a novel measurement framework that had already been used to develop disease-specific instruments (eg, for infants, chronic pain, and transplantation).^{2,31,32} Being self-administered and web-based, it allows for a seamless user-friendly, fast, and attractive data collection process.

Most developers of health outcome instruments have realized that content validity cannot be established through quantitative psychometric analyses. This point was highlighted in the Food and Drug Administration's Patient-Reported Outcome guidance (2009).

Table 2 – Items and their levels for CS-Base.

Items	Levels
Mobility	<ol style="list-style-type: none"> 1. No problems with mobility 2. Some problems with mobility 3. Moderate problems with mobility 4. Severe problems with mobility
Vision	<ol style="list-style-type: none"> 1. Good vision 2. Limited vision 3. Poor vision 4. Blind
Hearing	<ol style="list-style-type: none"> 1. Good hearing 2. Limited hearing 3. Poor hearing 4. Deaf
Cognition	<ol style="list-style-type: none"> 1. No cognitive problems 2. Some cognitive problems 3. Moderate cognitive problems 4. Severe cognitive problems
Mood	<ol style="list-style-type: none"> 1. Good mood 2. Slightly bad mood 3. Bad mood 4. Dark mood
Anxiety	<ol style="list-style-type: none"> 1. Not anxious 2. Slightly anxious 3. Anxious 4. Highly anxious
Pain	<ol style="list-style-type: none"> 1. No pain 2. A little pain 3. Moderate pain 4. Severe pain
Fatigue	<ol style="list-style-type: none"> 1. Not tired 2. A little tired 3. Quite tired 4. Very tired
Social functioning	<ol style="list-style-type: none"> 1. No problems with social functioning 2. Some problems with social functioning 3. Moderate problems with social functioning 4. Severe problems with social functioning
Daily activities	<ol style="list-style-type: none"> 1. No problems with daily activities 2. Some problems with daily activities 3. Moderate problems with daily activities 4. Severe problems with daily activities
Self-confidence	<ol style="list-style-type: none"> 1. Strong self-confidence 2. Good self-confidence 3. Low self-confidence 4. Very weak self-confidence
Self-reliance	<ol style="list-style-type: none"> 1. Self-reliant 2. Somewhat dependent 3. Largely dependent 4. Fully dependent

CS-Base indicates Château Santé Base.

Nevertheless, researchers often rely on statistical techniques to determine which items are important. For example, factor analysis is often used on existing data for this purpose.³³ Nevertheless, factor analysis entails deriving relational information from correlations between the items. If some items are not very important but are scored in line with other items, then these less important items will show up in a factor. If some items are very important but are reported by a small number of patients or only at modest response levels, the correlation with the other items will be low. Consequently, the important items will not show up in the factor solution.⁹ To find out what the important items are, we have

to conduct qualitative research or studies with specific response tasks to generate data that can be properly analyzed.^{2,9}

Most PROMs are not preference-based. Most are profile instruments (eg, questionnaires) that do not measure the experienced impact of a patient's health condition. The scales used in profile instruments comprise multiple items that are related to each other (ie, Short Form-36 health survey and European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire [Core, 30 items]). There is some concern that existing generic preference-based health status instruments (eg, EuroQol 5-dimensional questionnaire, Health Utilities Index, and 6-dimensional health state Short Form-6D) are not sufficiently sensitive to the perspective of the individual patients, particularly with regard to specific patient groups.^{10,12,34} The health items for all current preference-based health status instruments were determined without significant patient input, because selection in this type of instrument predominantly relies on consensus and expert opinion.³⁵ By saying there was no significant patient input, we mean that patients were not involved in the selection of items. Sometimes, though, they were asked to comment on a draft version or to help reduce the number of items in a first version. The argument in favor of getting them involved is that patients understand the impact of their own health state on their lives better than someone trying to imagine it. Another limitation of the existing preference-based instruments is that they do not include items related to self-esteem/self-confidence and self-reliance/autonomy/independence, except for the Assessment of Quality of Life.²⁸ This could affect the relevance of those instruments for the future, given that elderly and disabled people are often supported by a combination of “conventional” healthcare and social care or long-term care.³⁶

This is the first time that we applied the HealthFAN approach using a selection of items from existing instruments. Our procedure for selecting the items that we deemed important may have some limitations. One could be the somewhat arbitrary grouping of items in the HealthFAN. For example, in our study we positioned speech under functioning, which is certainly defensible if speech is impaired because of a full or partial removal of the larynx (voice box). Nevertheless, the impairment could also be due to brain injury (aphasia), whereby it would be more logical to place speech under cognition. Many such ambiguities can be found, and careful consideration is needed to deal with them. It, however, remains to be investigated whether the grouping of items has an impact on how respondents select what is most important to them, and it could turn out to be only a minor factor in the process. Another limitation might be that we used in this study the relatively simple HealthFAN method, which is based on frequencies, to select important items for the CS-Base instrument. The selection procedure can be extended, for example, to include ranking exercises as subsequent tasks after the respondent has selected the most important items. We might then apply one of the special procedures, such as Q methodology, to highlight specific relationships and show clusters in more detail.³⁰ Nevertheless, our current frequency approach seems adequate for our present purposes, because responses were collected from a large sample and we were not interested in relationships or clusters.

CS-Base may be less appropriate in clinical practice, however. Not all patients are competent to assess their own health condition or to complete the task on a smartphone or computer. These obstacles are not unique to the CS-Base, however. Some specific groups of patients are unable to use this method because of their cognitive impairments (eg, mental illness and dementia), developmental stage (young children), communication deficits, blindness, or the severe distress caused by their illness. In such cases, assessment by proxies (eg, caregivers or spouse) may be the second-best solution.

Systematic empirical research is needed to determine the relevant items that constitute patients' health status. Even reflections from other disciplines such as philosophy and the social sciences may be drawn upon to broaden the concept of health and health status.^{37,38} Studies are being planned to reveal in more detail which items are most important to a wide range of patients. Patients are also invited to perform an additional task in the HealthSnApp where they are asked to mention health items that they consider important but are lacking in the current CS-Base. Revision of the instrument on the basis of this kind of patient input is part of the continuous development cycle. Step-by-step enhancements are envisioned that will eventually improve the instrument. This is possible because the measurement framework we use (the MAPR model and mobile app) is based on continuous data collection.

The CS-Base instrument is the first preference-based PROM that fully incorporates patient input in selecting the health items and that can be administered by means of a mobile app. Eventually, if the values are normalized (dead = 0), utilities for cost-effectiveness analyses can be produced.

Conclusions

A total of 12 health items were included in the novel generic classification system: CS-Base. Its content is largely based on patient input. The CS-Base can be administered by means of an mobile app, which makes it a convenient and attractive tool for patients and researchers. Moreover, the CS-Base is embedded in a preference-based measurement framework, that enables capturing patients' health status in a single score.

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