

China Health Related Outcomes Measures (CHROME): Development of a new generic preference-based measure for the Chinese population

Supplementary Material

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Appendix 1: Qualitative interview guide outline (English translation version)

Appendix 2: Items extracted from the existing generic PBMs

Appendix 3: Cognitive debriefing interview guide outline (English translation version)

Appendix 4: Inclusion process of candidate items based on specific selection criteria

Appendix 5: Distribution of the population representing the 31 provinces of mainland China

Appendix 1: Qualitative interview guide outline (English translation version)

I. Demographic information

[The information of age, gender, current residence, educational level are used to confirm whether the respondent meets the sampling quota.]

1. Age: _____

2. Gender: male female

3. Ethnic group: _____

4. Current residence: _____ province _____ city

5. Residence area: urban area rural area

6. Educational level:

primary or lower junior high school

senior high school (including technical secondary school)

college (including junior college) or higher

7. Employment status:

employed retired student unemployed

8. Marital status:

unmarried married divorced widowed

9. Family monthly income (in RMB):

<¥4000 ¥4000~10000 ¥10000~20000 >¥20000

10. Type of health insurance:

urban employee basic medical insurance

urban resident basic medical insurance (new cooperative medical scheme)

self-employed commercial health insurance others: _____

none

11. Type of chronic disease:

none cancer or malignant tumor hypertension

dyslipidemia pathoglycemia liver disease

kidney disease lung disease asthma

stomach/other digestive disease arthritis and rheumatism

stroke heart disease memory-related diseases

others: _____

II. Open-ended questions

[To identify factors that respondent proposed on his/her own initiative.]

Q1: Could you please describe your current health status in your own words?

Q2.1: (If the respondent thinks he/she is in a bad health status)

Question example
<ul style="list-style-type: none">• Why do you think your health status is not in a good condition?• How does XXX (Factors that the respondent mentioned) affect your health-related quality of life?• Besides XXX, do you have any other health problems? How do these problems affect your health-related quality of life?• Are there any positive aspects in your health status?• Do you think whether XXX improves your health-related quality of life?

Q2.2: (If the respondent thinks he/she is in a good health status)

Question example
<ul style="list-style-type: none">• Why do you think your health status is in a good condition?• How does XXX improve your health-related quality of life?• Besides XXX, are there any other aspects that can reflect you are in a good health condition? How do these aspects improve your health-related quality of life?• Are there any negative aspects in your health status?• Do you think whether XXX decreases your health-related quality of life?

Q3: In general, what kind of factors do you think will affect someone's health-related quality of life?

Question example
<ul style="list-style-type: none">• What do you think a good health status is?• What do you think a bad health status is?• How do these aspects you mentioned above impact/improve someone's health-related quality of life?

III. Probing questions

[To identify factors that respondents proposed after probing.]

This part is mainly for the respondents who have difficulty in providing information in the previous part. The following questions will be used to probe the respondent only if the total time spent on answering all the open-ended questions was less than 10 mins or the respondent mentioned less than two different aspects for each of the open-ended questions. Otherwise, the interviewer will only ask about the aspects that the respondent has not mentioned (*such as "Do you think emotional or mental factors can affect the health-related quality of life?"*).

Q1: The aspects you mentioned before are mainly focused on XXX. Furthermore, physical health/mental health/social health may also affect someone's health-related quality of life.

Q1.1 Physical health

Question example
<ul style="list-style-type: none">• For the physical health, what factors do you think will affect someone's health-related quality of life?• Do you think whether and how XXX (factors that were not mentioned before) can affect someone's health-related quality of life? [The interviewer can use the factors listed in Appendix 2: physical dimensions including physical movement, daily activity, pain/ discomfort, physical function, vitality, external image, and lifestyle]• Do you think there are any other factors of physical health that can affect someone's health-related quality of life?

Q1.2 Mental health

Mental health also plays an important role in health-related quality of life, so ...

Question example
<ul style="list-style-type: none">• For the mental health, what factors do you think will affect someone's health-related quality of life?• Do you think whether and how XXX (factors that were not mentioned before) can affect someone's health-related quality of life? [The interviewer can use the factors listed in Appendix 2: mental dimensions including negative emotion, positive emotion, cognition, life attitude, and emotion control.]• Do you think there are any other factors of mental health that can affect someone's health-related quality of life?

Q1.3 About social health

Social health also plays an important role in health-related quality of life , so ...

Question example

- For the social health, what factors do you think will affect someone's health-related quality of life?
- Do you think whether and how XXX (factors that were not mentioned before) can affect someone's health-related quality of life? [The interviewer can use the factors listed in Appendix 2: social dimensions including social activities and social relationship.]
- Do you think there are any other factors of social health that can affect someone's health-related quality of life?

IV. Summary questions

[To identify any factors beyond physical health, mental health, and social health.]

Q1: As we discussed before, factors in physical health, mental health, and social health can affect someone's health-related quality of life. While do you think these three aspects are comprehensive enough? If not, do you think there are any other aspects beyond physical health, mental health, and social health?

Q2: How does the COVID-19 pandemic affect your health-related quality of life?

Q3: Do you have anything to add to all the questions we have just discussed?

Q4: Do you have any other comments or questions before we end this interview?

(ENDING)

Appendix 2: Items extracted from the existing generic PBMs

Dimension	Item
Physical aspect	
Physical movement	Mobility (going outside and walking); climbing stairs; body inclining; bending over; squatting; kneeling; jumping; dexterity; vigorous activities (such as running, lifting heavy objects, laboring in the field); moderate activities (such as moving table, pushing vacuum cleaner, playing golf, riding bike)
Daily activity	Going to work; going to school; housekeeping; self-care (such as eating, bathing, dressing, grooming); doing things with friends and family; usual activities; ability of life; medical need
Pain/ Discomfort	Pain; discomfort; symptom
Physical function	Sense (vision, hearing, speaking, voice); fertility; breathing; sleeping; urination and defecation; sexual function; diet (appetite, taste); digestion; body constitution (hot palms and feet, afraid of cold, easy to catch a cold); sweating; the function of five internal organs (heart, liver, spleen, lungs, kidneys)
Vitality	Energy; tired/ feeble; physical power; spirit
External image	Complexion (face and lips); spirit of eyes
Lifestyle	Diet habit; drinking and smoking
Mental aspect	
Negative emotion	Sad/ depressed/ downhearted/ unhappy; worried/anxiety/ nervous; fear; annoyed; disappointed; despair; fretful; angry/irritable; shock; complaining; hesitant; confused; lonely; helpless; listless; lossing of confidence; feeling worthless; sense of burden; sense of defect; sense of insecurity; willing to give up
Positive emotion	Happy/joyful; passionate; grateful; confident; self-esteeming; satisfied; well-being/happiness; calm; carefree; joy of life; full of expectation; sense of security
Cognition	Learning; memory; thinking; solving problems; concentration; judgment; clear-headed
Life attitude	Optimistic; peace
Emotion control	Emotion control; emotion venting
Social aspect	
Social activities	Visiting family or friends; shopping; doing hobby activities, recreational activities, and religious activities; social and collective activities
Social relationship	Close relationships (with family and friends); interpersonal relationships (with colleagues, superior and subordinate); social integration/social isolation; social roles (roles in community and roles in sporting, church or cultural activities; taking social responsibility)

Appendix 3: Cognitive debriefing interview guide outline (English translation version)

I. Demographic information

[The information of age, gender, current residence, educational level are used to confirm whether the respondent meets the sampling quota.]

1. Age: _____

2. Gender: male female

3. Ethnic group: _____

4. Current residence: _____ province _____ city

5. Residence area: urban area rural area

6. Educational level:

primary or lower junior high school

senior high school (including technical secondary school)

college (including junior college) or higher

7. Employment status:

employed retired student unemployed

8. Marital status:

unmarried married divorced widowed

9. Family monthly income (in RMB):

<¥ 4000 ¥ 4000~10000 ¥ 10000~20000 >¥ 20000

10. Type of health insurance:

urban employee basic medical insurance

urban resident basic medical insurance (new cooperative medical scheme)

self-employed commercial health insurance others: _____

none

11. Type of chronic disease:

none cancer or malignant tumor hypertension

dyslipidemia pathoglycemia liver disease

kidney disease lung disease asthma

stomach/other digestive disease arthritis and rheumatism

stroke heart disease memory-related diseases

others: _____

II. Item-specific questions

[To identify whether the contents of the descriptive system and corresponding instructions, recall period, and response options, were relevant, comprehensive, and understandable to the respondents.]

Content	Example questions
<p>Recall period: According to your health status <u>in the past 7 days</u>, please answer the following questions: Or according to your health status <u>today</u>, please answer the following questions:</p>	<ol style="list-style-type: none"> 1. Could you please describe this sentence in your own words? 2. Do you have difficulty understanding this sentence? 3. Are you able to recall the situation of your health in the past 7 days? 4. Which recall period do you prefer, “the past 7 days” or “today”? 5. Do you have any other comments or suggestions for the recall period?
<p>Pain Four response levels: no, mild, moderate, and severe problems Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the pain refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the pain you had in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Discomfort Four response levels: no, mild, moderate, and severe problems Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the discomfort refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the discomfort you had in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. After answering the question about pain, do you think we also need another question about discomfort?

	<ol style="list-style-type: none"> 7. (If the respondent thinks it is needed, then ask) Compared with the item "Did you have discomfort (except pain)", which item do you prefer? Why? 8. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 9. (If the respondent chooses 5 levels, then ask) What is the difference between "severe" and "extreme"?
<p>Appetite</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the appetite refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the situation of your appetite in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between "severe" and "extreme"?
<p>Sleeping</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the sleeping refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the bad sleeping you had in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between "severe" and "extreme"?
<p>Vision</p> <p>Four response levels: no, mild, moderate, and severe problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the vision refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding?

<p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 3. Are you able to recall the situation of your vision in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Hearing</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the hearing refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the situation of your hearing in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Mobility</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the mobility refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the situation of your mobility in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?

<p>Memory</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the memory refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the situation of your memory in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. Do you think whether we need to ask about memory in a health-related quality of life questionnaire? 7. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 8. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Depression</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the depression refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the depression you had in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Worry</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the worry refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the worry you had in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering?

	<ol style="list-style-type: none"> 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Daily activities</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the daily activities refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the situation of your daily activities in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 7. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Fatigue</p> <p>Four response levels: no, mild, moderate, and severe problems</p> <p>Or five response levels: no, mild, moderate, severe, and extreme problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the fatigue refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding? 3. Are you able to recall the fatigue you had in the past 7 days? 4. Which level do you prefer to choose? Why? Is this the most appropriate level for you? 5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering? 6. Compared with this official description, do you prefer the simple one? Why? 7. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why? 8. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?
<p>Social interaction</p> <p>Four response levels: no, mild, moderate, and severe problems</p>	<ol style="list-style-type: none"> 1. Could you please describe this question in your own words? What does the social interaction refer to? 2. Do you have difficulty understanding this question? How to improve this question if you feel there is any difficulty in understanding?

Or five response levels: no, mild, moderate, severe, and extreme problems

3. Are you able to recall the situation of your social interaction in the past 7 days?
4. Which level do you prefer to choose? Why? Is this the most appropriate level for you?
5. Do you have difficulty answering this question? How to improve this question if you feel there is any difficulty in answering?
6. Do you think whether we need to ask about social interaction in a health-related quality of life questionnaire?
7. There are two options for the response level for this question, that is, 5 response levels or 4 response levels. Which one do you prefer? Why?
8. (If the respondent chooses 5 levels, then ask) What is the difference between “severe” and “extreme”?

General questions:

1. We have just discussed all these 13 items with you. Do you think they are relevant to someone’s health-related quality of life?
2. Do you think they are comprehensive to describe someone’s health-related quality of life? Do you think there are any other important questions that need to be added?
3. Overall, do you have difficulty understanding this question? How to improve this questionnaire if you feel there is any difficulty in understanding?
4. Overall, do you have difficulty answering this question? How to improve this questionnaire if you feel there is any difficulty in answering?
5. Do you have any comments or suggestions on this interview?

Appendix 4: Inclusion process of candidate items based on specific selection criteria

No.	Themes	Sub-themes	Reasons of exclusion
1	Physical function	Speaking	(3) (5)
2	Physical function	Neural control	(3) (5) (7)
3	Physical function	The function of the specific organs (e.g., stomach, liver, kidney)	(4) (5) (7)
4	Physical function	Metabolic rate	(3) (5) (7)
5	Physical function	Endocrine function	(3) (5) (7)
6	Physical function	Sexual function	(2)
7	Physical function	Blood circulation	(5) (7)
8	Physical function	The coordination of organs	(3) (5) (7)
9	Daily activities	Self-care	(5)
10	Daily activities	Recreational activities/sports	(2)
11	Daily activities	Social activities	(2)
12	Emotion	Anger/irritation	(6)
13	Emotion	Emotional control	(3) (6)
14	Cognition	Attention	(3) (5)
15	Cognition	Logical thinking	(3)
16	Cognition	The ability to respond or react	(3) (5)
17	Cognition	Learning ability	(2) (3)
18	Social function	Social relationships	(1)

Selection principles: (1) capturing the constructs measured by the instrument under development; (2) relevant to all members of the target population; (3) worded in a clear manner and consistent with the expressions used by the target population; (4) measuring a single construct, rather than a multidimensional concept; (5) not likely to be prone to the ceiling or floor effects within the target population; (6) appropriate for the recall period; and (7) appropriate for self-reporting.

Appendix 5: Distribution of the population representing the 31 provinces of mainland China



Number of respondents representing the 31 provinces of mainland China